Creating a Response to Hoarding in the Town of Winthrop, MA

METROBRIDGE

About this Report

This report is a product of student work in Boston University's Mental Health and Social Policy course taught by Heidi Sulman in Fall 2019.

Acknowledgments

The MetroBridge program at Boston University's Initiative on Cities wishes to thank our partners in the Town of Winthrop, especially Public Health Director Meredith Hurley, for their collaboration and support on this project.

About BU MetroBridge

MetroBridge empowers students across Boston University to tackle urban issues, and at the same time, helps city leaders confront key challenges. MetroBridge connects with local governments to understand their priorities, and then collaborates with Boston University faculty to translate each city's unique needs into course projects. Students in undergraduate and graduate classes engage in city projects as class assignments while working directly with local government leaders during the semester. The goal of MetroBridge is to mutually benefit both the Boston University community and local governments by expanding access to experiential learning and by providing tailored support to under-resourced cities. MetroBridge is funded by the College of Arts and Sciences and housed at Boston University's Initiative on Cities.
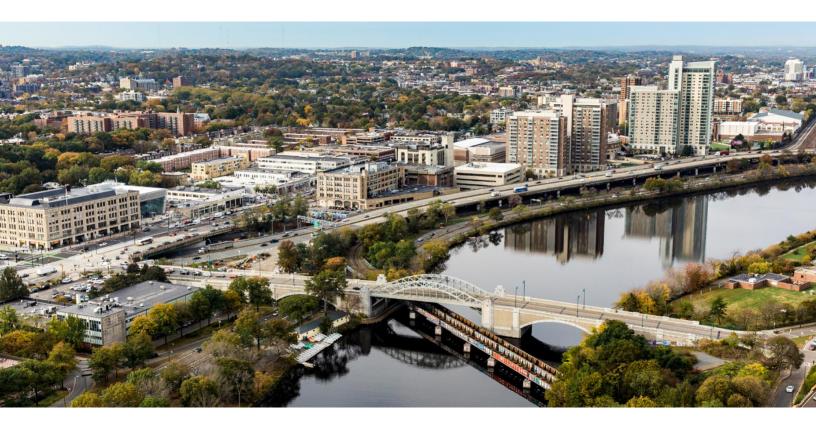
Table of Contents

Executive Summary

The Town of Winthrop recently begun to tackle hoarding and squalor situations with a coordinated approach between Public Health, Inspectional Services and first responders. However, most hoarding situations are discovered during a response to a crisis, rather than through proactive outreach. Town officials reached out to the MetroBridge program for help exploring ways to identify hoarding scenarios before a crisis arises.

Students in Boston University's Mental Health and Social Policy course addressed this MetroBridge project by:

- Researching best practices from literature and other communities in Massachusetts
- Reviewing state and federal policies related to hoarding
- Developing, analyzing, and recommending policy approaches for the Town of Winthrop to consider
- Creating a proposal to build a Community Task Force to address hoarding, including suggested participants, a proposed agenda for the first meeting, and recommended projects for the task for to undertake
- Building a Hoarding Toolkit for the town featuring information about hoarding behaviors, assessment tools, treatment and intervention plans, and local community resources

Three student teams prepare a final report on: hoarding best practices, community coalition planning, and the hoarding toolkit. Each of these reports are included in full below. The stand-alone resources – 1) a handout on hoarding for the religious community in Winthrop 2) a guide on building a Community Task Force 2) a comprehensive Hoarding Toolkit – are included at the end of this report as appendices.

Best Practices for Hoarding: Education and Communication

The Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5), hoarding was no longer considered a symptom or type of Obsessive-Compulsive Disorder. As of 2013, hoarding is its own category within Compulsive Spectrum Disorders with unique diagnostic criteria. The definition of hoarding according to the DSM-5 is, "Persistent difficulty discarding or parting with possessions, regardless of their actual value. This difficulty is due to a perceived need to save the items and to distress associated with discarding them. The difficulty discarding possessions results in the accumulation of possessions that congest and clutter active living areas and substantially compromises their intended use." (American Psychiatric Association, 2013, p247-251). The International OCD Foundation further describes the focus of hoarding behavior as, "...items do not have a specific theme, usually many different types of items...are not acquired in a planned fashion...is often excessive and, items may be free and/or purchased." (https://iocdf.org/, 2019). In an increasingly aging America, the problem of hoarding is prevalent enough to warrant coverage in mainstream television. Hoarding can, and does, occur in every type of community, including Winthrop, Massachusetts. Winthrop is a town populated by 18,190 people packed into 1.6 square miles located just outside the City of Boston and adjacent to Chelsea and Revere. Its median household income of $69,928 (US Census Bureau, 2019), places it solidly as middle class. Winthrop is also one of an estimated 100 communities nationwide with a designated hoarding task force. (Lilienfeld, S. and Arkotitz, H, 2013).

There are many avenues for data collection regarding Hoarding Disorder in the Town of Winthrop including prevalence of hoarding, hoarding's impact on municipal departments and/or agencies, and resources to address hoarding. Winthrop is unique in that enough recognition has been given to justify creating a task force dedicated to the problem. Meredith Hurley, RN and current Director of Public Health and Clinical Services, reported in her presentation, "Winthrop Department of Public Health and Clinical Services" that Hoarding Disorder affects approximately 4% of the population (Hurley, 2019, slide 6), or about 800 Winthrop residents based on the American Community Survey (ACS) 2012-2016. US Census data reports 17.8%, or about 3,300 Withrop community members, are 65 years or older. "The disorder may show up in adolescence, but it's often intensified in older age, exacerbated by bereavement, divorce, fuzzy thinking, or financial crisis." (Hogstel,1993, p45) Having this data allows the task force to reflect on current practices to develop a strategy to widen their outreach to the members of their community who are most at risk and resistant to intervention by engaging them in a proactive and preventative approach to remove barriers for accessing help.

The Winthrop task force consists of four health professionals with strong relationships within the provider and town network. To facilitate the expansion of the task force in its mission to reach more community members before a crisis occurs, we can look to the ACS (compiled by Winthrop) for suggestions. One interesting data point is that 19% of survey respondents attended a faith-based group meeting in the last year. Considering this data in light of the known triggers of hoarding, creating a partnership between Winthrop's taskforce and faith-based organizations in the community could be a meaningful partnership. A likely place people struggling with loss turn to for solace is their local church. At these churches, community members communicate with empathetic and skilled clergy members that are in a perfect position to listen and offer guidance with sensitivity

toward privacy. Therefore, our group is proposing a policy that will target clergy members for education and training to foster the relationship between older residents struggling with loss and the task force's resources. In addition to the direct involvement of the ministry, our proposal incorporates churches as a community function of hosting/organizing hoarding support/intervention groups for community residents.

Literature Review

As explained in the introduction above, hoarding is most prevalent in elders, or older adults. Muroff et al (2010) outlines a handful of reasons why working with elders who hoard may be more difficult compared to younger people. First, because elders have lived longer, they typically have accumulated more items. Second, elders are more likely to have declining mental and physical capabilities, making it harder to communicate, educate, and intervene with them. Next, elders typically have less social support, as their friends may have passed away and their families may live far away. Finally, elders have a heightened risk of injury, so the likelihood of an injury related to a fall or topple hazard increases (Muroff et al, 2010). So, it is extremely important to successfully engage with elders who hoard, as a failure to do so could cause injury, death, or increased mental health problems.

A large portion of research surrounding hoarding focuses on intervention, rather than prevention. In terms of intervention, research has concluded that a well-rounded, interdisciplinary community task force is the most effective way to help resistant populations, including our target population of elders (Whitfield et al, 2012; Koenig et al, 2013). Singh and Jones (2013) found that over 50% of hoarding cases that did not have a community task force intervention showed no improvements, and 15% of the cases exhibited increased hoarding behaviors. While these task forces often look different from town to town, research has indicated that some combination of the following professionals/providers are the most successful: firemen, nurses, social workers, psychologists, primary care physicians, professional cleaners/organizers, public health workers, landlords, and senior service workers (Bratiotis, 2013; Koenig et al, 2013; Whitfield et al, 2012). While it is clear that community task forces have been identified as a best practice in treating hoarding, there are many barriers to this type of intervention, including lack of funding and resources, inability of community members to volunteer their time, and a lack of trained mental health providers (Bratiotis, 2013; Koenig et al, 2013; Whitfield et al, 2012).

Another large area of research focuses on psychological intervention, mainly in a group format. Jordana Muroff (2009), professor at Boston University's School of Social Work, conducted a study on the efficacy of G-CBT (cognitive behavior therapy for groups) with people who hoard. In the study, respondents were put into groups of 5-8 people and participated in 16-20 two-hour weekly sessions facilitated by a mental health professional. In addition, each participant received two 90-minute home visits. Using many different hoarding rating scales and tools, the study found that respondents had an average of 14% reduction in hoarding symptoms, as well as reported decreases in illness severity and depression symptoms (Muroff et al, 2009).

Gillium et al (2009) conducted a comparable study, but wanted to eliminate the home visit component in order to test efficacy in a more community-based setting. Group size and intervention length was similar (average of 9 people per group, 16-20 90-minute sessions). While 31% of

participants showed significant improvement of hoarding symptoms, the study had quite a high attrition rate at 33%. While researchers can hypothesize that this might be attributed to the lack of home visits (and therefore a potential lack of accountability), they cannot conclusively isolate that variable. But, it appears like a home visit component, which could be done in collaboration between the psychological interventionist and a community task force, could boost positive outcomes for a larger population of people who hoard.

Now that it has been established that group support is a best practice for hoarding intervention and education, what does the research say about who should facilitate these groups? A study by Mathews et al (2011) compared therapist-led and peer-led hoarding groups in a community-based setting. The therapist-led group followed a G-CBT model, and the peer-led group followed a G-BiT model (a hoarding intervention manual). Using pre- and post-data from the two groups, researchers found no significant difference between outcomes in the G-CBT, therapist-led model and the G-BiT, peer-led model, with a 22% improvement in overall hoarding symptoms across both conditions. In addition, G-BiT appears to the more affordable option, as it cost about $100 less for each participant compared to G-CBT. Knowing that peers, or potentially trained clergy members, are just as capable at executing support groups is crucial. This is good news for a community-based program, as we know that there is a shortage of mental health professionals available and a lack of funding to pay these individuals.

Like mentioned in the introduction, our group's policy proposal involves educating people and intervening where they already go: church. Currently, though, mental health is not a common topic of discussion in places of worship. As outlined by Grcevich (2018), a study by LifeWay Research that surveyed churchgoers and clergy members found that about half of pastors reported that they never or rarely speak about mental health during services, with 2/3 of the pastors only mentioning mental health once per year. With that being said, a majority of churchgoing respondents agreed that they wished clergy members would talk publicly about mental health in order to decrease stigmatization. Another aspect of this area that must be addressed is non churchgoers beliefs about the church's open-mindedness. The same LifeWay Research study found that 55% of respondents who did not regularly attend church agreed that churches would not be welcoming of them if they were struggling with mental health (Grcevich, 2018). So, the goal of implementing hoarding support groups in a church setting would involve two objectives: encourage clergy to incorporate conversations about mental health within sermons and private counseling, and promote a community that is welcoming and will not perpetuate the stigmatization of mental health struggles.

Current Approaches to the Topic

The idea of educating and communicating with Winthrop citizens about hoarding is still something that has not been entirely successfully done for a few reasons. First, it is not clear which government body will take charge on this initiative. Second, there are no concrete goals and objectives regarding education around hoarding in the town. Lastly, an efficient way to educate the community about this issue has not yet been determined. For all these reasons, there are limited bodies tackling this initiative of educating the community about hoarding; one is the Council on Aging in Winthrop and the other is the Winthrop Housing Authority. Both of these bodies are departments of the town, therefore belonging to the local level.

The Council on Aging in Winthrop is categorized as a town agency, which is responsible for planning and coordinating services for residents 60 years and above. The programs and activities designed by the Council on Aging have elders in mind. The goal of the agency is to make everyone that comes through the doors feel welcome, safe, and engaged (The Town of Winthrop Massachusetts). Just recently, the Council on Aging hosted a hoarding specialist from McLean Hospital to discuss hoarding behaviors. This talk was well attended by senior citizens as the Council promoted the event after learning about the increased prevalence of hoarding behaviors in elders. Interestingly, attendees were mostly close family members or friends of individuals who were exhibiting hoarding behaviors, not the individuals themselves. However, the turnout was pretty successful, so the Council is planning on hosting a follow up presentation in the Spring as well (Hurley, 2019).

The Council of Aging approaches the issue of education from a mental health perspective. They look at hoarding as a symptom of an underlying mental illness, so educating people on these symptoms of underlying mental illness is important so that family members and friends can take notice of other notable behaviors their loved ones could be exhibiting. Additionally, the Council puts emphasis on how hoarding specifically affects elders in the community. Because the Council approaches this issue from a mental health perspective, it gets to the bottom of why hoarding behaviors exist in the community, focusing on things like grief, depression, obsessive compulsive disorder, etc. It also allows friends and family members to understand that hoarding is not synonymous with being lazy, dirty, or unwilling to clean up. Rather, it is indicative of something larger happening underneath (Hurley, 2019).

Winthrop Housing Authority is also a committee of the town and is responsible for ensuring housing in Winthrop is up to code. The Housing Authority has also taken initiatives to educate the community surrounding hoarding behavior (The Town of Winthrop Massachusetts). The Housing Authority has held panels trying to educate the community on housing standards and how hoarding behaviors drives residents to defy those standards for healthy living. In cases where the Housing Authority comes across residents with extreme situations, they have attempted to connect them with mental health providers in the area who focus on hoarding behaviors. The Housing Authority works independently making it extremely expensive; therefore, it cannot be done on a regular basis. It does not seem like the approach the Housing Authority is taking has been successful in the Winthrop community. Because Winthrop's Housing Authority presents hoarding as a defiance of housing standards, the underlying mental health issues are not even mentioned. Any education the Housing Authority is providing for the residents is completely centered on concrete housing standards. The lack of mental health focus makes this attempt at education and communication fall short. This method is comparable to the way the Fire Department in Winthrop handles hoarding cases. As we learned from the presentation given by Meredith Hurley, the Fire Department is generally concerned with regulations and whether the house meets the standards for fire safety. Of course this is extremely important because it keeps the residents safe, but it is not effective in terms of targeting underlying mental health issues (Hurley, 2019).

The Board of Health in Winthrop has mentioned hoarding as an agenda item in their meeting minutes, indicating that it is an issue that they would like to allocate resources to. Although they have not yet directly done any sort of education work with the community, they have talked about

creating a Hoarding Task Force. This Task Force could do a range of things from educating the community about hoarding behaviors, connecting residents to mental health providers, or providing emotional support for individuals exhibiting hoarding behaviors as well as for their loved ones. Meredith Hurley, the Director of Winthrop Department of Public Health & Clinical Services has worked with the Board of Health in the development of the force. The creation of a task force is a great indication that the Board of Health considers this as a public health issue and not an individual one (The Town of Winthrop).

Overall, the town of Winthrop has been handling the initiative to educate residents about hoarding behaviors through panels and talks by specialists. Additionally, the state of Massachusetts has taken the effort to provide information about hoarding behaviors on their website (https://www.mass.gov/). However, the State also approaches the hoarding issue as one that is dangerous for living conditions and one violates house codes, similar to the way that Winthrop's Housing Authority and Fire Department are. There is barely any mention of mental health and resources for dealing with the underlying issues at hand. In addition, there has not been any direct form of education from the State regarding hoarding behaviors. In this sense, it seems as if the local agencies are doing most of the work to effectively and appropriately educate citizens about hoarding. In terms of the federal level, when looking on the United States government's website, it refers to hoarding on a state-by-state basis, rather than on a national level. This indicates that the U.S. government has determined hoarding to be handled by state legislation rather than federal.

Current Policy & Practice

In 2000, the Massachusetts Department of Public Health reported in a survey of health officers in an area of 1.8 million residents, that four hundred and seventy-one complaints were filed due to concerns about sanitation, fire hazards, odor, odd behavior and three deaths due to fire- all likely related to hoarding behavior (Hoarding Best Practices Committee, 2012). Creating new hoarding groups is a great way to involve communities that may be unaware of how prevalent hoarding is in their community (Hoarding Best Practices Committee, 2012). Creating groups also allows for new members to feel less stigmatized by their hoarding. Creating groups in new communities allows for more outreach opportunities and the development of community partnerships.

When developing policy, it can be helpful to see what other towns of similar size and composition are doing to address the issue (in this case, hoarding). Greenfield and Easthampton, out of all cities and towns in Massachusetts, are the two most similar to Winthrop in terms of population size and composition. The United States Census (2017) data found, Winthrop had a total population of 18,391, 34.3 percent of the population was over 55. Greenfield had a total population of 17, 474, 34.8 percent of the population was over 55. East Hampton had a total population of 16, 051, 34.4 percent of the population was over 55. Based on these percentages, the age demographics in these three cities was similar in 2017. The unemployment rate in Winthrop was 5.1%, Greenfield had an unemployment rate of 5.2% and Easthampton had an unemployment rate of 6.6% (U.S. Census Bureau, 2017).

Greenfield, MA. The Greenfield Recorder (Broncaccio, 2018) published a story about a young man that began hoarding as a child to make friends. The man in the story describes how being socially

awkward and shy made it difficult to connect with his peers, so he connected with them through toys and other knick-knacks. The story gives details about the public health concerns of hoarding. It also briefly discusses how the behavior is more complex than some of the stereotypes associated with it. This article was published in April of 2018. Publishing an article like this exposes an issue that may be affecting more members of the community. This article might encourage others to get help as well.

Easthampton, MA. The Easthampton Council on Aging does not currently offer a hoarding support group. They do offer different health groups for elderly individuals, but there seems to be a gap in mental health care. Many of the support groups offered focus on social support. The groups that are more health-focused revolve around physical health conditions like diabetes and Parkinson's disease. The Easthampton Gazette published a similar article to the Greenfield Recorder about a man's experience with hoarding. The article detailed his struggle and what helped him seek help to declutter his home effectively.

There is not current state or federal level policies in place that target hoarding. This may be because there is a lack of education on hoarding and best practices for treatment. Increased funding for mental health policy would allocate funds for hoarding treatment and interventions. Research on hoarding shows that most individuals begin hoarding by age 13, however, most are unlikely to seek treatment before the age of 50 (Hoarding Best Practices Committee, 2012). The two treatment modalities mentioned across studies are group therapy and the use of psychopharmacology to treat symptoms of mental illness associated with hoarding. There are examples of these approaches at some local senior centers. At Lynn Senior Services, groups use non-threatening group names to help individuals struggling with hoarding feel less stigmatized by their behavior (Hoarding Best Practices Committee, 2012). Lynn Senior Services runs a 10-week psychoeducation group consisting of 2-hour sessions. Group membership is capped at 8 members. However, Hoarding Best Practices Committee (2012) reports that 5 is a more comfortable number for all group members to feel heard and supported. The group at North Shore Elder Services runs for 15 weeks (Hoarding Best Practices Committee, 2012). This group applies Cognitive Behavioral Therapy theories to treat and manage symptoms associated with hoarding.

Muroff, Bratiotis, & Steketee (2010) found the effectiveness of psychopharmacology as treatment for hoarding to be low. Initially, SSRI-type drugs were thought to be useful in treating hoarding because it is a subtype of OCD. Muroff et al., (2010) found that participants that used serotonergic medications showed poorer responses to treatment than participants not taking medication. Muroff et al., (2010) also reported that participants who did respond to medication as the primary treatment modality were less likely to have symptoms on the Yale-Brown Obsessive-Compulsive Scale. This scale documents the different types of obsessions the individual has and breaks them down by category. Conversely, Muroff et al., (2010) found that symptoms of hoarding did decrease when the individual's co-occurring mental illness improved with medication. Based on this information, it seems that medication can be a useful treatment modality when an individual is experiencing other mental health symptoms. This underlines the importance of correct diagnosing of symptoms. It also speaks to the importance of and need for accurate psychoeducation on what hoarding looks like and what are some preventative steps that can be taken. Kress, Stargell, Zoldan, & Paylo (2016) also found that psychopharmacology treatment modalities were more successful when hoarding was co-

occurring with other mental illness. Kress et al. (2016) noted the lack of research done on the use of medication as treatment for hoarding. For future studies or policies this may be an area of interest. This further highlights the importance of access to mental health care.

The purpose of a support group for hoarding behavior is to provide a safe and nurturing environment for individuals to share experiences, strengths, and hopes with each other in order to educate and support those who have symptoms of compulsive hoarding (Hoarding Best Practices Committee, 2012). Ideally, the group operates using a closed group model. This means no new members will join once the first meeting occurs. A Cognitive Behavioral Therapy Model (CBT) can be used to teach group members different skills to manage their mental health symptoms. Using CBT, clinicians work with clients to help them better understand their thoughts and feelings associated with hoarding. Helping clients to better understand their behavior is the first step in making change. The support groups function as both social and psychological support. Online support groups also offer services to individuals who may not have access to transportation. Muroff, Steketee, Himle, & Frost (2010) cite online CBT-based self-help for hoarding as a "promising intervention strategy that may extend access to treatment." Muroff et al. (2010) highlight the importance of evaluating the benefits of internet self-help groups as popularity and demand for web-based interventions increases. There is little research about the ineffectiveness of group therapy as a treatment for hoarding among elders. Most studies support group cognitive therapy for elder adults who are struggling with hoarding. Muroff, Steketee, Bratiotis, & Ross, (2009) found that adding cognitive group therapy was more effective in reducing symptoms of hoarding than adding home care aids alone. Muroff et al., (2009) also highlight the importance of social support in the treatment of hoarding behaviors. Group therapy brings individuals together to discuss commonalities and get advice from peers about best practices for coping.

Policy Recommendation

In studying both the effects of hoarding and the possible solutions, it became important to analyze the strengths already present in the community. According to the iCHNA Data Placemat in 2019, 74% of Winthrop residents attended a community event in the past year. This is a town which operates out of closeness and a reported 66% of residents expressed being proud of their community. In effectively addressing the holistic problems of hoarding, which often begins with untreated mental health problems, the network of community presents itself as an obvious tool for mediating this issue. According to the Hoarding Project, over 53% of people struggling with hoarding have depression (2013), and sources of unresolved trauma and loss contribute to hoarding (Sampson, Yeats & Harris). In this way, involving the biggest strength of the community in addressing root causes of the issues is the best approach to tackling Winthrop's struggle with hoarding. As earlier proposed, a task force will serve to holistically involve the town as well as holistically deal with each facet of the problem at hand. Being a small city of 18,031, Winthrop has a significant rate of church attendance at 19%. This wide network of institutions and community members can be used as an example of the benefits that come when citizens and leaders are informed and involved. The church offers potential resources in the form of financial support, building space for events, and peer networks. Harnessing this portion of the community could serve in widening awareness and offering opportunities to connect family members and friends to participate in treatment and support. This should not be the only population involved in the process but can be an important example in how to

get the wider community involved in not only tackling hoarding but healing its underlying causes of loss and depression. According to these ideas, this group has put together a sampling of literature to be made available to church communities. Drawing on their values as a group, the literature appeals to their realm of knowledge while encouraging a deepening of support through community engagement. Critically, literature like this should also work to build a community coalition by providing other Winthrop resources and groups for its members to call upon.

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Building a Hoarding-Focused Coalition in Winthrop

Hoarding disorder is believed to affect two to six percent of the US population, and is far more common among older adults ages 55-94 years old (American Psychiatric Association, 2019). The town of Winthrop, MA is a small suburban town north of Boston, near Logan International Airport that is currently working to address hoarding disorder both on an individual and town-wide level. With a population of 17,497, there could be around 700 people in Winthrop dealing with hoarding disorder based on estimated percentages (US Census Bureau, 2018). Part of the emergence of hoarding disorder within the town of Winthrop may be due to the higher population of adults over 65 than the Massachusetts average, at 17% of the town population (Community Health Needs Assessment Data Placemats, n.d.).

Hoarding disorder includes challenges with disposing of possessions, to the extent that it affects individuals' safety and quality of life. Hoarding disorder has been found to be significantly co-occurring with major depressive disorder (Frost, Steketee, & Tolin, 2011), traumatic life experiences (Cromer, Schmidt, & Murphy, 2007), and substance use disorder (Frank & Misiaszek, 2012). Winthrop town officials have found this to be true at the local level, reporting high levels of co-occurrences between hoarding disorder and each of these conditions (Meredith Hurley, personal communication, October 30, 2019). Although reasonable estimates can certainly be made with existing data, down the line additional data and research may be needed to find the exact prevalence, so that prevention and intervention strategies can be targeted at co-occurring or underlying causes of the disorder. Among the top five concerns of Winthrop residents in 2019, mental health was the third-highest, affecting 49% of the population, and aging problems was the fifth-highest, affecting 35% of the population (Community Health Needs Assessment Data Placemats, n.d.). Each of these concerns are related to hoarding disorder. Taken together, this data demonstrates the need for a targeted, person-centered approach to the issue of hoarding disorder in Winthrop. A community mental health coalition, bringing together people from diverse fields centered upon those who are most impacted, is one potentially effective intervention.

Coalition Research and Best Practices: Theory and On-the-Ground Practice

In determining whether a hoarding-focused mental health coalition would be an effective intervention for the town of Winthrop, we began by researching both the theory and best practices behind coalitions, as well as other local coalitions in Massachusetts to learn more about their process and outcomes.

Community Coalition Action Theory

The idea of a coalition stems from Community Coalition Action Theory. The theory is based in multiple different fields of study including community development, citizen participation,

political science, inter-organizational relations, and group process. When people from different backgrounds in a community come together to form a coalition, they create specific opportunities that will provide a greater benefit to the entire community. The development of coalitions is often anchored by a government or community-based organization whose mission is to support community initiatives and health-based activities, and then involves community members and professionals from all different fields and backgrounds (Butterfoss, Goodman, and Wandersman 1993). The entire group then meets regularly and takes on projects based on community need, using knowledge and perspectives from their different backgrounds to strengthen the work.

Within this theory, there are several assumptions as to why coalitions work in the long run, and why it is a model that would be beneficial for Winthrop. One assumption is that communities can develop their own capacity to deal with localized issues, and therefore residents should participate in making, adjusting, or controlling changes taking place within their community. Another assumption of this theory is that changes in community living that are self-imposed or self-developed have a greater meaning and permanence than changes imposed by outside forces (Butterfoss & Kegler, 2009). Taking these theoretical assumptions from theory into on-the-ground practice is the next step in understanding whether a coalition would be an effective intervention for Winthrop in tackling the hoarding issue. Before conducting a plan for Winthrop, research on the work of local coalitions in Massachusetts needed to be put in place to understand the feasibility of using a coalition model to implement change.

Local Coalitions

The first organization researched was the Somerville Committee for Suicide Prevention and Mental Health. The Mayor's Suicide and Mental Health Taskforce was convened through this committee to implement strategies to prevent youth suicide and promote the emotional well-being of youth. The taskforce is broken into four different sections: youth development activities, support services, education, and community building & data surveillance. The youth development sector teamed up with the Somerville Youth Workers Network and the YMCA to implement youth centered activities as a positive outlet. Within support services, they created the Somerville Youth Trauma Response Network to offer a response when youth suicide, homicide, or overdose occurs. In the education realm, the mayor's taskforce has conducted focus groups with youth, created a community forum dealing with opiate related issues, and planned ceremonies for the victims of overdoses and suicides. The last aspect is community building and data surveillance. In this taskforce, the health agenda director serves as the conduit and liaison between the various coalitions working on promoting emotional and mental well-being of youth in Somerville (City of Somerville, 2019). Beyond this taskforce, Somerville has created a coalition called Somerville Cares About Prevention with an alcohol awareness project evaluation, and student health survey task force to help create noticeable change in their community. In doing so, Somerville has

created feasible changes in these specific domains that are heavily impacting their community.

Another organization researched was the Cape Cod Hoarding Task Force. As this is the topic of our coalition, it serves a useful tool to better understand a coalition with similar objectives. The mission of the Cape Cod Hoarding Task Force is to provide education, collaboration and support to those in their community who are affected by clutter and hoarding, and do this by providing resources and information for individuals and their families (Cape Cod Hoarding Task Force, 2019). They are fighting against not only hoarding itself, but the way it negatively impacts one's day to day life. Within this framework, this task force provides six resources that can be used by the client: support groups, donations or pick-up, community involvement, treatment and counseling, professional organizers and transition specialists, and cleaning and restoration. The coalition provides information about three support groups, as well as other resources like local hoarding-focused therapists. One support group about which the task force provides information is Clutterers' Anonymous. This group is a twelve-step self-help recovery program for clutterers and hoarders, using varying approaches to address the physical health and emotional distress that can come with hoarding. Another support group is called "Buried in Treasures," and provides a supportive, peer-led environment in which individuals can address and make steps to change hoarding behaviors (Cape Cod Hoarding Task Force, 2019).
Neither of these task forces have available information about their impact or results. This may be an effect of limited resources and time, which is a reality many coalitions face. Although this lack of information makes it difficult to assess the impact empirically, even a project as seemingly simple as providing online information about local resources that individuals and families can access, as the Cape Cod Hoarding Task Force did, can make a significant difference for individuals and their families. Coalitions often do this work of bridging gaps in knowledge and services.

Despite the lack of research about the impact of local coalitions, it is clear from other research that coalitions are an effective way to combat a problem holistically. Butterfoss, Goodman, and Wandersman (1993) state reasons why coalitions can be an effective intervention, including: they can enable organizations to become involved in community issues while collaborating to come up with solutions, not having to figure them out themselves. Coalitions can also demonstrate and develop support for needs assessment, and subsequent action to address those needs. Thirdly, coalitions thrive on partnership. Using joint action can accelerate change by plugging into individuals' strengths and achieving objectives that better the group as a whole. In the same vein as a partnership, coalitions work by bringing in diverse voices from a wide variety of different backgrounds, which gives organizations a chance to create the best strategic map, using their resources effectively (Butterfoss, Goodman, & Wandersman, 1993).

Although a community coalition is a great way to solve a problem or issue within a community, there are downsides to this tactic that must be addressed. When initially working with a big pool of participants it is sometimes hard to come up with clear and common objectives. Therefore, there should be a grace period where the task force needs to find their stride before creating change. Forming and managing coalitions can also be time consuming. Aligning the schedules of people from different backgrounds and organizations can be challenging, and it can be difficult for members to find the time to commit to it given their other urgent responsibilities. Lastly, depending on availability of resources and partnerships, it can be a slow process in creating long term change (World Animal Net, 2017).

Both the Somerville Cares About Prevention Taskforce and the Cape Cod Hoarding Task Force were multifaceted and engaged different organizations from various sectors of their community. In Somerville, they worked with health departments, schools, and community institutes to create a well-rounded plan to prevent suicide and bring about alcohol awareness. In Cape Cod, the task force used various resources such as therapy and mental health outreach, clinicians, clean-up crews, as well as resources for families and friends dealing with this issue. It is clear both from the research literature and on-the-ground examples that a diverse group of individuals and organizations must have a seat at the table to ensure that change is lasting and is led by those experiencing the issue most directly.

Current Approaches
Due to the prevalence of hoarding as a mental health problem, there have been government bodies at the local, state, federal and international levels approaching the issue in various ways. In particular, policymakers and mental health professionals have addressed hoarding through the development of varying social service agencies and organizations. These organizations have helped individuals within the Winthrop community and beyond with their hoarding and cluttering behaviors.
At the local level, the North Shore Center for Hoarding and Cluttering is a support center located in Danvers. Both north of the city of Boston, Danvers is considered geographically close in distance to the town of Winthrop. The center is able to provide a safe, supportive, and educational environment for individuals, families, and their support systems who struggle with hoarding and excessive cluttering (Elder Services of Merrimack Valley, Inc., 2019). The center believes that its employees and volunteers should keep safety and functionality in mind when working with an individual with hoarding and cluttering behaviors. In turn, this means being able to stay objective and setting their own ideals aside in order to adequately help the individual (Elder Services of Merrimack Valley, Inc., 2019).

Winthrop residents can participate in the North Shore Center for Hoarding and Cluttering as it offers many services in order to help improve the lives of individuals impacted by hoarding. It provides its clients with the opportunity to participate in weekly support groups. These

groups focus on helping clients figure out and develop ways to manage their behaviors in order to obtain and maintain progress (Elder Services of Merrimack Valley, Inc., 2019). The program provides support groups twice a year for family members or those who identify themselves as a caregiver as well as counseling for individuals and their families. Also, the program offers crisis case management based on a client-centered multi-disciplinary team approach where individuals are treated through both a medical and mental health aspects (Elder Services of Merrimack Valley, Inc., 2019). In addition, it is able to educate and provide training to individuals and members of the community about hoarding as a disorder. Nonetheless, in order to participate, individuals must be referred to the program by a caregiver, a medical or mental health provider or even themselves (Elder Services of Merrimack Valley, Inc., 2019). Therefore, if an individual wants to become provided with resources from the program it is important for a referral to be submitted where individuals may have to wait up to several weeks to be called.

At the state level, an organization known as Children of Hoarders is a not-for profit organization run by adult children of hoarders for children of hoarders (Children of Hoarders, 2014). The organization is dedicated to increasing awareness and understanding of the challenges that children of hoarders face, while helping them to support themselves and each other. In turn, the agency provides various services that allow children and their families to function although presenting these behaviors. The organization is able to address the issues that hoarding and cluttering can do by raising awareness of the impact of hoarding on children, families, and communities (Children of Hoarders, 2014). They provide educational materials and programs, increase access to practical support, advocate for public policies that effectively address the needs of children of hoarders and build connections with mental health professionals. Within this organization, resources vary but include and are not limited to help from doctors, therapists, counselors, cleaning companies, crisis cleaning advice, hoarding task forces, and chronic disorganization organizers (Children of Hoarders, 2014). The agency prides itself on helping improve the lives of children and families of hoarders throughout the state.

At the federal level, Address Our Mess is a professional specialty cleaning company that handles hoarding, clutter, sorting, removal, and larger organizational projects (Address Our Mess, n.d.). The company offers its services to all of the states within the United States including the District of Columbia and Hawaii. In addition, there are direct contacts for states that are listed on their website. For instance, Megan is the contact person for most of the New England area including states such as Connecticut, Maine, Massachusetts, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, and Vermont (Address Our Mess, n.d.). Although not specifically located in each of these states, she is able to address any needs that individuals may need in these states and could point them to local services in the state they live in. To that end, in order to encourage healthier behaviors, the company offers their services by putting an emphasis on psychological well-being, working with a

compassionate and non-judgemental attitude continuously training and educating themselves on the hoarding disorder. Also, the company ensures their clients' safety by maintaining their vehicles and company materials do not have signs saying "hoarding" as well as having all their employees go through intense background, criminal and drug checks (Address Our Mess, n.d.). The company believes that these are ways in which they protect their clients while also affirming their non-judgemental values.

At the international level, the International Obsessive Compulsive Disorder (OCD) Foundation is a not-for-profit international membership-based organization. The international agency has affiliates in over 25 states and territories including global partnerships in places such as Canada, China, France, Ireland, Japan, Ireland, the Netherlands, Norway, South Africa, Spain, Sweden and the United Kingdom (International OCD Foundation, 2019). On the website, there are mental health professional contacts that reside in each of these places that could assist individuals globally. The organization offers many services to individuals possessing hoarding and cluttering behaviors which include but are not limited to providing resources, promoting awareness about hoarding patterns, increasing access to effective treatment and care, and further educating clinicians and mental health professionals. Also, the foundation emphasizes its values with policy practices and research as it has prompted the initiation as well as the continuation of hoarding based research. Mental health advocates and professionals around the world are able to become provided with a space for collaboration and supporting research that could positively impact treatment for individuals who suffer from hoarding disorders (International OCD Foundation, 2019).

Similarly, the town of Lynn also located north of Boston is working to address their hoarding and cluttering problem, and was chosen as a point of comparison due to its proximity. Although Lynn has a much larger population than Winthrop, with around 93,000 residents, the towns share similar numbers in the amount of individuals needing services for hoarding and clutter (Data USA, 2019). The prevalent hoarding crisis has not only negatively impacted Winthrop residents but also Lynn residents, and they are able to share local resources such as the North Shore Center for Hoarding and Cluttering. Therefore, the towns are able to receive the same support, care, and educational material to help them improve their lives. Also, Lynn residents can be referred into the support program just like Winthrop residents. Lynn residents dealing with hoarding also have access to services from the Greater Lynn Senior Services, including in-home family counseling, support groups, mediation with landlords, and referrals to other resources (Greater Lynn Senior Services, 2019). A coalition in Winthrop could work to implement some of these needed services within their community, so their residents have easier access to them. Lynn currently utilizes this individual-level service approach and has not yet implemented city-wide policy changes or a coalition, but due to their similarity and shared resources, a coalition could be an effective intervention for the city. Further, coalition projects taking place in Winthrop may also have a positive effect on nearby cities like Lynn as well.

There are organizations that support individuals who have patterns of hoarding and cluttering from the local level nearby Winthrop to the international level. In particular, these organizations effectively offer varying services that allow individuals to feel supported and connected to other people who suffer from the same or similar disorders. For instance, all of the agencies that were mentioned within each government body offered support groups that were geared to individuals, children, families, and communities impacted by the disorder. This ensures that individuals have a community of supporters and do not feel alone while facing the challenges of having a hoarding disorder.

Overall, the organizations allow individuals to have a wide range of options when it comes to treatment and care. These individuals, caregivers, families, and communities have options ranging from formal services such as support groups to informal services which include online professional contacts as well as cleaning companies willing to help them with their obsessive patterns. This is important because many individuals are not impacted the same way which necessitates unique treatment methods. If offered different services, individuals are allowed a sense of authority over how they want to be cared for, which is why multiple organizations working to combat hoarding in different ways is beneficial.

Nevertheless, although these organizations attempt to address a lot of the concerns that people with hoarding and cluttering patterns have, they do not address every concern. Many of the organizations fail to recognize that although many of the people who hoard are older than 50, there are many teenagers and young adults who possess these behaviors as well. For example, the North Shore Center for Hoarding and Cluttering targets the eldery population as they are supported by the Elder Services of Merrimack Valley, Inc. With that, many times teens and young adults are ignored, as research reports that many of the serious hoarding cases are of those individuals who are 50 and older (International OCD Foundation, 2019). A coalition in Winthrop could address this diversity in age and also work to address the root causes and co-occurring disorders that often come with hoarding disorder, which is outside the mission and scope of many of these organizations.

Additionally, the process to receive assistance and support from these professional and social service agencies are extensive which may deter individuals from participating. For example, many organizations require individuals, caregivers, medical or mental health professionals to contact them personally. The North Shore Center for Hoarding and Cluttering requires individuals to submit a referral in order to participate in their program. Therefore, individuals who do not submit a referral are not able to receive the services that the agency offers. In addition, once a referral is submitted individuals may have to wait several weeks in order to receive an official call inviting them to participate in the organization (Elder Services of Merrimack Valley, Inc., 2019). To that end, this may impact whether or not individuals are able to participate. Since a coalition differs from a social

service agency, they would be able to address the issue on a more fundamental level and these logistical challenges faced by other organizations would be lessened.

Our Recommendations

After analyzing the available literature on coalitions and current approaches, the group found it necessary to converse with other hoarding-focused coalitions in Massachusetts in order to gain a better understanding of the necessary steps to start a coalition in Winthrop. After providing the advice and best practices from those leaders, this section provides the concrete steps to building a hoarding-focused coalition in Winthrop, from finding a space, a first meeting agenda, and ideas for potential projects.

Talking with Local Task Force Leaders

Two task force leaders responded to the group's inquiries including Will Turner, a Behavioral Health Clinician in Elder Services of Berkshire, and Christina Murphy, the Hoarding Outreach Specialist at Greater Lynn Senior Services. In the conversation with Will Turner, he discussed his role in helping restart their coalition, after it had disintegrated for many months due to lack of leadership. During this conversation, he provided some of his own insight and recommendations on how to proceed in Winthrop, given the lessons he had learned in restarting their group in Berkshire (W. Turner, personal communication, December 6, 2019). Some of Turner's suggestions included: meeting once a month in order to ensure the task force remained connected but not too overwhelmed; creating a detailed mission with members of the group, in order to ensure members felt connected to their objective; and starting small, both in terms of the amount of members in the coalition and in terms of the amount of projects, as this would help build the group's cohesion and rhythm (W. Turner, personal communication, December 6, 2019).

Christina Murphy's insight and advice was rooted and informed in her role as the Outreach Specialist. Throughout the conversation, she frequently stressed the importance of building and maintaining relationships, and described this as integral to running an effective coalition (C. Murphy, personal communication, December 6, 2019). Murphy addressed the need and the importance of building relationships in person, and not only through email and phone calls. Murphy stated, "Because we are busy, we are used to fulfilling most of our tasks and conversations from the comfort of our offices, but it is important to meet people in person and in their workplace" (C. Murphy, personal communication, December 6, 2019). Murphy continued on to describe the ways in which the Greater Lynn Senior Services' Hoarding Task Force conducted in-person outreach in various settings, including workplaces, conferences and events. These in-person conversations allow for people to connect and begin to brainstorm the ways in which they could support one another (C. Murphy, personal communication, December 6, 2019).

Application of Research to the City of Winthrop

As shown in the Community Coalition Action Theory, a Hoarding-Focused Coalition in Winthrop could be highly effective due to its focus on creating a long lasting and fundamental impact, its holistic and multi-perspective approach, and its centering of voices that are most impacted. Given this understanding, the following section will focus on several concrete steps and suggestions that could help Winthrop create a coalition within their community. The first part of this section will focus on areas to consider prior to starting, and the second part will focus on areas to consider once the coalition has started.

Before Starting

Prior to starting a coalition, the leads and point people should begin to consider who to include in the coalition. As stated prior, coalitions succeed best when including individuals from a variety of different avenues and professions (Butterfoss, Goodman, & Wandersman, 1993). The Newton Hoarding Task Force, for example, includes social workers, psychologists, doctors, attorneys, property owners, a representative from the Department of Environmental Health, and a representative from the Fire Department, among others (City of Newton, 2019). However, as advised by Turner, the task force leader in Berkshire, it is important to start with a smaller group in order to ensure group cohesion and commitment (W. Turner, personal communication, December 6, 2019).

While considering Turner's advice, a graph was created with several recommendations for who to include first in the coalition; this is included in the handout. At the core of the graph, the members of the Property Task Force were included, due to their commitment and expertise on issues of hoarding and collecting within Winthrop. In the branches of this graph, some of the recommended members include, (1) a clinician or social worker from a local mental health organizations, such as the North Suffolk Mental Health Association, in order to address the root causes of hoarding disorder; (2) a staff member of the Winthrop Housing Authority, as their expertise on housing may be beneficial in terms of legal issues; (3) a religious leader in Winthrop, preferably someone who works with elders, as religious leaders are considered to be connected and trusted members of their communities; (4) a staff member at Winthrop's Council on Aging, Pamela Aranov's name was specifically suggested given her role as the Program's Coordinator; (5) Christina Murphy, Lynn Senior Services' Hoarding Outreach Specialist, was also included in the graph given her expertise in hoarding, in coalitions, and her proximity to Winthrop. (6) Finally, and most importantly, a Peer Support Specialist is also recommended, given the success Winthrop has had with peer work in the past (Meredith Hurley, personal communication, October 30, 2019), and the importance of valuing and centering the voices of those most impacted.

Two other central aspects to consider prior to starting a Hoarding-Focused Coalition are space and funding. Firstly, when determining space it is critical to ensure it is a reliable space, it is accessible by public transportation and accessible for people who use a wheelchair. Secondly, it is vital to consider funding sources, in order to finance projects and efforts. Two sources that have provided funding to hoarding focused coalitions in the past are MassHousing and the Department of Mental Health. MassHousing provided funding to twelve different hoarding-focused coalitions in 2018, and do so every year. These funds range from $2,500-5,000 (MassHousing, 2018). The Department of Mental Health has also provided funding for various causes around hoarding. In 2011 they provided a grant to the Police Department in Arlington for $87,500 towards their Hoarding Initiative which included a task force (City of Arlington, 2019). Will Turner, also mentioned the Department of Mental Health as one of their funding sources at the Berkshire Hoarding Task Force (W. Turner, personal communication, December 6, 2019).

First Meetings and Projects

Once the first logistical issues have been addressed in terms of space, funding and members, it is vital to begin considering the goals and purpose of the group, which will inform the coalition's work. Within the first meetings, it is crucial to work together and begin to establish a mission statement for the coalition, the roles of the members, and the norms for the group. Suggestions for how to do so, have been included within the deliverable under "First Meeting." These steps are vital to work on as a team, as they will inform the coalition's work, and will ensure members are committed and passionate about the purpose and mission of the coalition.

Once the mission statement and norms have been established, the group can begin to dream about the various projects that will coincide with the mission statement of the coalition. As Will Turner cautioned, it is important to start with a couple projects, in order to not overwhelm the coalition with group, especially early on in the process (W. Turner, personal communication, December 6, 2019). The deliverable includes these projects in greater detail, however, some of the recommended projects include: (1) a community mapping exercise, where individuals can create a visual map of the various related organizations within Winthrop; (2) a case protocol, where members of the coalition can create a step-by-step flow chart of what officials can do once they are made aware of a hoarding situation; (3) an event that centers around addressing root causes of hoarding, including campaigns that inform community members about these conditions, and resources available in the area; (4) support groups for individuals who have had issues with hoarding or for their family members; (5) trainings in the community for professionals around issues of hoarding; (6) case consultations where individuals can bring a case in a confidential manner and seek resources and advice on how to proceed in a sensitive and informed approach; (7) connections to community resources, which could include

organizations that specialize on issues of hoarding, donation centers, professionals who specialize in cleaning, restoring and organizing homes.

Beginning a hoarding-focused task force in the town of Winthrop is certainly an undertaking: both Community Coalition Action Theory and those involved in similar efforts in Massachusetts caution that they can be time-consuming and take significant time to come to a consensus. However, this also demonstrates exactly why they are effective and important — they are a mental health intervention led by the community. Collaborating by involving people from all different backgrounds, ensuring accessibility, and establishing a shared mission with aligned projects all take time, but it is an effort that will bear incredible fruit. As community action theory tells us, the changes implemented by the coalition will be far more meaningful and lasting than anything that is imposed from outside forces (Butterfoss & Kegler, 2009). Our guide to building a hoarding-focused coalition in Winthrop is intended to serve as a step-by-step tool in this process, and carries with it this message: lasting, fundamental change in the challenge of hoarding in Winthrop is possible through this model, and is well worth the undertaking.

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Winthrop Hoarding Toolkit

Hoarding affects around 6 to 15 million people in the United States (Donnelly, 2012). The average age that a person who accumulates objects is around 50 years old, with rates of hoarding for adults in the age range 55 to 94 being higher compared to younger cohorts (Parekh, 2017). This leads to significant risk to populations with high rates of residents in the age range of 80 and up. In Winthrop specifically, "...elders in North Suffolk communities' have higher rates of depression and anxiety than Massachusetts" which functions in conjunction with hoarding. There is also concern around the rate of age-adjusted mortality per 100,000 people, as it is higher in Winthrop (928.7) compared to Massachusetts (668.9) (Massachussetts General Hospital, 2019).

Accumulating content usually begins in childhood or adolescence (Ivanov, Mataix-Cols, Serlachius, Lichtenstein, Anckarsäter, Chang, & Rück, C., 2013). Hoarders tend to be single and have a high rate of divorce, with no specific race, ethnicity, age, or socioeconomic status having particularly high rates. In fact, hoarding rates are believed to be universal among cultures, socioeconomic status, race, and ethnicity. Though men statistically have more hoarding behaviors, women in comparison seek treatment at higher rates (Kessler, Brown, & Broman, 1981). Around 75% of those with hoarding disorder have comorbid mental health conditions, which commonly include major depressive disorder, social anxiety disorder, and generalized anxiety disorder. There is a 20% comorbidity rate of hoarding disorder and obsessive compulsive disorder (International OCD Foundation, n.d.)

What is Hoarding?

"Hoarding is the accumulation and failure to discard a large number of possessions that appear to most people to be useless or of limited value, extensive clutter in living spaces that precludes activities for which the rooms were designed, and significant distress or impairment in functioning caused by the hoarding" (Saltus, Andrews-Semler, Conlin, Dixon, Gousseynoff, & Lozyniak, (n.d.), as cited in Steketee & Frost, 2007, p. 3).

Hoarding can also be digital and is described as "the accumulation of digital files to the point of loss of perspective, which eventually results in stress and disorganization" (Van Bennekom, Blom, Vulink, Denys, 2015, as cited in Sweeten, Sillence, & Neave, 2018). There is no impact on physical living spaces, however, personal and professional lives can be impacted. There is no formal diagnosis of digital hoarding yet established.

Acquisition can be acquiring items through shopping, picking up free items or passively acquiring items. The act of acquiring those objects cultivates a habit that works in conjunction with hoarding and can result in positive or euphoric feelings. Compulsive acquiring is also associated with dissociation and may be used as a tool to cope with negative affective states (Kyrios, Frost, & Steketee, (2004). The other component of hoarding is non-discarding of sentimental, instrumental, and intrinsic items.

Items hoarded for sentimental reasons often comes with the fear that discarding the object will lead to losing the memory attached to the object. Grief could be a significant part of sentimental hoarding. Instrumental hoarding is the fear of wasting or potential purpose in objects. Intrinsic hoarding is when objects are kept because of the intrinsic purpose or beauty of the objects.

Animal hoarding can also lead to a slew of other issues, with animal abuse and safety being a risk. Animal hoarding is a public health issue with a very high recidivism rate of almost 100 percent, affecting about 250,000 animals each year (Almendarez, 2015). Animals can be found with inadequate amounts of water, food, and clean space which can be emotionally and physically traumatizing.

The *Diagnostic and Statistical Manual of Mental Diseases, Fifth Edition* (DSM-5) describes hoarding as individuals who collect and save items excessively. Additionally, the idea of discarding items causes extreme stress (American Psychiatric Association, 2013). The collection also results in impaired functioning due to excessive clutter. The criteria are listed below. Hoarding is also included in discussion with Traumatic Brain Injury (TBI), schizophrenia, Prader-Willi Syndrome, tic disorders, and neurodegenerative disorders. (American Psychiatric Association, 2013).

1. This difficulty is due to a perceived need to save the items and distress associated with discarding them.
2. The difficulty discarding possessions results in the accumulation of possessions that congest and clutter active living areas and substantially compromises their intended use. If living areas are uncluttered, it is only because of the interventions of third parties (eg. Family members, cleaners, authorities).
3. The hoarding causes clinically significant distress or impairment in social, occupational or other important areas of functioning including (including maintaining a safe environment for self and others).
4. The hoarding is not attributable to another medical condition (eg., brain injury, cerebrovascular disease, Pracer-Willis syndrome).
5. The hoarding is not better explained by the symptoms of another mental disorder (eg. Obsessions in obsessive-compulsive disorder, delusions in schizophrenia or another psychotic disorder, cognitive deficits in major neurocognitive disorder, restricted interests in autism spectrum disorder).

Personal Consequences

People with hoarding disorder are more likely to have chronic and severe medical problems, are three times more likely to be overweight or obese than family members, and have an age of onset in the teen years. Late onset hoarding is tied to significant losses or traumatic events (Tolin, Meunier, Frost, & Steketee, 2010).

Health and Safety Issues

Other consequences of hoarding include "health and safety concerns, such as fire hazards, tripping hazards... and health code violations" (Saltus, Andrews-Semler, Conlin, Dixon, Gousseynoff., & Lozyniak, n.d.). There can also be conflicts between the person who accumulates objects and their

family, as well as isolation and loneliness as a result of the unwillingness of the person with hoarding behavior to allow others to enter their home. The reduction of mobility/accessibility of rooms can leave one unable to cook or bathe.

Hoarding can become known to local officials when an emergency occurs within the home and a resident calls 911 for assistance; police or firefighters then entering the home might discover the dangerous conditions of the home. If the local health or housing inspector becomes aware of an issue or inspects the home, this may make local officials aware of ongoing health and safety risks. If a child or a person living with a disability is in the home, these could lead to further health and safety concerns. For rental properties, landlords may enter the unit and inspect, and maintenance staff may also report those risks.

The main issues of hoarding include fire, health, and safety hazards to the residents and their neighbors. Excessive clutter greatly increases the likelihood that tenants may be unable to quickly exit the home during a fire, and it also poses potential danger to any firefighters trying to enter the space. The lack of maintenance of the home could lead to poor condition of smoke detectors or heating systems, increasing the fire risk. A collection of combustible materials in the home also increases risk. Though only 0.25% of fires involve hoarding, around 24% of fire-related deaths involve hoarding, meaning fires are highly lethal when hoarding is involved (Saltus et al., n.d.)

The health hazards that exist if there is hoarding can lead to increased health risks due to the presence of insects, rodents, or pests. The lack of maintenance to the home could lead to the lack of use for a sink, toilet, or tub. For animal hoarding, health hazards exist for the accumulated presence of animal waste. The safety hazards include the possibility of objects weighing down the integrity of the structure, leading to potential floor or ceiling collapse. There could also be a risk of objects falling due to the height of the piles of objects.

Data Needs

Because 84% of Winthrop residents are between the ages of 35 and 80, the proportional rate of hoarding of 4% could potentially mean an estimated 727 residents are suffering from hoarding within Winthrop's total population of 18,190 (North Suffolk Community Health Needs Assessment Community Survey, 2016). Though the true rate of hoarding in Winthrop is currently unknown, an estimated 727 residents who hoard in high-density neighborhoods could potentially pose significant public health, safety, and fire risks (Personal Communication, 2019). Although it is unknown how many Winthrop residents struggle with acquisition, comparable rates from other small cities in the Northeast may be able to provide comparable estimates which is mentioned below.

Current Research and Best Practices

As previously mentioned, hoarding is a disorder that affects a wide range of people and can stem from an array of root causes, such as the loss of a loved one or moving out of a childhood home (About Hoarding, n.d.). Although the onset of hoarding disorder may appear as young as age 13, the

average age for seeking care is around age 50 (Bratiotis, Sorrentino, & Steketee, 2011, as cited in MassHousing, 2012).

Hoarding Best Practices

According to the *Hoarding: Best Practices Guide* by MassHousing (2012), a guide utilized by the state of Massachusetts, many persons being treated for hoarding disorder have not sought treatment willingly. The discovery of the hoarding situation in this case, then, is often an intrusion into their personal environment and can be as a result of involvement with a mandated reporter, family, or neighbors (MassHousing, 2012). This creates an influx of people, decisions, and ultimately building stress, which can culminate into refusal of help (MassHousing, 2012). Unfortunately, if this is the case, this can lead to more involvement with town/city officials and the court system. In addition, the individual may be made to leave their home, resulting in homelessness (MassHousing 2012). Even if the person is not rendered homeless, the process of simply clearing out the home without any sort of behavioral component is extremely ineffective and has a level of recidivism close to 100% (MassHousing, 2012).

The success of a treatment method, and subsequently for a decrease in recidivism rates, often relies on the willing participation of the individual suffering from hoarding (Bratiotis et al., 2011, as cited in MassHousing, 2012). However, the willing participation of the individual must be combined with a community task force composed of a variety of sources, supports, and niches of expertise. As hoarding is a complex disorder, its treatment must be too (Bratiotis, Woody, & Lauster, 2019).

Best Practices: Case Management Approach

CM approaches, involving such a collaborative team of care professionals, are used to provide access to a variety of services necessary in the ongoing treatment for vulnerable populations. This approach, utilizing social service workers to create an ongoing cushion of support, allows clients to safely and more effectively navigate care management resources (Bratiotis et al., 2019). The CM approach developed on the heels of deinstitutionalization and reinvigorated the need for community-based care. The theory behind this was that the individual would be able to live at home and be able to remain where it was most comfortable and familiar to access treatment (Bratiotis et al., 2019). CM is meant to be client-centered, focused on the goals toward overall wellness through frequent, long-term care (Bratiotis et al., 2019). It is more than just a "brokering of resources," though this is certainly a key factor in processes such as benefits paperwork and referrals for treatment (Bratiotis et al., 2019, pg. 94).

Best Practices: Cognitive Behavioral Therapy (CBT)

CBT is another well-regarded and effective treatment solution for those with a hoarding disorder, especially if in an individual setting (Rodriguez et al., 2016). In a study conducted by Tolin et al. (2010), fourteen adults entered outpatient treatment at Boston University and Hartford Hospital, all having met the criterion for having at minimum a moderate level of difficulty managing hoarding disorder symptoms (Muroff, Bratiotis, & Stekeete, 2010). Treatment in this study took place over twenty six sessions, and included at least one monthly home visit (Muroff et al., 2010). Masters-level practitioners delivered the treatment, and the CBT treatment focused largely on decision-making, cognitive and exposure methods with the express purpose of "reducing acquiring and increasing discarding," (Muroff et al., 2010, pg. 412). Post treatment, it was found that 50% of "treatment

completers" were more than moderately improved by the standard of the Clinical Global Impression (CGI) (Muroff et al., 2010, pg. 412).

CBT has several techniques within it that are especially functional in bringing about positive change in work with clients, as well as a number of corollary techniques that can be used to bolster its effectiveness. One such technique is Socratic Questioning, a strategy that is considered to be a pillar of CBT and critical to its success (Roth & Pilling, 2007, as cited in Braun, Strunk, Sasso, & Cooper, 2015). The process of Socratic Questioning helps to guide the client's thought process and ultimately behavior in the direction of the established therapeutic goals (Braun et al., 2015). The process is intended to be engaging in nature, and ultimately center around critical thinking in examination of the client's current situation (Braun et al., 2015). Questions asked by therapists are typically open-ended in nature, and designed to further broaden the client's perspective (Braun et al., 2015).

A study was conducted by Braun et al. (2015) to test the empirical nature of Socratic Questioning, with the goal being to find within-patient variability in use of Socratic Questioning as a therapeutic technique, and symptom change over the course of various sessions (Braun et al., 2015). It was found that indeed, use of Socratic Questioning as a piece of CBT ultimately did show success in symptom improvement (Braun et al., 2015). While the study conducted specifically related to depression, the technique of Socratic Questioning in and of itself is still a reliable method for broadening one's understanding of the present situation and inducing critical thinking (Braun et al., 2015).

Best Practices: Motivational interviewing (MI)

MI is a corollary to CBT that can be utilized when the person with hoarding disorder expresses ambivalence toward treatment or the disorder itself (Treatment of HD-Motivational Interviewing (MI), n.d.). The goal of this particular intervention is to motivate change from within the client and reduce the level of outward defensiveness of the behavior (Treatment of HD- Motivational Interviewing (MI), n.d.). A major component of MI is the positive buildup of confidence in one's own ability to make a change and incorporate the client's own vision of how a change should and could occur (Treatment of HD- Motivational Interviewing (MI), n.d.). The entire process looks at how the person's life is being lived now, how clutter affects it, and how basic values the person holds may have fallen by the wayside as a result of their current living situation (Treatment of HD- Motivational Interviewing (MI), n.d.).

Best Practices: Group Therapy

Another best practice with regard to hoarding disorder and treatment is utilizing group therapy with a client's peers (MassHousing, 2012). Support groups in this way have been a key part of treatment success, as participants are able to feel safe and connected with peers of similar situations (MassHousing, 2012). The general purpose behind a support group dedicated to persons with hoarding disorder is to provide a safe space of commonality, where members may learn about their disorder, as well as tactics to address behaviors and thoughts related to it (MassHousing, 2012). Group therapy is also effective in that it is less expensive and can function as an affordable option for those with hoarding disorder, further amplifying it as a viable and successful option (MassHousing, 2012). A distinguishing feature is that these groups allow those with hoarding

disorder wider access to clinicians, and at a closer proximity (MassHousing, 2012). Groups can utilize the conceptual model, whereby members are tasked with thinking about their physical and social environments, and how these affect and interact with their hoarding disorder, both positively and negatively (MassHousing, 2012).

Psychoeducational groups, like the one currently operating at North Shore Elder Services, show members how to work through the thoughts and behaviors that influence the disorder, and provides homework for members to reinforce group learning (MassHousing, 2012). Groups such as this are also a great way to address and work with a community that might be more hesitant to recognize or discuss hoarding in any capacity, and can operate under a non-stigmatizing name such as the "Declutter Group" (MassHousing, 2012). They are closed, meaning members may not join in after the first meeting occurs, and typically include 5-8 individuals so that all voices may be heard and addressed (MassHousing, 2012). Group therapy in this modality also serves to reduce social isolation and stigma, especially when it is combined with CBT techniques, ultimately forming a therapy called G-CBT (group cognitive behavioral therapy) (Muroff, Steketee, Rasmussen, Gibson, Bratiotis, & Sorrentino, 2009). G-CBT has also been proven to be effective in treating clients with comorbid disorders such as anxiety and depression (Muroff et al., 2009). This is especially pertinent, as hoarding disorder does not typically present on its own (Muroff et al., 2009).

Best Practices: Harm Reduction

Another approach, one that does not rely on active and willing participation, is harm reduction. Harm reduction is founded on the principle that the consequences of high-risk behaviors can be decreased without the behavior stopping altogether (Tompkins, 2011). Originally an approach developed for substance use disorder, the approach has already been utilized in other behavioral disorders and has a history of success for those who are resistant to change (Tompkins, 2011). Harm reduction practices, as they relate to hoarding disorder, include small, reasonable (relative to the client) goals centered on the management of symptoms, rather than treatment of symptoms (Tompkins, 2011). Treatment is focused on erasing all symptoms, whereas the management of symptoms allows the person to eliminate a crisis situation and manage any subsequent issues that may arise (Tompkins, 2011). This may be an approach worth considering for the often wide array of those with hoarding disorder who do not see it as a problem, or have low insight as it relates to the disorder (Tompkins, 2011).

Harm reduction (HR) may be a more reasonable and accepted approach to working with those with hoarding disorder as it does not necessitate a change in one's core beliefs or thought processes, as those with hoarding disorder who do not submit for treatment may view the problem to simply be lack of space to acquire items (Tompkins, 2011). In a wider context, it was found that 73% of social service workers believed their client to have "impaired insight" or understanding of their situation as it relates to the definition of hoarding disorder (Tompkins, 2011, pg. 499). Such a lack of insight into their situation then results in few reporting to or seeking out treatment (Tompkins, 2011). Harm reduction does not require "acceptance of treatment," and instead focuses on only discarding items that put the individual in immediate danger, whether that be with law enforcement, their landlord, or actual physical danger (Tompkins, 2011). Harm reduction allows the person to continue to acquire, and focuses instead on management as issues arise (Tompkins, 2011). This approach is again best

utilized in a team, and can be interwoven within a taskforce or coalition's overall goals (Tompkins, 2011).

Current Policies & Approaches

Current Policies and Approaches Addressing Hoarding

There are currently no policies on the federal, state, and local levels of government that specifically address hoarding. Most of the policies related to hoarding regard housing. These policies lie at different levels of government, which impact their implementation and practice in the various governing bodies. The federal policies related to hoarding are the Fair Housing Act, the Americans with Disabilities Act, and Section 504 of the Rehabilitation Act of 1973. The state policies related to hoarding are the Massachusetts Fair Housing Law and safety and sanitation codes. Furthermore, numerous local levels of the government in Massachusetts follow state safety and sanitation codes as well as some of their own safety and sanitation codes.

Fair Housing, Disability, and Reasonable Accommodations

Hoarding disorder is classified under "Obsessive-Compulsive or Related Disorders" in the DSM-5 (American Psychiatric Association, 2013). Therefore, it is considered a disability under the federal and state laws of the Americans with Disabilities Act, Fair Housing Act, Section 504 of the Rehabilitation Act of 1973, and the Massachusetts Fair Housing Law (Weiss & Kahn, 2015). Under these laws, "property owners, landlords, property managers, mortgage lenders, and real estate agents," as well as others, in public or private systems are not allowed to discriminate against a person based on disability in any process related to obtaining or maintaining housing (Mass.gov, 2019a). Therefore, it is illegal for them to deter or refuse a prospective tenant from buying or renting based on disability. It is also illegal to evict tenants based on disability (United States Department of Housing and Urban Development [HUD], n.d.a). With these laws in place, people with hoarding disorder are protected.

These federal and state laws also provide further protections for people with disabilities through reasonable accommodations. Reasonable accommodations under federal and state fair housing laws are changes in "rules, policies, practices, or services, when such accommodations may be necessary to afford a handicapped person equal opportunity to use and enjoy a dwelling" (General Court of the Commonwealth of Massachusetts, 2019, n.p.). Therefore, a person with a disability has the right to request a reasonable accommodation, and it is required to be provided (HUD, n.d.b). Reasonable accommodation requests can be made by a person with hoarding disorder or a person on his, her, or their behalf. They can be written or spoken (United States Department of Housing and Urban Development & United States Department of Justice [DOJ], 2015). If the disability and need for a reasonable accommodation is clearly visible or "known to the provider," documentation is not needed to prove disability (HUD & DOJ, 2015). However, if the need for the reasonable accommodation is not clearly visible or known, then a provider may request documentation to attest to the need for an accommodation due to disability. However, severity or specific details of the disability do not need to be shared in documentation (HUD & DOJ, 2015; Worcester Fair Housing Project [WFHP], n.d).

There are circumstances where a reasonable accommodation request can be denied. It can be denied if it was not made by the person with the disability, a person speaking on behalf of the person with the disability, or if it is not related to disability. A request can also be denied if it creates "an undue financial and administrative burden" on the provider or if it changes the basics of a program (HUD & DOJ, 2015). This would determine the accommodation to be unreasonable. An "undue financial or administrative burden" is determined by case (HUD & DOJ, 2015). If a request is denied for this reason, the provider is required to provide a tenant with an alternative reasonable accommodation that does not create financial and administrative hardship or change the basics of a program. If a provider and tenant do not reach an agreement about a reasonable accommodation, then it can mean that a provider did not allow for the accommodation. In this case, a tenant can file a Fair Housing Act complaint or lawsuit (HUD & DOJ, 2015).

A person with hoarding disorder who may lose their home due to violation of health, safety, and sanitation codes can make a reasonable accommodation request. Due to the high rate of recidivism and distress from discarding items, it is recommended that these reasonable accommodations address the underlying hoarding disorder (Saltus et al., n.d.; Weiss & Kahn, 2015). This could include a plan to provide consistent check-ins, mental health services, cleaning services and schedules, and skill-building services (MetroHousing Boston, n.d.; Saltus et al., n.d.). Other reasonable accommodations could be to extend the amount of time needed to clean as well as provide additional assistance with cleaning (Saltus et al., n.d.; WFHP, n.d.). It is also important that the time given is feasible and accounts for the nature of hoarding disorder (Weiss & Kahn, 2015). Another accommodation that could be made is to modify a rent payment plan in the event that one is behind on payments due the expenses of accommodation services (Saltus et al., n.d.; WFHP, n.d.). If a tenant is in a federal housing program, then the provider is required to pay for the accommodations under Section 504 of the Rehabilitation Act of 1973 unless it causes extreme financial and administrative hardship or changes the basics of the program (HUD, n.d.b).

Even though these laws are in place to protect people with disabilities and allow reasonable accommodations, they do not seem to successfully address hoarding. The third leading cause of eviction in Massachusetts is hoarding (Metropolitan Boston Housing Partnership, n.d.; Saltus et al., n.d.). Therefore, it is not clear if and how these reasonable accommodations are being practiced. Obtaining information about this process would be challenging since accommodations are typically a personal exchange between the tenant and provider. Another challenge is that numerous individuals with hoarding disorder may lack insight into the health and safety concerns of their living conditions and may not seek treatment or accommodations (Tompkins, 2011; Weiss & Kahn, 2015). Since an accommodation must be made by the person with hoarding disorder or another person on his, her, or their behalf, this could be a barrier to receiving a reasonable accommodation (Weiss & Kahn, 2015). Additionally, the extent of the code violations could be considered a hardship to the provider financially or administratively (MetroHousing Boston, n.d.). Therefore, it is not clear how helpful an alternative accommodation would be, or if an agreement was ever made.

Safety and Sanitation Codes
State and local governments have safety and sanitation codes. All local governments in Massachusetts are required to enforce the Massachusetts State Sanitary Code (Mass.gov, 2019b).

As previously stated, first-responders, local departments, or housing inspectors typically discover a person with hoarding disorder due to an emergency that occurs in the home or an issue that is raised regarding the home. They can also be discovered if there are concerns about the safety of children, elders, persons with disabilities, or animals in the home. Therefore, a number of state and local departments could become involved with a person who is suffering from hoarding, including police departments, fire departments, health departments, housing departments, Child Protective Services, Elder Protective Services, Disability Protective Services, and Animal Control (Chapter 8.40, n.d.; Saltus et al., n.d.). If there is a risk of eviction due to the violation of these health and safety codes, a reasonable accommodation can be requested.

The Town of Winthrop has formed the Problem Properties Task Force to help address hoarding. Numerous departments in Winthrop are involved with inspections and enforcement of safety and sanitation codes, such as the Health Department, Building Department, Fire Department, and Police Department (Chapter 8.40, n.d.). The town has developed the Problem Properties Task Force, which is made up of the Fire Department, Police Department, Inspectional Services, Public Health Department, and Town Attorneys. They all work together to provide resources to people with hoarding disorder and ensure their health and safety in a compassionate manner. However, there are limited resources available in terms of "mental health, elder services and financial assistance" (Hurley, 2019, n.p. [PowerPoint slides]). Therefore, it is challenging to successfully address the needs of the community when it comes to hoarding.

Approaches of Other Towns and Cities Similar to Winthrop

Other cities and towns in Massachusetts are also working to address hoarding and help individuals with hoarding disorder and their families. Gloucester, Massachusetts and Danvers, Massachusetts are communities similar to Winthrop in terms of income, age, and race. Due to these similar key demographics, they were chosen as comparators to Winthrop. These communities have engaged local partners to form task forces.

Gloucester, Massachusetts: Cape Ann Task Force. In 2009, the Gloucester Health Department partnered with the Gloucester Housing Authority, SeniorCare, and police and fire departments to form the Cape Ann Hoarding Task Force. The purpose of the task force is to provide resources and referrals for a variety of services for people with hoarding disorder or tendencies. Numerous public and private agencies and professionals, such as police departments, fire departments, building departments, faith organizations, mental health professionals, and social service professionals, are involved with the task force (Gloucester Health Department, 2015). The task force has developed a Hoarding Response Protocol (City of Gloucester Health Department, 2013). The task force is also working to train first responders to assess for hoarding. It is also working to coordinate enforcement and support systems (Metropolitan Area Planning Council, 2017). Another aim of the task force is to educate people with hoarding disorder, families, property owners, and landlords about hoarding, laws, legal rights, and supports (Gloucester Health Department, 2015; Metropolitan Area Planning Council, 2017). Furthermore, it is working on developing a case matrix to help city departments with responding to cases (Metropolitan Area Planning Council, 2017).

Danvers, Massachusetts: North Shore Hoarding Task Force. In the Spring of 2010, the North Shore Hoarding Task Force was formed through North Shore Elder Services, which is located in Danvers,

Massachusetts (MassHousing, 2019; Roman, 2010). This task force works with local partners to accomplish a variety of goals. The task force works to create and deliver client centered, multi-disciplinary services (Girodat, 2019; North Shore Center, n.d.). They offer peer-led and professional support groups as well as crisis case management to people in the community. The task force also works to provide trainings, education, and resources to individuals, professionals, and the community. It also works to form plans and strategies for individuals with hoarding disorder and their families. Additionally, the task force provides the services of "coaching, sorting, discarding and cleanups" (Girodat, 2019, n.p.). The task force also collects data (MassHousing, 2019). A variety of these services are provided in the North Shore Center for Hoarding and Cluttering, which is part of North Shore Elder Services. They provide support groups, counseling for individuals and families, crisis case management, consultations, and trainings (North Shore Center, n.d.). Services provided also utilize evidence-based practices, such as cognitive-behavioral therapy and harm reduction (Girodat, 2019).

Analyses of Current Policies and Approaches

Strengths

As a whole, all of these policies have numerous strengths. Most of them recognize the need for multidisciplinary services to address hoarding from a mental health perspective. Safety and sanitation codes may feel more punitive for persons with hoarding disorder, even though the intention is to keep them, people living with them, and the community safe. Reasonable accommodations could allow for mental health services, cleaning assistance, and time to meet health and safety codes in the event that codes are violated. Furthermore, Winthrop and other local governments are also recognizing the mental health needs of these individuals. Through task forces, hoarding cases are being treated through a multidisciplinary approach. The task forces are also working to train the numerous professionals who may come in contact with people with hoarding disorder. This is also a strength because it moves toward integrating and coordinating services. These approaches could be less expensive than cleanouts or evictions while improving the quality of life of tenants in the long-term (Davis & Edsell-Vetter, 2015; Saltus et al., n.d.). Overall, these approaches seem to be better for community hoarding and mental health.

Weaknesses and Barriers

There are also numerous weaknesses across these policies as well. It may be challenging to implement these approaches and evidence-based practices as intended due to the lack of resources in numerous communities, such as lack of funding, personnel, and various services. Therefore, it may not be feasible to fully implement these approaches. This could also have an exaggerated negative effect on vulnerable populations, which tend to have even fewer resources and investment. This lack of resources may continue to keep different systems apart and hinder the multi-disciplinary, therapeutic response that is important to address hoarding. A barrier to implementing some of these approaches is a person with hoarding disorder may not seek treatment or have a lack of insight. Another barrier to implementing these approaches is that people with hoarding disorder may not be discovered until there is an emergency, which can hinder preventative services. Furthermore, communities may lack education about hoarding as well as negative ideas of about it due to media representation (Weiss & Kahn, 2015). All of these were similar to the gaps that

Winthrop identified for their community (Hurley, 2019). Therefore, our group expanded the toolkit to help build on the community's strengths.

Winthrop Hoarding Toolkit

Hoarding can result in major public health concerns, and as such, this toolkit aims to provide helpful resources, best practices, and assessment tools for those who may work with individuals suffering from hoarding behaviors. In fact, a wide range of individuals may find this toolkit helpful, including social workers, housing providers, domiciliary care provides, teachers, and first responders (e.g., police officers, firefighters). The objectives of this toolkit are as follows: (1) clearly identify leading problems associated with hoarding behavior, (2) to understand the underlying factors of hoarding behavior, (3) provide respondents with informed ways to support a person who hoards, and (4) provide a process for planning solutions that are tailored to meet the needs of the person. Ultimately, this toolkit provides an ideal educational resource for the community of Winthrop as they strive toward helping individuals who experience hoarding behaviors.

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Appendices

Appendix A: Handout on Hoarding for the Religious Community

Loss, Depression and Loving your Community

◊ In 2019, Winthrop community members reported Mental Health as their 3rd top health concern.

◊ 24% of Winthrop Middle School and High School students reported feeling sad or hopeless for more than two weeks

◊ 35% of Winthrop's 65+ population have depression

*These may seem like alarming numbers, but **the Bible is full of people who experienced loss and struggled with depression.***

…David chronicles his sorrows throughout the book of Psalms

"My soul is in deep anguish. How long, LORD, how long? Who praises you from the grave? I am worn out from groaning. All night long I flood my bed with weeping. My eyes grow weak with sorrow; they fail because of all my foes."
Psalm 6:3-7

…Job deeply mourned the loss of his family and friends

"My days are swifter than a weaver's shuttle, and they come to an end without hope. Remember, O God, that my life is but a breath; my eyes will never see happiness again."
Job 7:6-7

…Jesus dreaded the future and experienced physical symptoms of anxiety

"Then he said to them, 'My soul is overwhelmed with sorrow to the point of death.'"
Matthew 26:38

"And being in anguish, he prayed more earnestly, and his sweat was like drops of blood falling to the ground."
Luke 22:44

What does depression look like?

As we see in the Bible, depression can manifest itself through feelings/behaviors of:

◊ **Hopelessness**
◊ **Loneliness**
◊ **Fatigue**
◊ **Isolation**
◊ **Physical discomfort**
◊ **Suicidal thoughts**

Just like the Bible offers us insights into the feelings of loss and depression, it also helps us **find a solution, through community.**

"Two are better than one, because they have a good return for their labor: If either of them falls down, one can help the other up. But pity anyone who falls and has no one to help them up. Also, if two lie down together, they will keep warm. But how can one keep warm alone? Though one may be overpowered, two can defend themselves. A cord of three strands is not quickly broken."
Ecclesiastes 4:9-12

"For just as each of us has one body with many members, and these members do not all have the same function, so in Christ we, though many, form one body, and each member belongs to all the others."
Romans 12:4-5

"Dear friends, since God so loved us, we also ought to love one another."
1 John 4:11

How can the Church be a loving part of the Community?
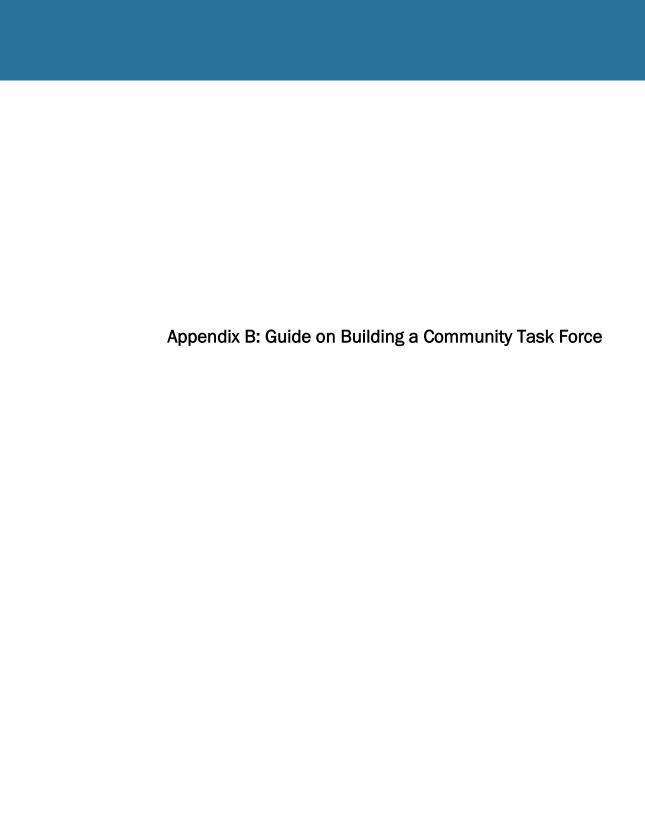
Although sharing faith is important, being an active support in the community is an equally important way to uplift, connect and restore.

The Church is a vital part of the community, interacting with the young and old. We have resources to share in the forms of: **financial support, community events, peer support and building space**.

This can mean hosting bereavement groups, being mindful of vulnerable members of the community, planning town-wide events or giving financially to mental health groups.

As Romans 12:4-5 teaches, The Church is one part of many groups in the community! The Church can be a good member by connecting others to resources:

Winthrop CLEAR Program **(Community Law Enforcement Assisted team) Mental Health & Addiction Help** 617-846-1852 Ext. 1063 or 1064 45 Pauline St. Winthrop	**National Suicide Lifeline** 1-800-273-8255 Available 24 Hours everyday Suicidepreventionlifeline.org	**B.E.S.T** **(Boston Emergency Services Team)** 1-800-981-4357 24/7 support, information, referral or in-person evaluations for those in crisis
Chelsea/Revere/Winthrop Elder Services 617-884-2500 http://www.crwelderservices.org 100 Everett Avenue Chelsea	**Meredith Hurley** **Winthrop Department of Public Health and Clinical Services** 617-846-1852 ext. 1061	**NSMHA** **(North Suffolk Mental Health Association)** 617-889-4860 301 Broadway Chelsea

Appendix B: Guide on Building a Community Task Force

BUILDING A HOARDING-FOCUSED COMMUNITY MENTAL HEALTH COALITION IN WINTHROP

Christian Radziwon, Genesis Guerrero, Hannah Field, & Michelle Gutiérrez

BEFORE STARTING

An outline of aspects to consider before starting a coalition, including who to include, funding sources & where to meet.

FIRST MEETING AGENDA

Ideas for icebreakers, goal-setting, mission statement & rapport building.
This "First Meeting" will go over some of the important aspects of the mission and purpose of the Coalition.

GOALS & PROJECTS

 Overlook of goals set by other coalitions, possibilities for various projects in Winthrop

Before You Start

Who do you Include?

Some Coalitions have included:

Impacted Leadership/Peer Specialists
Social Workers
Psychologists
Fire Department
Housing Authority
Medical Professionals
Police Officers
Department of Public Health

Housing Attorneys
Elder services
Doctors
Nurses
Board of Health
Tenancy Preservation Program
Animal Control
Religious Leaders
Teachers

This may seem overwhelming, but you can first start small!

Note: The Leader in Berkshire County Hoarding Task Force recommended starting with a group of 5-7 committed people!
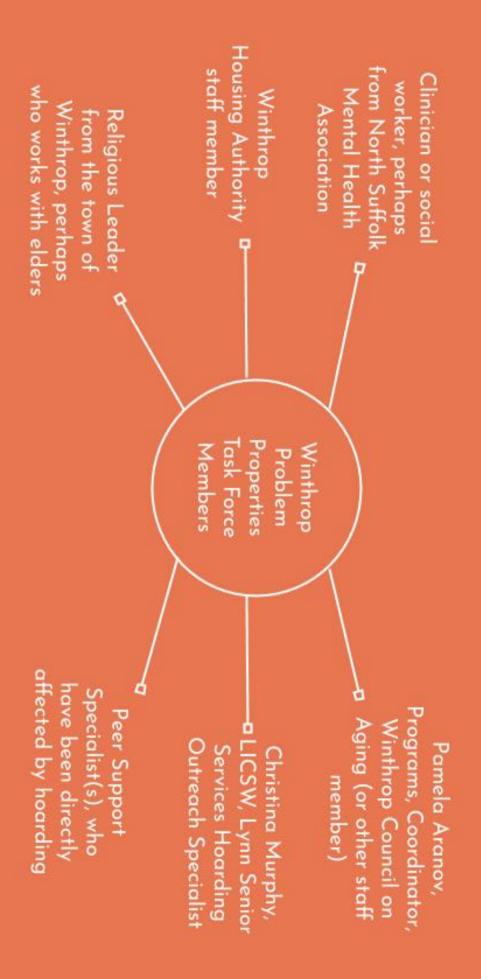
Peer leadership is Important!

Explore options for providing stipends/incentives

Contact other coalitions in the area! There are 29 listed in an online Directory posted by Mass Housing!

Note: The Leader of the Greater Lynn Senior Services Hoarding Task Force recommends inviting stakeholders in person

Ideas for Winthrop Coalition Members

Winthrop Problem Properties Task Force Members

Clinician or social worker, perhaps from North Suffolk Mental Health Association

Winthrop Housing Authority staff member

Religious Leader from the town of Winthrop, perhaps who works with elders

Pamela Aranov, Programs, Coordinator, Winthrop Council on Aging (or other staff member)

Christina Murphy, LICSW, Lynn Senior Services Hoarding Outreach Specialist

Peer Support Specialist(s), who have been directly affected by hoarding

$ Funding! $

A vital aspect of starting a coalition is seeking funding sources, and this can be expanded upon as the coalition grows. You may want to consider creating a "Grant & Funding Committee"!

Where to Start:

- **Mass Housing**
  Mass Housing awarded 12 Grants in August of 2019 to various hoarding Task Forces in MA! (ranging from $2,000-$4,300). They award these every year! At the end of this booklet, you can find their application requirements from 2019.
  Website: www.masshousing.com/hoarding
  Contact Person: Edward Chase, echase@masshousing.com

- **Department of Mental Health**
  Department of Mental Health awarded The Police Department in Arlington an $87,500 Grant for their Hoarding Initiative, which included a two-year salary for a clinician, and funds for their task force ($7,000) in 2011.   The Elder Services of Berkshire also utilize them as a funding source.

Finding Space Checklist

- ## Can you meet there consistently?

It's important to choose a reliable and consistent space that can host you. It's one less aspect to plan!

- ## Is it accessible by public transportation?

If not, ensure there other ways to accommodate individuals who may not have access to cars.

- ## Is it wheelchair accessible?

Ensure there are ramps, elevators, accessible bathrooms & seating.

- ## Is it conducive for dialogue?

Choose a welcoming setting, where everyone will feel comfortable in the space. Preferably one where everyone will fit comfortably in a circle.

First Meeting Agenda

Goals for First Meeting:

Build rapport, Set Goals/Mission, Establish Norms, Assign Roles

Introductions:

Name, why you agreed to be part of this coalition/why it matters to you, your favorite thing about the town of Winthrop.

Shared purpose/goals:

Exercise:

1. Everyone gets three sticky notes, on which they are asked to write their goals for the coalition, or what they see as the purpose of the coalition.
2. Go around in a circle and have everyone read their sticky notes aloud .
3. Afterward, everyone attaches their sticky notes to a flip chart paper or large piece of paper
4. Before the next meeting, coalition leader can synthesize these goals into a mission statement, and gather input and feedback from coalition members about it at the second meeting.

Key aspects to establish early as a group: Mission Statement, Goals, Norms & Roles

Note: These larger goals will help to guide the coalition's planning, for example, providing an idea of what events or initiatives the coalition may want to work toward. Helping coalition members feel like they are heard and respected from the beginning will lead to higher levels of engagement and group formation.

Note: Shared norms are group-generated guidelines about how the group will work and communicate as a team. The group generation process takes time at the beginning, but saves time overall, since it helps avoid potential conflicts through clarity. Establishing these at the beginning will help the group work together more effectively and is in line with guidelines about coalition processes (Osmond, 2008).

Shared Norms:

Exercise:

1. Coalition members take 10 minutes to think/write about their ideal working group. How often would it meet? Where would it meet? What time would it meet? Would there be food? Would there be a check-in at the beginning? How would communication happen — phone calls, email, texting? How would decisions be made? Do different people lead the meetings?

First Meeting Agenda Continued

2. The facilitator writes the following categories on a board or flip chart:
    a. Meetings — location, timing, frequency
    b. Meeting roles — Role rotation (if desired).
    c. Communication — type, frequency, guidelines
    d. Decision-making — processes
    e. Additional — any additional needs or desires that would make this coalition a better experience for everyone?

3. Beginning with the first category, the group moves into a conversation about their needs and desires for the group. The ideas are written on the board. A general time guideline could be ten minutes per category. A scribe takes notes.

4. Similarly to the mission statement, the facilitator can synthesize and summarize the discussion later, before the next meeting, and bring the summary back to the next meeting for any further discussion

Note: potential roles: facilitator, timekeeper, scribe, hospitality, (food), finance committee.

For example: childcare needs, accessibility needs, food, etc.)
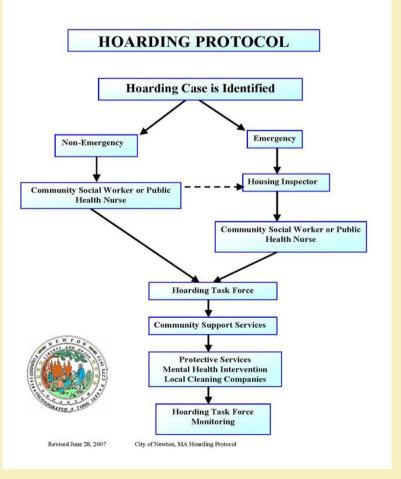
Potential Projects

Community Mapping Exercise and Outreach

1

Early in the process of the group's work together, creating a visual map of the different organizations and individuals, within Winthrop and the surrounding area, who could be potential assets/resources/collaborators in this work. This is helpful because it is very morale boosting, providing a visual reminder of the great many assets and allies that the coalition has in this work. A potential community mapping exercise could look like: a facilitator brings a large printed map of Winthrop and the surrounding area and sticky notes. All coalition group members are encouraged to write at least 3 individuals or organizations that may be helpful in this work on separate sticky notes. Coalition members then add their sticky notes to the map. Afterward, the group could have a discussion about next steps with at least one individual or organization that each member brought up. This can help to spread the word to possible collaborators about the coalition and help to spark ideas about projects that these individuals and organizations would benefit from.

Case protocol.

2

Coalitions on hoarding sometimes work to implement a protocol, or a step-by-step guide for what to do when officials are made known of a hoarding situation. The Winthrop Coalition could map out a protocol based on Winthrop's available resources. This ties in nicely with an asset-mapping or strengths based approach, and could be conducted following asset mapping.

Hoarding Case protocol for Newton, MA

Potential Projects Continued

Root Causes

3

Because trauma, depression, and other unmet mental health needs are root causes of hoarding, the coalition could plan an event or campaign centering these issues. For example, this could be an event to educate the public about these conditions and the resources available to them in the area. It could be a campaign to increase screening for trauma at schools and/or community health clinics. Any project in this realm that is feasible, exciting to the coalition, and based on Winthrop's strengths and needs will likely be of great benefit to the community, especially because there is often such stigma around these conditions and any effort to change that culture makes an impact.

Support group

4

A potential project of the task force could be to start a support group for those affected by hoarding. Since Winthrop has had success with peer models in the past, perhaps it could be led by someone who has experienced hoarding disorder. The goal of the support group could be for folks dealing with the disorder directly, their family members, or could be related to an underlying cause like depression. The coalition could generate ideas for what they see as most needed for those who are most impacted before forming the group.

Provide Trainings

5

Some coalitions have worked on providing holistic trainings for professionals working with individuals who have experienced hoarding disorders. These trainings can occur in a variety of different settings, and can include doctors, nurses, clinicians, case managers, housing officials, firefighters, police officers, teachers, among others. This is also a great way to get the community involved in the taskforce, and form personal relationships with various professionals in the city.

Case Consultations

6

Another potential project is holding a monthly/bi-monthly meeting with the task force, and discussing situations/cases in a confidential manner. This can provide professionals with the needed resources and advice on how to work on a particular case, ensuring the whole person is considered, and their needs are met.

Potential Projects Continued

7

Online Presence

Create an online presence, which will allow for people in the community to access your resources, and find ways to get involved! Hoarding Greater Cape Cod is a great example of a website: www.hoardingcapecod.org.
They provide their mission statement, resources, meeting minutes/agenda, trainings and more!

Connecting to Community Resources

- This can include **organizations who specialize in Hoarding**: For example, the Cape Cod Hoarding Task Force provides connections to Department of Health & Environment, Mass Housing, Legal Services, Elder Services, Department of Public Health, and various councils on aging.

8

- Organizations who Accept **Clothing & Furniture Donations**: This can include foundations, thrift stores, shelters, clothing drives, libraries and other local organizations that are in need of donations.

- **Professional Organizers & Transition Specialists:** refer individuals to professionals who can assist in cleaning and organizing clutter accumulated through hoarding.

- **Restoration:** Provide resources to address problems of Mold/Moisture and Cleaning/Restoration.

Begin by prioritizing two to four goals/projects; this will help create momentum for the Coalition, establish group cohesion & rhythm, and prevent the group from becoming overwhelmed with work.

Appendix C: Hoarding Toolkit

Winthrop Hoarding Resources Toolkit, Version 2

Compiled by Brenna Cleeland, Chelsea Mondock, Megan Neely, Helen Ni, and Skylar Seligman

December 2019
Boston University

Based on the *Winthrop Hoarding Resources Toolkit, Version 1* from June 2019, compiled by

Kay Jewels, The Next Step to ReOrganization, Inc. & McLean Hospital
Dominique Rouleau, Harvard T.H. Chan School of Public Health
Part of a collaboration with the Town of Winthrop

Table of Contents

Introduction

This toolkit uses the generalist intervention model, also known as the generalist practice model, to organize its contents. Sections of this toolkit have been broken down to incorporate the different intervention phases (engagement, assessment, treatment planning, intervention/implementation, progress evaluation, and termination/follow-up) that would presumably be involved when working with someone who experiences hoarding behaviors and/or their loved ones.

Following these stages of the generalist intervention model assists workers in effectively intervening with clients to resolve problems and improve wellbeing while keeping the client involved in the entire problem-solving process. It is important to remember that there is no set length of time for any stage, and in some cases, workers and clients will need to return to a previous stage, depending on the client's progress. The client should be at the center of any problem-solving process, and the generalist intervention model offers a useful guide to supporting clients on their path to self-determination and biological, psychological, and social health.

Source: https://mswcareers.com/generalistinterventionmodel/

Purpose of this Toolkit

This toolkit was compiled to help with the assessment, documentation, and response planning in cases of hoarding or clinically impaired clutter among the residents of the town of Winthrop.

Winthrop has around 18,300 residents, and 84% are between the ages of 35 and 80. Nationally, the proportional rate of hoarding is 4%, which suggests that around 730 residents of the Winthrop community may suffer from hoarding disorder (HD). Hoarding can be a major public health concern, and as such, this toolkit aims to provide helpful resources, best practices, and assessment tools for practitioners who may encounter working with individuals who experience HD.

Who Might Use this Toolkit

A wide range of individuals may find this toolkit helpful, including public and private sector service providers, such as mental health, housing, social service, and public health agencies, as well as community enforcement organizations (e.g., fire, police, legal, and animal control) (Bratiotis, 2013).

Aims & Objectives of the Toolkit

- Clearly identify leading problems associated with hoarding behavior
- Outline the underlying factors of hoarding behavior
- Provide respondents with informed ways to support a person who hoards
- Provide planning & solutions that are tailored to meet the needs of the person

Hoarding 101

Hoarding is a complex mental health issue that impairs the physical health and safety of the person with the hoarding behavior, as well as their family and the larger community around them (Bratiotis, 2013). It affects people across age, gender, socioeconomic, and racial lines. On average, hoarding affects between 6 and 15 million people in the United States (Donnelly, 2012). Hoarding disorder is progressive and chronic, it often begins early in life, and the severity of the hoarding behavior increases with age. Unfortunately, compulsive hoarding is largely unrecognized and untreated in older adults (Ayers, Saxena, Golshan, & Wetherell, 2010). The average age that people tend to be diagnosed with hoarding disorder is around 50 years old (APA, 2013).

Definition of Hoarding

Hoarding is "the accumulation and failure to discard a large number of possessions that appear to most people to be useless or of limited value, extensive clutter in living spaces that precludes activities for which the rooms were designed, and significant distress or impairment in functioning caused by the hoarding" (Steketee & Frost, 2007).

Key Characteristics of Hoarding Behaviors

According to the DSM-5 hoarding has five characteristics:

1. Persistent difficulty discarding or parting with possessions, regardless of their actual value.

2. Difficulty discarding possessions results in the accumulation of possessions that congest and clutter active living areas and substantially compromises their intended use. If living areas are uncluttered, it is only because of the interventions of third parties (e.g., family members, cleaners, authorities).

3. The hoarding causes clinically significant distress or impairment in social, occupational, or other important areas of functioning, including maintaining a safe environment for oneself and others.

4. The hoarding is not attributable to another medical condition (e.g., brain injury, cerebrovascular disease, Pracer-Willis syndrome).

5. The hoarding is not better explained by the symptoms of another mental disorder (e.g., obsessions in OCD, delusions in schizophrenia, or another psychotic disorder, cognitive deficits in major neurocognitive disorder, restricted interests in autism spectrum disorder).

Common Factors Associated with Hoarding Behavior

Though the exact causes of hoarding are unknown, common possible reasons for hoarding include but are not limited to the following:

- Inability to maintain own self-care and household chores
- Comorbid mental disorders such as obsessive compulsive disorder (OCD), schizophrenia, tic disorders, and neurodegenerative disorders
- Significant loss or traumatic life events
- Impact of abuse or neglect
- Loss of employment and/or housing
- Post-traumatic stress disorder (PTSD)

(*Source:* Rethinking Hoarding Intervention: MBHP's analysis of the Hoarding Intervention and Tenancy Preservation Project)

Impact on Individuals with Hoarding and Cluttering Behaviors

We obtained information about how hoarding and cluttering behaviors affect individuals and about their needs through a focus group, a consumer survey, and discussions with Task Force members.

Effect of hoarding and cluttering on individuals and their families.

Individuals with hoarding behaviors described the effects of these behaviors as follows:

Hoarding causes them to feel isolated.

- "I can't invite friends to visit me in my home unless they 'understand' the problem."
- "I no longer give dinner parties or have people over."
- "I socialize out of the house and am guilty about not cleaning up."
- "[N]o one comes over, which increases anxiety."

Hoarding impedes the development of relationships.

- "I do not think marriage is possible in the next 20-25 years."
- "I can't date women because eventually they would expect to visit my living quarters."

Hoarding leads to concerns for safety in their homes.

- "I've tripped on my floor piles, jammed my feet [and] toes on them. I have gotten bruises on my legs and arms and had to navigate paths."

- "I don't want to have my appliances repaired because the repairman has to enter my house. I don't want to let strangers enter my house."

- "I am worried about safety—falling and slipping, bags, no clear area in which to walk."
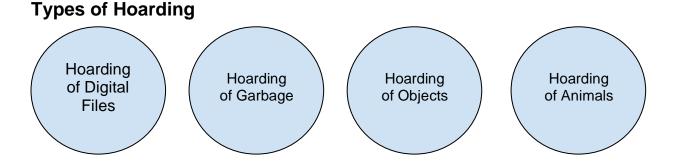
Hoarding causes them to fear eviction.

- "I have a pest control inspection every month where the property manager comes to inspect the apartment. They do a manual inspection annually. I have 3 or 4 other inspectors a year. I am concerned about being evicted from the apartment."

- "Any landlord visit is a crisis for me to get it 'presentable'…."

Hoarding causes problems in their family relationships, leading in some cases to loss of contact and even divorce and custody loss.

- "My wife left. My adult children don't visit."

- "I lost custody of my daughter because of my hoarding."

- "My family has completely abandoned me."

- "My husband hurt himself while walking through the house…. He has no place to relax…."

(*Source:* Beyond Overwhelmed: The Impact of Compulsive Hoarding and Cluttering in San Francisco and Recommendations to Reduce Negative Impacts and Improve Care)

Types of Hoarding

Hoarding of Digital Files	Hoarding of Garbage	Hoarding of Objects	Hoarding of Animals

Health and Safety Concerns Associated with Hoarding Behavior

- Chronic and/or severe medical problems
  - Anxiety
  - Depression
- Health concerns
  - Physical hygiene (e.g., inability to bathe)
  - Inability to cook
  - Obesity
  - Accumulated presence of animal waste
- Safety
  - Reduction of mobility and accessibility
  - Risk for poor housing structures and lack of repairs
  - Risk of objects failing
  - Risk of fire

Engagement

During the engagement stage, the worker should focus on building trust and rapport with the client so that mutually-agreed-upon goals can be determined. In the engagement stage, the worker is actively involved with the client, listening to their perspectives on their problems, their reasons for seeking treatment, and their desired outcomes of treatment.

Source: https://mswcareers.com/generalistinterventionmodel/

Ten Top Tips/Ten Areas to Consider

When working with a person who hoards, the following areas should be considered:

1. Ability to discard things and the impact this has on them
2. Impact of the clutter on the person
3. When did the hoarding behaviors begin?
4. What kinds of things are being hoarded?
5. Does the person intentionally save items?
6. Can their rooms be used for their intended purpose?
7. Does the person have difficulty sorting objects?
8. Has the person's ability to function socially and occupationally been affected?
9. What other disorders may be impacting the person?
10. Does the person need to be referred?

Sample Referral Form

©Hoarding: Best Practices Guide

Available online here, Appendix 1: pages 25–26.

- The Hoarding: Best Practices Guide was developed by a Hoarding Best Practice Committee, which included members of the Greater Lynn Senior Services, Brookline Community Mental Health, and other elder service providers.

- This form is part of a "Pre-Meeting/Referral Process," which aims to gather as much information as possible over the phone from the referring person or the individual themselves. This is designed to help to plan an initial approach and to better understand the condition of the home and prepare for any precautions needed when entering the home.

Hoarding: Best Practices Guide

SAMPLE REFERRAL FORM [APPENDIX 1]

REFERRAL DATE: _____

REFERRAL SOURCE:

Name of Referring Person: _____ Agency/Relationship: _____

Phone Number: _____ Email: _____

Is Client Aware of Referral: ☐ Yes ☐ No

Level of Risk: ☐ Low   ☐ Medium   ☐ High   Explain: _____

Any Risk to Worker: _____   Explain: _____

CLIENT INFORMATION:

Name: _____ Phone: _____ OK to Call? ☐ Yes ☐ No

Address: _____ City/State: _____

E-mail: _____ Language Spoken: _____ DOB: _____

Marital Status: ☐ Married   ☐ Widowed   ☐ Divorced ☐ Single   Veteran: ☐ Yes ☐ No

Other people living in the home/relationship to client: _____

_____

Condition of the home: _____

Pets in the home: ☐ Yes ☐ No How many/what kind: _____

Are there insects/rodents in the home: ☐ Yes ☐ No If yes, what kind: _____

Are there weapons in the home: ☐ Yes ☐ No   If yes, what type _____ Stored away: _____

Insurance –include numbers Primary: _____ Secondary: _____

Medications: _____

Health concerns: _____

_____

_____

Hoarding: Best Practices Guide

Memory Loss: ☐Yes ☐ No Explain: _____

Loss/Stressors: _____

Present or Past Substance Abuse: ☐Yes ☐ No Explain: _____

Current or Past Mental Health Treatment: _____

Current Therapist, Counselor, Psychiatrist, Psychologists or Social Worker: _____

SUPPORT SERVICES:

Current PS Client: ☐Yes ☐ No   PSW Name: _____

Current HC Client: ☐Yes ☐ No CM Name: _____

Past client of GLSS: ☐Yes ☐ No How? _____

Other Services in the Home: _____

Friends/Family in the Area: _____

Emergency Contact Name: _____ Phone: _____

PRESENTING ISSUE: *Descriptive reason for referring client to program (include time/dates of incidents):*
_____
_____
_____

ADDITIONAL INFORMATION: _____
_____
_____
_____

- -

REFERRAL FORM COMPLETED BY: _____ **DEPT:** _____

DATE RECEIVED/REVIEWED: _____ **BY:** _____ **PROGRAM:** _____

SCREENED IN FOR INITIAL VISIT/ASSESSMENT _____ **MEETING DATE/TIME** _____

SCREENED OUT _____ **REFERRED TO:** _____

ll | P a g e

How to Speak with Someone Who is Hoarding

When Speaking with Someone Who Hoards, Do:

- Imagine yourself in that person's shoes
- Match the person's language
- Use encouraging language
- Highlight their strengths
- Focus the intervention initially on safety and the organization of possessions and the late work on discarding

When Speaking with Someone Who Hoards, Do Not:

- Use judgmental language
- Use words that devalue or negatively judge possessions
- Use negative nonverbal expressions
- Make suggestions about the person's belongings
- Try to persuade or argue with the person
- Touch the person's belongings without permission

Assessment

During the assessment stage, the focus shifts to information gathering. In assessment, workers should collect key data about the client through interviews and other assessment techniques, instruments, and collateral contacts. This information will assist both the client and the worker in defining the problems and possible solutions. During assessment, workers must remember to operate from a strengths-based perspective, with careful attention to seeking information about the client's skills, capacities, resources, and other strengths and capabilities.

Source: https://mswcareers.com/generalistinterventionmodel/

The Structured Interview for Hoarding Disorder (SIHD 2.0)

©Oxford Handbook of Hoarding and Acquiring

Available online here through Oxford Handbooks Online.

- The questions in the SIHD interview relate to each of the 6 criteria needed to evaluate the presence of hoarding disorder and its two specifiers. These questions appear in bold print and should be asked during the course of the interview, whereas the text in italics is present only to assist the rater.

- For a diagnosis of hoarding disorder, all 6 criteria must be endorsed. If any of the criteria are not met, the diagnosis is ruled out. The specifiers are only relevant for individuals endorsing all diagnostic criteria.

King's College London, Institute of Psychiatry and the Karolinska Institutet, Stockholm

Permissions: The authors hold the copyright but the scale is free to use by researchers and clinicians who have an interest in hoarding disorder.

Citation: If you use the instrument, please cite it appropriately as follows: Nordsletten, A. E., Fernández de la Cruz, L., Pertusa, A., Reichenberg, A., Hotopf, M., Hatch, S. L., & Mataix-Cols, D. (2013). The Structured Interview for Hoarding Disorder (SIHD): Development, further validation, and pragmatic usage. *Journal of Obsessive-Compulsive and Related Disorders, 2 (3),* 346–350.

Correspondence: For any correspondence regarding the SIHD, please contact Dr Pertusa (alberto.pertusa@kcl.ac.uk) or Professor Mataix-Cols (david.mataix-cols@ki.se).

Instructions for the rater

The questions contained in this interview relate to each of the 6 criteria needed to evaluate the presence of hoarding disorder and its two specifiers. These questions appear in bold print and should be asked during the course of the interview, whereas the text in italics is present only to assist the rater. For a diagnosis of hoarding disorder all 6 criteria must be endorsed. If any of the criteria are not met, the diagnosis can be ruled out. The specifiers are only relevant for individuals endorsing all diagnostic criteria.

It is important to carefully distinguish hoarding disorder from nonpathological collecting, as well as from the general medical and DSM-5 conditions that may result in the accumulation of possessions (e.g., brain injury, obsessive-compulsive disorder, autism spectrum disorder, etc.). Therefore, this interview should ideally be used as a complement to a more comprehensive assessment of the patient's medical history and psychopathology. If in doubt about the endorsement of a specific criterion, the rater should complete the interview and consider all available information before rendering a diagnosis. Special sections are provided at the end of this document to assist with some of the most common differential diagnoses.

Ideally, the interview should be conducted directly with the sufferer and in the person's home. If the individual of interest is not available or refuses to be interviewed, this interview may be administered to a reliable informant. This approach may also be employed for cases presenting with poor or absent insight, where the subject's responses may significantly conflict with the reality of the hoarding behavior. In cases where there is a strong clinical suspicion of HD (e.g., based on familial or legal reports), paired with poor insight on the part of the hoarding individual, the interviewer should use his or her clinical judgment to determine the relevance of each criterion.

If a home visit is not possible, photographs of the person's home environment may be helpful to assess the presence of clinically significant clutter (Criterion C). The presence of clutter may also be quantified with other available instruments such as the Clutter Image

Rating Scale[1]. On the Clutter Image Rating Scale, a room score greater than 4 is usually indicative of clinically significant clutter, however this is only for guidance and all available information needs to be taken into account.

Criterion A

Persistent difficulty discarding or parting with possessions, regardless of their actual value.

Do you experience difficulty discarding or parting with possessions? *This may include throwing away, selling, giving away, recycling, and so on*.

    □ **YES** → *go to* ***next question***
    □ **NO** → *hoarding disorder not present*

How long have you had this problem? _____**months/years**.

If hoarding is a persistent problem that has been present for a long period of time → ***Criterion A is present*** *→go to* ***next question***

If hoarding has been present for a relatively short period of time (i.e., only a few weeks or months), inquire about temporary factors that may account for the difficulties discarding (e.g., recent inheritance of a large number of possessions, moving to a different home). If the hoarding behavior can be entirely explained by these circumstances→ hoarding disorder not present

What items do you find most difficult to discard? *Please list items below* (*both valuable and worthless items should be taken into account for the diagnosis*).

_____

_____

_____

_____

_____

If **CRITERION A** is present, place a check in the circle and go to CRITERION **B**

Criterion B

This difficulty is due to a perceived need to save items and to distress associated with discarding them.

Do you intentionally keep these items (are they important/ useful for you)?

Do you generally feel distressed or upset when discarding possessions?

These questions are intended to evaluate whether the accumulation of objects is intentional/active and whether the discarding process causes distress (or would cause distress, in cases where discarding is entirely avoided). Where the accumulation is due to passive accumulation, or where the discarding process does not cause distress, the hoarding may be subclinical or attributable to an alternative psychopathology.

    □ If **YES** to both of the above questions → **CRITERION B is present**
    □ If **NO** to any of the above questions → *hoarding disorder not present*

If **CRITERION B** is present, place a check in the circle and go to CRITERION **C**

Criterion C

The difficulty discarding possessions results in the accumulation of possessions that congest and clutter active living areas and substantially compromise their intended use. If living areas are uncluttered, it is only because of the interventions of third parties (e.g., family members, cleaners, authorities).

Do you have a large number of possessions that congest and clutter the main rooms in your home? *Note that "clutter" refers to the presence of a large number of items that are lying about in a disorganized way. The question refers to the key living spaces such as bedrooms, kitchen, or living room. Here exclude garages, attics, lofts, basements, and other areas that may commonly be cluttered in the homes of nonhoarding individuals.*

To meet Criterion C, active living spaces that are necessary for everyday life must be cluttered to the extent that their use is substantially compromised. If unclear, ask about the level of obstruction for particular rooms or domestic activities:

Because of the clutter or number of possessions, how difficult is it for you to use the rooms in your home?

- *Kitchen (sink, fridge, worktop, etc.):*
  _____
  _____
- *Bathroom (sink, toilet, shower/bathtub, etc.):*
  _____
  _____
- *Bedroom (bed, wardrobe, drawers, etc.):*
  _____
  _____
- *Living room (sofa, chairs, table, floor, etc.):*
  _____
  _____
- Other (halls/corridors/stairs; difficult to walk through due to piles of items):
  _____
  _____

    □ **YES** → **CRITERION C is present**
    □ **NO** → *go to the* **next question**

Have other people (such as family members or local authorities) helped you to remove (or forcibly removed) some of your possessions? If so, how cluttered was your house/room before their intervention? *Explore to what extent the living spaces are currently clutter free because of the intervention of other people. If this is the case, the criterion can be endorsed in the absence of significant clutter*.

> □ **YES** → *CRITERION C is present*
> □ **NO** → *hoarding disorder not present*

If **CRITERION C** is present, place a check in the circle and go to CRITERION **D**

Criterion D

The hoarding causes clinically significant distress or impairment in social, occupational, or other important areas of functioning (including maintaining a safe environment for self and others).

Do the difficulties discarding or the clutter cause you distress? *Note that some individuals with poor insight may not acknowledge being distressed, though any attempts to discard possessions by third parties will result in distress or anger*.

Do the difficulties discarding or the clutter interfere with your family life, friendships, or ability to perform well at home or work? *Note that the impairment may only be apparent to those around an individual with poor insight*.

> □ If **YES** to one or both of the above questions → *CRITERION D is present*
> □ If **NO** to both questions → *hoarding disorder not present*

If **CRITERION D** is present, place a check in the circle and go to CRITERION **E**

Criterion E

The hoarding is not attributable to another medical condition (e.g., brain injury, cerebrovascular disease, Prader-Willi syndrome).

Do you have any general medical conditions, a history of head injury or cerebrovascular disease? *Review past medical history for neurological dis-orders and inquire about history of severe head trauma. Some relevant conditions include traumatic brain injury, surgical resection for the treatment of a tumor or seizure control, cerebrovascular disease, infections of the central nervous system (e.g., herpes simplex encephalitis), or neurogenetic conditions such as Prader-Willi syndrome. If appropriate and available, additional investigations (e.g., EEG, CT, MRI, neuropsychological assessment) may be useful to help confirm the presence of brain damage.*

> □ **YES** → *go to next question*
> □ **NO** → *CRITERION E is not present*

Did you have difficulties with discarding/clutter before you became ill? *Try to establish whether there is a clear temporal link between the medical condition and the onset of the hoarding behavior.*

□ **YES** → *CRITERION E is present*
□ **NO** → *if hoarding clearly preceded by a general medical condition → hoarding disorder not present*

If **CRITERION E** is present, place a check in the circle and go to CRITERION **F**

Criterion F

The hoarding is not better explained by the symptoms of another mental disorder (e.g., obsessions in obsessive-compulsive disorder, decreased energy in major depressive disorder, delusions in schizophrenia or another psychotic disorder, cognitive deficits in major neurocognitive disorder, restricted interests in autism spectrum disorder).

Ideally, this interview should be administered in the context of a full psychopathological assessment. If this is not available, ask the interviewee or informant about current or past psychiatric diagnoses. Note current and lifetime mental dis-orders here:

_____

_____

_____

_____

_____

The presence of another mental disorder does not preclude the diagnosis of hoarding disorder. However, hoarding disorder is not diagnosed if the symptoms are judged to be secondary to or a direct consequence of another mental disorder, such as:

- *Obsessions or compulsions in obsessive-compulsive dis-order.*
- *Special or circumscribed interests in Autism Spectrum Disorder or intellectual disability.*
- *Decreased energy, psychomotor retardation or fatigue in Major Depressive Disorder.*
- *Delusions or negative symptoms in Schizophrenia Spectrum or other psychotic disorders.*
- *Cognitive deficits in a Neurocognitive disorder such as frontotemporal lobar degeneration or Alzheimer's Disease.*

If another mental disorder is present, it is useful to establish the temporal relation with the onset of hoarding symptoms.

PLEASE SEE APPENDIX FOR FURTHER GUIDANCE ON THE DIFFERENTIAL DIAGNOSIS WITH OBSESSIVE-COMPULSIVE DISORDER AND AUTISM SPECTRUM DISORDER.

If **CRITERION F** is present, place a check in the circle.

If all six criteria are met, the diagnosis of **hoarding disorder** should be coded.

If hoarding disorder is present, please place a check mark in the circle.

Specifiers

If hoarding disorder has been diagnosed, assess the presence of Excessive Acquisition and determine the Degree of Insight.

Excessive Acquisition Specifier

If the difficulty discarding possessions is accompanied by excessive acquisition of items that are not needed or for which there is no available space.

Do you often acquire free items that you don't need or for which you have no available space at home?

    □ **YES**
    □ **NO**

Do you often buy items that you don't need, you can't afford, or for which you have no available space at home?

    □ **YES**
    □ **NO**

Do you sometimes steal things that you don't need, you can't afford, or for which you have no available space at home?

    □ **YES**
    □ **NO**

If YES *to **any** of the above 3 questions,* **With Excessive Acquisition** *should be coded.*

Please place a check mark in the circle.

Insight Specifier

With good or fair insight: *The individual recognizes that hoarding-related beliefs and behaviors (pertaining to difficulty discarding items, clutter, or excessive acquisition) are problematic.*

With poor insight: *The individual is mostly convinced that hoarding-related beliefs and behaviors (pertaining to difficulty discarding items, clutter, or excessive acquisition) are not problematic despite evidence to the contrary.*

With absent or delusional insight: *The individual is completely convinced that hoarding-related beliefs and behaviors (pertaining to difficulty discarding items, clutter, or excessive acquisition) are not problematic despite evidence to the contrary.*

To what extent do you think that your saving behavior (including your difficulties discarding, the resulting clutter, and the excessive acquisition) is problematic? *If in doubt, refer back to information provided by the subject during the interview. If a reliable informant is present, check for discrepancies between the subject's and the informant's report and assess degree of insight accordingly.*

> □ **Good/Fair** insight
> □ **Poor** insight
> □ **Absent/Delusional** insight

Risk Assessment

This section helps the rater document any possible risks associated with problematic hoarding behavior. Please check whether the following are present:

Fire hazard
> □ *Are there flammable materials near a heat source?*
> □ *Are there electrical hazards?*

Blocked exits
> □ *Is the door that allows entry and exit to the house clear?*
> □ *Are there additional doors within the property that are blocked?*

Risk of falling
> □ *Is there a lack of clear pathways, impeding movement throughout the property?*
> □ *Is it necessary to climb piles of objects in order to move between rooms or access objects?*

Insects, infestations
> □ *Is there any evidence of insects (visible individuals, swarms, cobwebs, droppings)?*
> □ *Are there any rodents or other infestations present?*

Unhygienic conditions
> □ *Is there human or animal waste/vomit in the property?*
> □ *Is there moldy or rotten food or dirty food containers in the kitchen or other areas of the property?*
> □ *Is the sink, washbasin, bathroom, shower, or bathtub clogged or notably dirty?*
> □ *Is there standing water anywhere in the property (sink, tub, basement, other)?*
> □ *Does the property emit a strong odor?*

Neglect of children, elder, or disabled people
> □ *If there are children, elders, or disabled people present, is there sufficient space to permit routine care and activities (e.g., a functioning kitchen, a place to eat meals, access to a shower or bathtub)?*
> □ *If there are children present, is there sufficient space for them to sleep, play, or do school homework?*

Animal hoarding
> □ *Are there starving, neglected, or maltreated animals on the premises?*

Additional notes *(please write any additional information that may be useful for risk assessment)*

APPENDIX: DIFFERENTIAL DIAGNOSIS ASSISTANT

HOARDING AS A SYMPTOM OF OBESESSIVE-COMPULSIVE DISORDER

This section will assist the rater in assessing whether the hoarding behavior is better conceptualized as a symptom of Autism Spectrum Disorder (ASD). First, establish whether ASD is present (independently of the hoarding). If there is an established diagnosis of ASD, then ask the following questions:

Are your discarding difficulties caused by a specific obsession or fear?

> □ **YES** (more likely in OCD)
> □ **NO**

If hoarding is mainly driven by prototypical obsessions → Hoarding disorder probably not present (hoarding likely to be a symptom of OCD)

Some examples of obsessions include:

- *Not discarding for fear of contaminating self or others.*
- *Superstitious thoughts about discarding, for example, fear of something bad happening to a loved one if certain items are discarded.*
- *Intense feelings of incompleteness.*
- *Saving to maintain a record of all life experiences.*

Is it difficult for you to discard things because this triggers endless rituals (e.g., washing or checking rituals)?

> □ **YES** (more likely in OCD)
> □ **NO**

If hoarding is the result of persistent avoidance of onerous compulsions → Hoarding disorder probably not present (hoarding likely to be a symptom of OCD)

Do you enjoy/find it comforting to acquire possessions and being around them?

> □ **YES**
> □ **NO** (more likely in OCD)

Are you emotionally attached to most of the items you save?

> □ **YES**
> □ **NO** (more likely in OCD)

Do you save items mainly because they are valuable/beautiful or they may come in handy in the future?

> □ **YES**
> □ **NO** (more likely in OCD)

Do you keep body products (feces, urine, nails, hair, used diapers) or rotten food?

> □ **YES** (more likely in OCD)
> □ **NO**

Individuals with hoarding disorder are more likely to report that their hoarding behavior is pleasurable/comforting, that they are emotionally attached to their saved objects, or that they save due to a belief that their items will prove handy in the future. The retention of body products or rotten food is, conversely, more often seen in OCD.

REMEMBER *that both OCD and hoarding disorder may be diagnosed at the same time when severe hoarding symptoms appear concurrently with other typical symptoms of OCD but are judged to be independent from these symptoms. In case of diagnostic uncertainty, we recommend diagnosing OCD only.*

Hoarding as a Symptom of Autism Spectrum Disorder

This section will assist the rater in assessing whether the hoarding behavior is better conceptualized as a symptom of Autism Spectrum Disorder (ASD). First, establish whether ASD is present (independently of the hoarding). If there is an established diagnosis of ASD, then ask the following questions:

Are the objects you save generally confined to a single, specific (circumscribed) area of interest?
A circumscribed interest, as seen in ASD, is typified by an intense interest in a specific, narrow, and often unusual topic. These interests may result in the accumulation of many similar objects, which are unified as exemplars of this area of interest. Individuals with hoarding disorder are more likely to accumulate a wide range of objects (e.g., not confined to a single area of interest, or unified by a highly specific characteristic). A lack of organization is, furthermore, more typical in hoarding disorder.

> □ **YES** (more likely in ASD)
> □ **NO**

If yes *to the preceding question:* **What is the area of interest?**

Do the objects you save largely share a particular, physical characteristic (e.g., material, texture or shape)?

> □ **YES** (more likely in ASD)
> □ **NO**

In ASD, the gathering of many like objects may signal an unusual, sensory preoccupation.

Examples of such preoccupations include intense fascinations with:

- *Visual stimuli (e.g., shiny objects, blinking lights, the motion of liquid – such as the rotation of water being flushed).*
- *Auditory stimuli (e.g., the sound of a vacuum clean-er).*
- *Tactile stimuli (e.g., smooth surfaces).*

Do you enjoy organizing and classifying your possessions?

> ☐ **YES** (more likely in ASD)
> ☐ **NO**

If yes *to the preceding question:* **Could you tell me a bit about your organizing system?**

A focus on uniformity and order with one's possessions is common to ASD. Unlike with OCD, in ASD this organization process should be egosyntonic and pleasurable.

If hoarding is primarily the result of a circumscribed interest, sensory preoccupation, or a desire to save/classify information → Hoarding disorder probably not present (hoarding likely to be a symptom of ASD).

REMEMBER *that both ASD and Hoarding disorder may be diagnosed at the same time when severe hoarding symptoms appear concurrently with other typical symptoms of ASD but are judged to be independent from these symptoms. In case of diagnostic uncertainty, we recommend diagnosing ASD only.*

Notes:
(1) Frost, R. O., Steketee, G., Tolin, D. F., Renaud, S. (2008). Development and validation of the Clutter Image Rating. *Journal of Psychopathology and Behavioral Assessment, 30(3), 193–203.*

UCLA Hoarding Severity Scale

© Oxford Handbooks Online

Available online [here](#).

- The UCLA Hoarding Severity Scale (UHSS), is a semi-structured, clinician-administered rating scale that measures the severity of both the core symptoms of Hoarding Disorder (HD) and the associated features of indecisiveness, perfectionism, task prolongation, and procrastination, which are significantly associated with the diagnosis and impairment of HD.

Name _____ID #_____Date_____

Rater_____

1. How much of your home is affected by clutter—items that should not be in those areas or that prevent those areas from being used in the way that they were intended?
    0) None.
    1) A small amount (about 25%).
    2) About half of your home.
    3) Most of your home (about 75%).
    4) All of your home.

2. How embarrassed would you be if someone were to see your clutter today?
    0) Not at all.
    1) Mild.
    2) Moderate.
    3) Severe.
    4) Extreme.

3. To what extent is excessive buying or acquiring of things a problem in your life?

0) Not at all.
1) Mild.
2) Moderate.
3) Severe.
4) Extreme.

4. How strong is the urge to keep things that others might not keep?
    0) Not at all.
    1) Mild.
    2) Moderate.
    3) Severe.
    4) Extreme.

5. How anxious would you become if you had to discard something that you thought you would need or want in the future?
    0) Not at all.
    1) Mild.
    2) Moderate.
    3) Severe.
    4) Extreme.

6. To what extent does your clutter affect your personal relationships or ability to socialize?
    0) Not at all.
    1) Mild.
    2) Moderate.
    3) Severe.
    4) Extreme.

7. To what extent does your clutter affect your ability to work, daily functioning, or hobbies?
    0) Not at all.
    1) Mild.
    2) Moderate.
    3) Severe.
    4) Extreme.

8. Do routine tasks take longer than they should, either because of clutter or a need to do things completely or perfectly?
    0) Not at all.
    1) Mild.
    2) Moderate.
    3) Severe.
    4) Extreme.

9. Do you have trouble making decisions, even about little things other people wouldn't think twice about?
    0) Not at all
    1) Mild.
    2) Moderate.
    3) Severe.
    4) Extreme.

10. How much do you procrastinate doing tasks (chores, discarding, organizing, etc.)?
    0) Not at all.
    1) Mild.
    2) Moderate.
    3) Severe.
    4) Extreme.

TOTAL _____

HOMES Multidisciplinary Hoarding Risk Assessment

©Bratiotis, 2009

Available online here through Tufts University.

- The HOMES Assessment was developed in conjunction with the Massachusetts Statewide Steering Committee on Hoarding. It provides a structural measure through which the level of risk in a hoarded environment can be conceptualized.

- It is intended as an initial and brief assessment to aid in determining the nature and parameters of the hoarding problem and organizing a plan from which further action may be taken—including immediate intervention, additional assessment or referral.

- HOMES can be used in a variety of ways, depending on needs and resources. It is recommended that a visual scan of the environment in combination with a conversation with the person(s) in the home be used to determine the effect of clutter/hoarding on Health, Obstacles, Mental Health, Endangerment and Structure in the setting.

HOMES® Multi-disciplinary Hoarding Risk Assessment

❑ **H**ealth

❑ Cannot use bathtub/shower ❑ Cannot prepare food ❑ Presence of spoiled food ❑ Presence of insects/rodents
❑ Cannot access toilet ❑ Cannot sleep in bed ❑ Presence of feces/Urine (human or animal) ❑ Presence of mold or
❑ Garbage/Trash Overflow ❑ Cannot use stove/fridge/sink ❑ Cannot locate medications or equipment chronic dampness
Notes:_____

❑ **O**bstacles

❑ Cannot move freely/safely in home ❑ Unstable piles/avalanche risk
❑ Inability for EMT to enter/gain access ❑ Egresses, exits or vents blocked or unusable
Notes:_____

❑ **M**ental health (Note that this is not a clinical diagnosis; use only to identify risk factors)

❑ Does not seem to understand seriousness of problem ❑ Defensive or angry ❑ Unaware, not alert, or confused
❑ Does not seem to accept likely consequence of problem ❑ Anxious or apprehensive
Notes:_____

❑ **E**ndangerment (evaluate threat based on other sections with attention to specific populations listed below)

❑ Threat to health or safety of child/minor ❑ Threat to health or safety of person with disability
❑ Threat to health or safety of older adult ❑ Threat to health or safety of animal
Notes:_____

❑ **S**tructure & Safety

❑ Unstable floorboards/stairs/porch ❑ Leaking roof ❑ Electrical wires/cords exposed ❑ No running water/plumbing problems
❑ Flammable items beside heat source ❑ Caving walls ❑ No heat/electricity ❑ Blocked/unsafe electric heater or vents
❑ Storage of hazardous materials/weapons
Notes:_____

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HOMES® Multi-disciplinary Hoarding Risk Assessment (page 2)

Household Composition

# of Adults _____ _____ # of Children _____ # and kinds of Pets _____

Ages of adults: _____ Ages of children: _____ Person who smokes in home ❑ Yes ❑ No

Person(s) with physical disability_____ Language(s) spoken in home_____

Assessment Notes:_____
_____

Risk Measurements

❑ Imminent Harm to self, family, animals, public:_____

❑ Threat of Eviction: _____ ❑ Threat of Condemnation:_____

Capacity Measurements

        Instructions: Place a check mark by the items that represent the strengths and capacity to address the hoarding problem

❑ Awareness of clutter

❑ Willingness to acknowledge clutter and risks to health, safety and ability to remain in home/impact on daily life

❑ Physical ability to clear clutter

❑ Psychological ability to tolerate intervention

❑ Willingness to accept intervention assistance

Capacity Notes:_____
_____

Post-Assessment Plan/Referral _____
_____
_____

Date: _____ Client Name: _____ Assessor: _____

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HOMES® Multi-disciplinary Hoarding Risk Assessment

Instructions for Use

- **HOMES** Multi-disciplinary Hoarding Risk Assessment provides a structural measure through which the level of risk in a hoarded environment can be conceptualized.

- It is intended as an *initial* and *brief* assessment to aid in determining the nature and parameters of the hoarding problem and organizing a plan from which further action may be taken-- including immediate intervention, additional assessment or referral.

- **HOMES** can be used in a variety of ways, depending on needs and resources. It is recommended that a visual scan of the environment in combination with a conversation with the person(s) in the home be used to determine the effect of clutter/hoarding on **H**ealth, **O**bstacles, **M**ental Health, **E**ndangerment and **S**tructure in the setting.

- The Family Composition, Imminent Risk, Capacity, Notes and Post-Assessment sections are intended for additional information about the hoarded environment, the occupants and their capacity/strength to address the problem.

Clutter Image Rating System

©International OCD Foundation

Available online [here](#).

- This tool is designed to get an accurate sense of a clutter problem through a series of pictures of rooms in various stages of clutter—from completely clutter-free to severely cluttered. First responders can pick out the picture in each sequence that comes closest to the clutter in their own living room, kitchen, and bedroom.
- In general, clutter that reaches level 4 or higher impinges enough on people's lives that it is encouraged for them to get help for their hoarding problem.

Clutter Image Rating Scale: Kitchen

Please select the photo below that most accurately reflects the amount of clutter in your room.

Clutter Image Rating: Bedroom

Please select the photo that most accurately reflects the amount of clutter in your room.
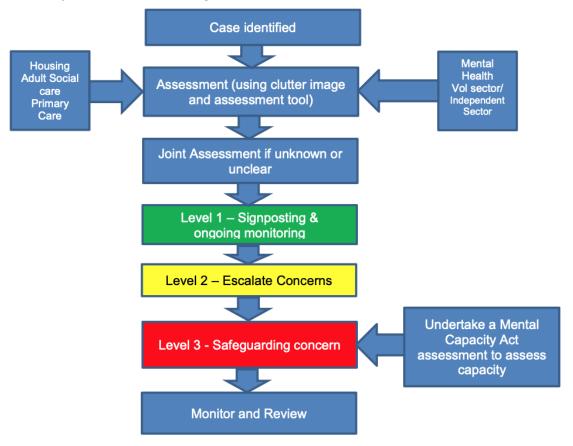
Clutter Image Rating: Living Room

Please select the photo below that most accurately reflects the amount of clutter in your room.

Process for Clutter Image Rating Tool (CIRT)

The flow chart below sets out the process for use of the Clutter Image Rating Tool. If in doubt, please ask your team leader / manager for assistance.

```
                        ┌─────────────────────┐
                        │   Case identified   │
                        └─────────────────────┘
                                  │
                                  ▼
┌──────────────┐        ┌─────────────────────────┐        ┌──────────────┐
│ Housing      │───────▶│ Assessment (using       │◀───────│ Mental       │
│ Adult Social │        │ clutter image           │        │ Health       │
│ care         │        │ and assessment tool)    │        │ Vol sector/  │
│ Primary      │        │                         │        │ Independent  │
│ Care         │        │                         │        │ Sector       │
└──────────────┘        └─────────────────────────┘        └──────────────┘
                                  │
                                  ▼
                        ┌─────────────────────────┐
                        │ Joint Assessment if     │
                        │ unknown or unclear      │
                        └─────────────────────────┘
                                  │
                                  ▼
                        ┌─────────────────────────┐
                        │ Level 1 – Signposting & │
                        │ ongoing monitoring      │
                        └─────────────────────────┘
                                  │
                                  ▼
                        ┌─────────────────────────┐
                        │ Level 2 – Escalate      │
                        │ Concerns                │
                        └─────────────────────────┘
                                  │
                                  ▼
                        ┌─────────────────────────┐        ┌──────────────────┐
                        │ Level 3 - Safeguarding  │◀───────│ Undertake a      │
                        │ concern                 │        │ Mental Capacity  │
                        └─────────────────────────┘        │ Act assessment   │
                                  │                        │ to assess        │
                                  ▼                        │ capacity         │
                        ┌─────────────────────────┐        └──────────────────┘
                        │ Monitor and Review      │
                        └─────────────────────────┘
```

Please use the clutter image rating to assess what level the adult's hoarding problem is at:

Images 1- 3 Level 1

Images 4- 6 Level 2

Images 7- 9 Level 3

Then refer to the clutter assessment tool to guide which details the appropriate action you should take. Record all actions undertaken in the agency's recording system, detailing conversations with other professionals, actions taken and action yet to be taken.

Home Environment Index (HEI)

©Rasmussen et al., 2014

Available online here.

- The HEI tool was developed as a measure of squalor associated with hoarding.
- To score the HEI, sum the responses for all 15 items—a score of 2 or above on any question warrants attention.

Home Environment Index (HEI)

Date: _____

Clutter and hoarding problems can sometimes lead to sanitation problems. Please circle the answer that best fits the current situation in the home.
To what extent are the following situations present in the home?

1. Fire hazard
   - ⃝ 0 = No fire hazard
   - ⃝ 1 = Some risk of fire (for example, lots of flammable material)
   - ⃝ 2 = Moderate risk of fire (for example, flammable materials near heat source)
   - ⃝ 3 = High risk of fire (for example, flammable materials near heat source; electrical hazards, etc.)

2. Moldy or rotten food
   - ⃝ 0 = None
   - ⃝ 1 = A few pieces of moldy or rotten food in kitchen
   - ⃝ 2 = Some moldy or rotten food throughout kitchen
   - ⃝ 3 = Large quantity of moldy or rotten food in kitchen and elsewhere

3. Dirty or clogged sink
   - ⃝ 0 = Sink empty and clean
   - ⃝ 1 = A few dirty dishes with water in sink
   - ⃝ 2 = Sink full of water, possibly clogged
   - ⃝ 3 = Sink clogged, with evidence that it has overflowed onto counters, etc.

4. Standing water (in sink, tub, other container, basement, etc.)
   - ⃝ 0 = No standing water
   - ⃝ 1 = Some water in sink/tub
   - ⃝ 2 = Water in several places, especially if dirty
   - ⃝ 3 = Water in numerous places, especially if dirty

5. Human/animal waste/vomit

○ 0 = No human waste, animal waste, or vomit visible
○ 1 = No human waste or vomit; no animal waste or vomit outside cage or box
○ 2 = Some animal or human waste or vomit visible (for example, in unflushed toilet)
○ 3 = Animal or human waste or vomit on floors or other surfaces

6. Mildew or mold

○ 0 = No mildew or mold detectable
○ 1 = Small amount of mildew or mold in limited amounts and expected places (for example, on edge of shower curtain or refrigerator seal)
○ 2 = Considerable, noticeable mildew or mold
○ 3 = Widespread mildew or mold on most surfaces

7. Dirty food containers

○ 0 = All dishes washed and put away
○ 1 = A few unwashed dishes
○ 2 = Many unwashed dishes
○ 3 = Almost all dishes are unwashed

8. Dirty surfaces (floors, walls, furniture, etc.)

○ 0 = Surfaces completely clean
○ 1 = A few spills, some dirt or grime
○ 2 = More than a few spills, may be a thin covering of dirt or grime in living areas
○ 3 = No surface is clean; dirt or grime covers everything

9. Piles of dirty or contaminated objects (bathroom tissue, hair, toilet paper, sanitary products, etc.)

○ 0 = No dirty or contaminated objects on floors, surfaces, etc.
○ 1 = Some dirty or contaminated objects present around trash cans or toilets
○ 2 = Many dirty or contaminated objects fill bathroom or area around trash cans
○ 3 = Dirty or contaminated objects cover the floors and surfaces in most rooms

10. Insects

○ 0 = No insects are visible
○ 1 = A few insects visible; cobwebs and/or insect droppings present
○ 2 = Many insects and droppings are visible; cobwebs in corners
○ 3 = Swarms of insects; high volume of droppings; many cobwebs on household items

11. Dirty clothes
○ 0 = Dirty clothes placed in hamper; none are lying around
○ 1 = Hamper is full; a few dirty clothes lying around
○ 2 = Hamper is overflowing; many dirty clothes lying around
○ 3 = Clothes cover the floor and many other surfaces (bed, chairs, etc.)

12. Dirty bed sheets/linens
○ 0 = Bed coverings very clean
○ 1 = Bed coverings relatively clean
○ 2 = Bed coverings dirty and in need of washing
○ 3 = Bed coverings very dirty and soiled

13. Odor of house
○ 0 = No odor
○ 1 = Slight odor
○ 2 = Moderate odor; may be strong in some parts of house
○ 3 = Strong odor throughout house

During the last month, how often did you (or someone in your home) do each of the following activities?

14. Do the dishes
○ 0 = Daily or every 2 days; 15 to 30 times per month
○ 1 = 1 or 2 times a week; 4 to 10 times per month
○ 2 = Every other week; 2 to 3 times per month
○ 3 = Rarely; 0 times per month

15. Clean the bathroom
○ 0 = Daily or every 2 days; more than 10 times per month
○ 1 = 1 or 2 times a week; 4 to 10 times per month
○ 2 = Every other week; 2 to 3 times per month
○ 3 = Never; 0 times per month

Environmental Cleanliness and Clutter Scale

©Graeme & Snowdon, 2012

Available online here through the University of Wisconsin-Madison.

- This scale was developed to rate the degree and various aspects of uncleanliness will facilitate description and research in cases of severe domestic squalor.

Environmental Cleanliness and Clutter Scale (ECCS)*

This form has been designed for service providers to respond to situations involving squalor. The form assists with rating the cleanliness of a person's accommodation.

This first page may be removed if it is desirable to de-identify the person when communicating with other agencies.

Demographic details			
Name of person	Surname	Other names	
Date of birth *and/or* approximate age of person			
Gender *(please circle)*	Male	Female	
Marital status *(please circle)*	Single Married/ de facto	Widowed Divorced Separated	Not sure?
Address			
Does he/she live alone? *(please circle)*	Yes	No	
If not, who with?			
Number and type of pets			
Home ownership	Owner Tenant – private	Tenant – DOH	Other – non-owner (e.g. lodger)
Accommodation type	House Unit	Bedsit	Other (specify)
How long has he/she been living like this? *(please circle)*	Less than 1 year 1–3 years	4–10 years	Over 10 years
Known medical illnesses and/or disabilities			
Mental disorders now or in the past			

---

* Source: Halliday G, Snowdon J, 2006 Environmental Cleanliness and Clutter Scale (ECCS) based on the version devised by Snowdon (1986), which mostly used items listed by Macmillan & Shaw (1966). Some descriptions used by Samios (1996) in her adaptation of the scale have been included.

Raters should circle the box or number that best fits their observations in relation to the different items. These descriptions are meant to be indicative, but raters may decide between one category and another based on aspects not mentioned in the boxes.

Name of rater:	
Rater's phone no:	Date:

A	Accessibility (clutter)			
	0	1	2	3
	Easy To enter and move about dwelling.	**Somewhat Impaired** access, but can get into all rooms.	**Moderately Impaired** access. Difficult or impossible to get into one or two rooms or areas.	**Severely impaired** access, for example, obstructed front door. Unable to reach most or all areas in the dwelling.
	0–29%	30–59%	60–89%	90–100%
	of floor space inaccessible for use or walking across			

B	Accumulation of refuse or garbage			
	In general, is there evidence of excessive accumulation of garbage or refuse, eg, food waste, packaging, plastic wrapping, <u>discarded</u> containers (tins, bottles, cartons, bags) or other <u>unwanted</u> material?			
	0	1	2	3
	None	**Little** Bins overflowing and/or up to 10 emptied containers scattered around.	**Moderate** Garbage and refuse littered throughout dwelling. Accumulated bags, boxes and/or piles of garbage that should have been disposed of.	**Lots** Garbage and food waste piled knee-high in kitchen and elsewhere. Clearly no recent attempt to remove refuse and garbage

C	Accumulation of items of little obvious value			
	In general, is there evidence of accumulation of items that most people would consider are of little use or should be thrown away?			
	0	1	2	3
	None	**Some accumulation**, but collected items are organised in some way and do not much impede movement or prevent cleaning or access to furniture and appliances.	**Moderate excessive accumulation:** items cover furniture in most areas, and have accumulated throughout the dwelling so that it would be very difficult to keep clean.	**Markedly excessive accumulation:** items piled at least waist-high in all or most areas. Cleaning would be virtually impossible: most furniture and appliances are inaccessible.

Please indicate types of items that have been accumulated:

❑ Newspapers, pamphlets, and so on   ❑ Clothing   ❑ Other items

(what? ....)

❑ Electrical appliances   ❑ Plastic bags full of items

(If known, what items? ....)

D	**Cleanliness** of floors and carpets (excluding toilet and bathroom)			
	0	1	2	3
	Acceptably clean in all rooms.	**Mildly dirty** Floors and carpets look as if not cleaned or swept for days. Scattered rubbish.	**Very dirty** Floors and carpets very dirty look as if not cleaned for months. Rate 1 if only one room or small area affected.	**Exceedingly filthy** With rubbish or dirt throughout dwelling. Excrement usually merits a 3 score.

E	**Cleanliness** of walls and visible furniture surfaces and window sills			
	0	1	2	3
	Acceptably clean in all rooms.	**Mildly dirty** Dusty or dirty surfaces. Dirt comes off walls on damp rag or finger.	**Very dirty** Grime or dirt on walls. Cobwebs and other signs of neglect. Greasy, messy, wet and/or grubby furniture.	**Exceedingly filthy** Walls, furniture, surfaces are so dirty (for example, with faeces or urine) that rater wouldn't want to touch them.

F	**Bathroom and toilet**			
	0	1	2	3
	Reasonably clean.	**Mildly dirty** Untidy, uncleaned, grubby floor, basin, toilet, walls and so on. Toilet may be unflushed.	**Moderately dirty** Large areas of floor, basin, shower/bath, are dirty, with scattered rubbish, hair, cigarette ends, and so on. Faeces and/or urine on outside of toilet bowl.	**Very dirty** Rubbish and/or excrement on floor and in bath or shower and/or basin. Uncleaned for months or years. Toilet may be blocked and bowl full of excreta.

G	**Kitchen and food**			
	0	1	2	3
	Clean. Hygienic.	**Somewhat dirty and unhygienic** Cooktop, sink untidy and surfaces dirty, maybe with some spilt food. Refuse mainly in garbage bin. Food that could go off (eg, meat, remains of meal) left uncovered and out of fridge. Rate 1 if no food, but fridge dirty.	**Moderately dirty and unhygienic** Oven, sink, surfaces, floor are dirty, with piles of unwashed crockery and utensils and so on. Bins overflowing. Some rotten or mouldy food. Fridge unclean.	**Very dirty and unhygienic** Sink, cooktop, insides of all cupboards filthy. Large amount of refuse and garbage over surfaces and floor. Much of the food is putrid, covered with mould and/or rotten, and unsafe to eat. Rate 3 if maggots seen.

H	Odour			
	0	1	2	3
	Nil. Pleasant.	**Unpleasant**, eg, urine smell, unaired.	**Moderately malodorous:** bad, but rater can stay in room.	**Unbearably malodorous:** rater has to leave room very soon because of smell.

I	Vermin (Please circle: rats, mice, cockroaches, flies, fleas, other)			
	0	1	2	3
	None	**Few** (for example, cockroaches).	**Moderate:** visible evidence of vermin in moderate numbers for example, droppings and chewed newspapers.	**Infestation:** alive and/or dead in large numbers.

J	SLEEPING AREA			
	0	1	2	3
	Reasonably clean and tidy.	**Mildly unclean** Untidy. Bed unmade. Sheets unwashed for weeks.	**Moderately dirty** Bed sheets unclean stained, for example, with faeces or urine. Clothes and/or rubbish over surrounding floor areas.	**Very dirty** Mattress or sleeping surface unclean or damaged. Either no sheets or (if present) extremely dirty bedding/linen.

Add up circled numbers to provide **total score**:

Do you think this person is living in **squalor?** (circle one)	**No**	**Yes**, mild – not clutter	**Yes**, moderate – not clutter	**Yes**, severe – not clutter
	Clutter – (lots), not squalor	Yes, mild + clutter (lots)	Yes, moderate + clutter (lots)	Yes, severe + clutter (lots)

Supplementary questions – to add to description, but not to score

Comments or description to clarify, amplify, justify or expand on above ratings:

Personal cleanliness
Describe the clothing worn by the occupant and their general appearance:

0	1	2	3
Clean and neat. Well cared for.	**Untidy, crumpled:** one or two dirty marks and in need of wash	**Moderately dirty:** with unpleasant odour. stained clothing.	**Very dirty:** stained, torn clothes, malodorous.

Is there running water in the dwelling?	YES or NO
Is electricity connected and working?	YES or NO
Can the dwelling be locked up and made secure?	YES or NO

Maintenance, upkeep, structure
This rates the state of repair and upkeep by owner/landlord. If the accommodation was cleaned up as much as possible, to what extent would the dwelling require painting, refurbishment, structural repairs and so on before it would be reasonably habitable?

0	1	2	3
None	**Little** – minor repairs and some painting.	**Fair amount** – some structural repairs plus painting.	**Lots** – major structural repairs required, and then painting.

To what extent do the living conditions make the dwelling unsafe or unhealthy for visitors or occupant(s)?			
0	1	2	3
Not at all	**Possible risk** – of injury for example, by falling.	**Considerable risk** – of fire, injury or health problem.	**Very unsafe** – the dwelling is so cluttered and unhealthy that people should not enter it, (except specialists with appropriate clothing and equipment) and/or there is high fire-risk.

Sample Assessment Form and Clutter Interview

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Available online here, Appendix 2 and 3, pages 27–32.

- Also developed by the Hoarding Best Practice Committee, these tools form part of the initial meeting and assessment phase. This might include open ended questions, the Clutter Image Rating scale, the Hoarding Interview, Activities of Daily Living Scale and general questions about what they are interested in learning and changing.

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SAMPLE ASSESSMENT FORM [APPENDIX 2]

DATE: _____

CLIENT NAME: _____ LIKES TO BE REFERRED TO: _____

ADDRESS: _____ CITY/ZIP: _____

PHONE: _____ E-MAIL: _____

PLEASE CHECK ALL THAT APPLY (☑)

BEST TIME TO WORK TOGETHER: ☐ Morning ☐ Afternoon ☐ Late Afternoon

HOUSEHOLD:

☐ Single Family ☐ Market Apartment ☐ Subsidized Apartment ☐ Senior Housing ☐ Multi-Family

Other: _____

1. How long have you lived at your current residence: _____

   Prior Residence: _____

2. Does anyone else live with you in your home? ☐ Yes ☐ No

   If yes, who: _____

3. Are you currently seeing a therapist, counselor, psychiatrist, psychologists, or social worker for any reason? ☐ Yes ☐ No

   If yes, who: _____

4. Have you ever received any previous mental health treatment? ☐ Yes ☐ No

   Where? _____

5. Have you worked with anyone in the past, attempting to process your belongings? ☐ Yes ☐ No

   If yes, who: _____

   How did they work out? _____

6. Do you have conditions that limit your physical mobility? ☐ Yes ☐ No

   If yes, explain: _____

   _____

7. Are you on any medications? ☐ Yes ☐ No

   If yes, what? _____

   _____

   _____

   _____

   _____

8. Are there any animals present in your home?   ☐ Yes ☐ No

   If yes, how many/what kind? _____

9. Are there any weapons in your home? ☐Yes☐ No

   If yes, what and where are they? _____

PERSONAL:

1. What do you value, what is important to you: _____

   _____

   _____

2. Interest/hobbies:_____

   _____

   _____

3. Education:_____

4. Did you work outside the home?_____

5. Likes: _____   Dislikes: _____

   _____   _____

   _____   _____

   _____   _____

   _____   _____

Hoarding: Best Practices Guide

SAMPLE CLUTER IMAGING RATING SCALE (APPENDIX 3)

The following questions help me understand how the clutter affects you.
Please answer <u>honestly.</u> There are no right or wrong answers.

CLUTTER IMAGE SCALE RATING: At beginning, middle and end of work together   _____

Client rates and Hoarding Specialist rates   _____

CLUTTER INTERVIEW:

To what extent do you find it difficult discarding ordinary things that other people would get rid of?

☐ Not at all Difficult   ☐ Mildly   ☐ Moderately   ☐ Extremely Difficult

Because of the clutter or number of possessions, how difficult is it for you to use the rooms in your home?

☐ Not at all Difficult   ☐ Mildly   ☐ Moderately   ☐ Extremely Difficult

To what extent do you currently have a problem with collecting free things or buying more things than you need or can use or can afford?

☐ Not at all Difficult   ☐ Mildly   ☐ Moderately   ☐ Extremely Difficult

To what extent do you experience emotional distress because of clutter, difficulty discarding or problems with buying or acquiring things?

☐ Not at all Difficult   ☐ Mildly   ☐ Moderately   ☐ Extremely Difficult

NOTES:

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

Hoarding: Best Practices Guide

PLEASE INDICATE THE EXTENT TO WHICH CLUTTER INTERFERES WITH YOUR ABILITY TO DO EACH OF THE FOLLOWING ACTIVITIES: <u>*Circle corresponding numbers*</u>

Activities of Daily Living	N/A	Can Do	Can Do With Difficulty	Unable to Do	Comments
Prepare Food (cut up food, cook it)	0	1	2	3	
Use Refrigerator	0	1	2	3	
Use Stove	0	1	2	3	
Use Kitchen Sink	0	1	2	3	
Eat at Table	0	1	2	3	
Move Around Inside of House	0	1	2	3	
Exit Home Quickly	0	1	2	3	
Use Toilet (getting to the toilet)	0	1	2	3	
Use Bath/Shower	0	1	2	3	
Use bathroom Sink	0	1	2	3	
Answer Door Quickly	0	1	2	3	
Sit on Your Sofas and Chairs	0	1	2	3	
Sleep in Your Bed	0	1	2	3	
Clean the House	0	1	2	3	
Do Laundry	0	1	2	3	
Find Important Things (bills)	0	1	2	3	
Care for Animals	0	1	2	3	

Hoarding: Best Practices Guide

SUPPORT NETWORK:

1. Do you have family/friends in the area? ☐ Yes ☐ No
   If yes, who: _____

2. Does anyone get upset by your collecting and clutter or do they mostly tolerate it?

   _____

   _____

3. Do your family members or friends help you get items or store them for you? _____

   _____

4. Does anyone help you organize things you can't deal with? _____

   _____

5. Do you prevent others from touching your things? _____

   _____

6. Are your family members or friends supportive of you getting help/treatment?   If so, would any of them be
   interested in coming with you to a session? _____

   _____

   _____

TO ACCOMPLISH AT THE FIRST FEW MEETINGS:
ISSUES WITH CLUTTER:

1. Are you currently involved with anyone (landlord, housing court, board of health, fire dept.) because of the
   clutter in your home?   ☐ Yes ☐ No
   If yes, explain:
   _____

2. What kind of things do you save? _____

   _____

3. Describe to me your emotions when you look at or think about the clutter? (e.g. anxiety, guilt, sadness,
   happiness)_____

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4. How much discomfort would you feel if you had to get rid of some of your _____
    (Ask about Each Category of saved items) with 0 being no discomfort to 100 being the most you have ever
    felt.

5.   Let's talk about the rooms in your home. How much does clutter interfere with how you'd like to use
     each room and which rooms bother you the most? (Let client guide you through the home.. compliment at
     least one item (a nice photo or lamp...).

_____

_____

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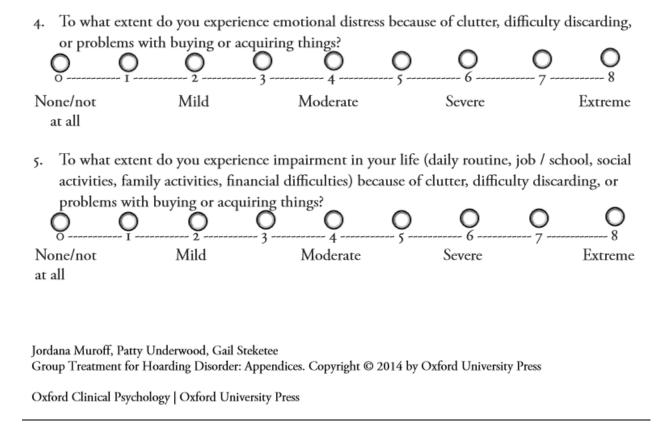
Hoarding Rating Scale

©Tolin, Frost, & Steketee, 2010

Available online here through Oxford Clinical Psychology.

- The Hoarding Rating Score can be used to assess the severity of hoarding behaviors.
- Its 5 questions assess clutter, difficulty discarding, acquisition, distress and interference with a Likert scale of preferences (from "not difficult at all" to "Extremely difficult"). Each of the 5 dimensions can be assessed using cutoff scores and typical HRS scores.

Hoarding Rating Scale (HRS)

Date: _____

1. Because of the clutter or number of possessions, how difficult is it for you to use the rooms in your home?

    0 ---------- 1 ---------- 2 ---------- 3 ---------- 4 ---------- 5 ---------- 6 ---------- 7 ---------- 8

Not at all Difficult	Mild	Moderate	Severe	Extremely Difficult

2. To what extent do you have difficulty discarding (or recycling, selling, giving away) ordinary things that other people would get rid of?

    0 ---------- 1 ---------- 2 ---------- 3 ---------- 4 ---------- 5 ---------- 6 ---------- 7 ---------- 8

Not at all difficult	Mild	Moderate	Severe	Extremely difficult

3. To what extent do you currently have a problem with collecting free things or buying more things than you need or can use or can afford? [Use the scale below]

    0 ---------- 1 ---------- 2 ---------- 3 ---------- 4 ---------- 5 ---------- 6 ---------- 7 ---------- 8

No problem	Mild, occasionally (less than weekly) acquires items not needed, or acquires a few unneeded items	Moderate, regularly (once or twice weekly) acquires items not needed, or acquires some unneeded items	Severe, frequently (several times per week) acquires items not needed, or acquires many unneeded items	Extreme, very often (daily) acquires items not needed, or acquires large numbers of unneeded items

4. To what extent do you experience emotional distress because of clutter, difficulty discarding, or problems with buying or acquiring things?

O ─────── 1 ─────── 2 ─────── 3 ─────── 4 ─────── 5 ─────── 6 ─────── 7 ─────── 8

None/not at all   Mild   Moderate   Severe   Extreme

5. To what extent do you experience impairment in your life (daily routine, job / school, social activities, family activities, financial difficulties) because of clutter, difficulty discarding, or problems with buying or acquiring things?

O ─────── 1 ─────── 2 ─────── 3 ─────── 4 ─────── 5 ─────── 6 ─────── 7 ─────── 8

None/not at all   Mild   Moderate   Severe   Extreme

Jordana Muroff, Patty Underwood, Gail Steketee
Group Treatment for Hoarding Disorder: Appendices. Copyright © 2014 by Oxford University Press

Oxford Clinical Psychology | Oxford University Press

Treatment Planning

The planning stage is focused on goal development based on a mutual understanding of the client's problems, lifestyle, and environment. During this stage, the worker and client work together to develop an action plan that is suited to the client's unique circumstances. This action plan should include specific objectives and tasks that work toward accomplishing the stated goals, a clear timeline for action, and expectations of who will do what.

Source: https://mswcareers.com/generalistinterventionmodel/

Sample Consent for Services and Service Plan

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Available online here, Section 4 and Appendices 4 and 5.

- This section of the Hoarding Best Practices Guide includes steps to plan and carry out an early intervention, including initiating the conversation about a service plan, a sample consent form and sample service plan form.

▶ Section ❹

EARLY INTERVENTION, WHEN YOU ARE ABLE TO DO PREVENTION WORK WITH OLDER ADULTS WHO HOARD

- **Pre-Meeting/Referral Process**: Gather as much information as you can over the phone from the referring person or the individual themselves. The more you know ahead of time the more you will be able to plan your initial approach. It is also important to know the condition of the home and prepare for any precautions you want to take when entering the home (more information Section 9). [Referral Form Appendix 1]

- **Schedule the Initial Meeting:** Depending on the person's comfort level you might meet at their home, the senior center, a park bench and it might just be a quick meet and greet or a full assessment and tour of the home. Remember you are building a long-term relationship so it is ok to take it slow and show the person that you are willing to partner in their clinical treatment/learning at their pace.

- **Assessment Tools:** This might include open ended questions, the Clutter Image Rating scale, the Hoarding Interview, Activities of Daily Living Scale and general questions about what they are interesting in learning and changing. [Assessment Tool - Appendix 2]

- **Create a Service Plan Agreement Together:** The service plan is used to formulize your partnership, identify the overall goal (often to maintain safety in the home), and both short and long term goals. Both the client and the professional sign the document to demonstrate that this is a joint effort and agreed upon plan of action. Review and reference often. The agreement should be used to guide your sessions and work time together. [Service Plan- Appendix 5]

- **Establish and Plan Consistent Appointments**: Mark the appointment date on a calendar in the person's home. It is a good practice to meet weekly/or every other week to start. Plan to move to once a month monitoring or checking in when the goals have been met. Make sure that you show up on time for appointments and model time management skills during your meetings. Make sure that the client knows how to contact you if they need to cancel.

- **Schedule 1 1/2 -2 Hour (max) Meetings:** *Make it clear what your role is-* supportive, therapeutic, and educational. You are not a heavy chore worker and this should be discussed at the beginning. With any type of memory or personality issues roles are often confused and it is important to discuss with the client right away so they are clear on what work you and others entering the home are there to perform.

- **Heavy Chore, Homemaking, Companion Services, Therapy, Supportive Housing Assistance:** These issues should be discussed from the beginning as a possible means of accomplishing the individual's short and long term goals. Student interns and volunteers can also be used with clients who *want to do the work* and need the accountability piece of having someone present in their home.

- **If the Person Who Hoards is Actively Acquiring Start Your Work Here:** You want to help the person learn that without limiting the acquiring the de-cluttering work won't go far.*

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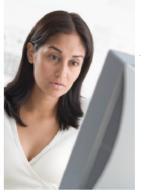
- **A Plan for Each Visit**:
  Check-In - Talk about homework, success/challenges. Make time to discuss challenges of the week and what is holding them back. You might run through a visualization of the small area you are working on together and the goals for that small area. Also talk about what it will look like and feel like after the work is done.
  Exposure Work - Work on an area for 30-40 minutes having the client do the hands on work. You are helping the client build a tolerance for de-cluttering and showing them that they can in fact do the work. Supporting, building their self-esteem, helping to stay focused and on task, and motivating the person to work towards their goals is your role during exposure work.
  Check-Out- How did it feel, what are goals for next week.*

- **Areas to Target:** Depending on the short and long term goals you will discuss the three areas of hoarding work at each visit: acquiring, sorting and discarding.

- **When is the Work Done:** This is a difficult question. Simply put the work might never be done, at least for the client. The first step for you to step out as the professional might be to move to meeting less frequently from every two or three weeks to a once a month monitoring meetings. After that offer that you are available for check-ins and to call if things build up at some time in the future. Success in hoarding work is hard to define because everyone has a different view of what is good enough. If the client feels successful in reaching their goals both short and long term and their home is safe and clear of health concerns then it is time to step out and let them manage their "chronic condition" on their own. You as the worker need to be careful and consistent on maintaining professional boundaries and not push your own agenda for your client's home. *They are in charge* and will only be successful if you let them know that their ideas matter. We are not striving to create Martha Stewart, just safe and healthy homes … whatever that means to the person with whom you are working with.

*Resources/Examples: What to do in sessions (the work) can be found on the reference page (Section 11)

"A Note on Notes":
The depth of notes you document will depend on your agencies requirements. In the very least keep a spreadsheet of clients and brief notes on what was accomplished during your visit. You might also want to keep a chart with important information and your notes that you jot down during your visit and any other important information- resources… You will also want to document to your agency how many clients you worked with and the number who refused services.

Hoarding: Best Practices Guide

SAMPLE CONSENT FOR SERVICES [APPENDIX 4]

I _____ agree to work with _____ on the projects listed below.

We have agreed to work together on _____on a _____basis.

Date/Time   Timeframe

I agree to use the sessions to learn why I hold onto things in my home and develop organizing, prioritizing and functioning/systems skills. I understand that _____ and I will work together processing through my belongings, and that it is my decision what I discard. I agree to work on homework assignments between sessions. This agreement is a fluid document and can be adjusted throughout our work together. We will review if we will continue to work together in 30 days, 60 days, and during a 6 month review.

Overall Goal of Work Together:_____

_____

Revised Goal _____:_____

Date

_____

_____

Achieved Goal _____:_____

Date

_____

_____

_____   _____

NAME   **DATE**

_____   _____

NAME   **DATE**

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SAMPLE SERVICE PLAN [APPENDIX 5]

Short-Term Interventions: (30-60 Days) *This should include any immediate safety issues to be addressed.*

_____ Achieved: _____

_____ Achieved: _____

_____ Achieved: _____

Short-Term Coping Techniques to Use: (30-60 Days)

_____

_____

_____

Long-Term interventions: (60 Days- 6 Months) *Include less immediate concerns, which may require intensive work, coordination of additional services…*

_____ Achieved: _____

_____ Achieved: _____

_____ Achieved: _____

Long -Term Coping Skills to Work on and Develop: (60 Days to 6 Months)

_____

_____

_____

_____

_____

_____

_____

_____

_____

Treatment Best Practices

Case Management

CM approaches involve a collaborative team of care professionals and are used to provide access to a variety of services necessary in the ongoing treatment for those living with or affected by hoarding disorder. This approach uses social service workers to create an ongoing cushion of support and allows clients to safely and more effectively navigate care management resources (Bratiotis et al., 2019). CM is meant to be client-centered, focused on the moving toward one's goals and overall wellness through frequent, long-term care (Bratiotis et al., 2019). It is more than just a "brokering of resources," though this is certainly a key factor in processes, such as benefits paperwork and referrals for treatment (Bratiotis et al., 2019, pg. 94).

Cognitive Behavioral Therapy (CBT)

CBT uses several techniques that can be especially effective in bringing about positive change in work with clients, as well as a number of related techniques that can be used in conjunction with CBT to bolster its effectiveness. One technique is Socratic Questioning, a strategy that is considered to be a pillar of CBT and can be critical to its success (Roth & Pilling, 2007, as cited in Braun, Strunk, Sasso, & Cooper, 2015). The process of Socratic Questioning helps guide the client's thought process and ultimately behavior in the direction of the established therapeutic goals (Braun et al., 2015). The process is intended to be engaging and centered on critical thinking to help the client examine their current situation (Braun et al., 2015). Socratic-based questions are typically open-ended in nature and are designed to further broaden the client's perspective (Braun et al., 2015).
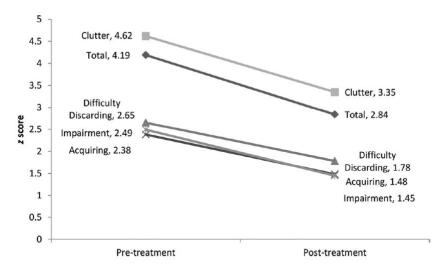

Figure 2. *z* Scores for hoarding outcomes from pre- to posttreatment.

(*Source*: Tolin, Frost, Steketee, & Muroff, 2015)

Motivational Interviewing (MI)

MI can be used with CBT when the person with hoarding disorder expresses ambivalence toward treatment or hoarding disorder itself. The goal of this kind of intervention is to motivate change from within the client and reduce the level of outward defensiveness of the behavior. A major component of MI is the positive buildup of confidence in the client's ability to make a change and incorporate their own vision of how a change could and should occur. The entire process looks at how the person's life is being lived, how clutter affects it, and how basic values the client holds may have fallen by the wayside as a result of their current living situation.

(*Source:* Treatment of HD—Motivational Interviewing, n.d.)

Group Therapy

Support groups for clients have been a key part of treatment success because participants are able to feel safe and connected with peers who are experiencing similar situations (MassHousing, 2012). The purpose behind a support group dedicated to people with hoarding disorder is to provide a safe space of commonality, where members may learn about their disorder, as well as tactics to address behaviors and thoughts related to the disorder (MassHousing, 2012). Group therapy is often much less expensive than one-on-one counseling or therapy sessions; it can be an affordable treatment option for those with hoarding disorder who may not have the resources to pay for other types of treatment (MassHousing, 2012). These groups allow those with hoarding disorder wider access to clinicians (MassHousing, 2012).

Psychoeducational groups show members how to work through the thoughts and behaviors that influence the disorder and provide homework for members to reinforce group learning (MassHousing, 2012). Group members are asked to reflect on and think about their physical and social environments and how these affect and interact with their hoarding disorder, both positively and negatively (MassHousing, 2012).

Support groups are also a great way to address and work with a community that might be more hesitant to recognize or discuss hoarding. They can operate under a non-stigmatizing name such as the "Declutter Group" (MassHousing, 2012). They are typically closed, meaning members may not join in after the first meeting occurs, and usually include 5–8 individuals. Keeping the membership within this range helps ensure that all voices in the group can be heard and addressed—it keeps the group at a manageable size (MassHousing, 2012).

Group therapy can reduce social isolation and stigma, especially when support groups are combined with CBT techniques, ultimately forming a therapy called G-CBT (group cognitive behavioral therapy) (Muroff, Steketee, Rasmussen, Gibson, Bratiotis, & Sorrentino, 2009). G-CBT has been proven effective in treating clients with hoarding disorder who have comorbid disorders such as anxiety and depression (Muroff et al., 2009). This type of treatment may be particularly important for providers because hoarding disorder does not typically present on its own (Muroff et al., 2009).

Harm Reduction

Harm reduction approaches may be particularly useful when working with a client who is not willing to actively participate in treatment. Harm reduction is founded on the principle

that the consequences of high-risk behaviors can be decreased without the behavior stopping altogether (Tompkins, 2011). Harm reduction practices, as they relate to hoarding disorder, include small, reasonable goals (relative to the client) that are centered on the management of symptoms rather than the treatment of symptoms (Tompkins, 2011). This may be an approach worth considering for those who do not see their hoarding disorder as a problem or who have low insight as it relates to their disorder and its effects (Tompkins, 2011).

Harm reduction (HR) may be a more reasonable and accepted approach to working with those with hoarding disorder since it does not require a change in one's core beliefs or thought processes (Tompkins, 2011). Harm reduction does not require "acceptance of treatment" and instead focuses on only discarding items that put the individual in immediate danger, whether that be with law enforcement, their landlord, or actual physical danger (Tompkins, 2011). Harm reduction allows the person to continue to acquire and focuses instead on management and maintenance as issues arise (Tompkins, 2011). This approach is best utilized in a team and can be interwoven within a task force or coalition's overall goals (Tompkins, 2011).

Implementation/Intervention

Intervention is the stage when the client and worker mobilize resources to implement the action plan, both complying with their agreed-upon expectations. During this stage, the worker should monitor the client's progress and the client should bring to the social worker's attention any challenges, obstacles, or threats to carrying out the action plan. Plans and timelines can be adjusted as needed to ensure that the intervention is working for the client.
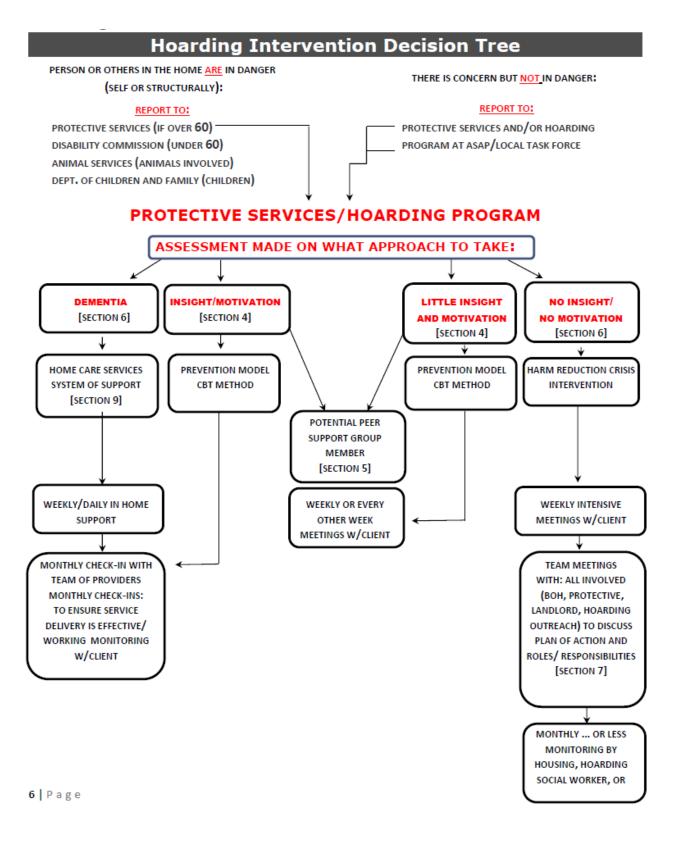
Source: https://mswcareers.com/generalistinterventionmodel/

Hoarding Intervention Decision Tree

©Hoarding: Best Practices Guide

Available online here, Section 3, page 6.

● The Hoarding Best Practices Committee formulated this decision tree to aid with understanding what approach to take based on the levels of insight, motivation, and dementia.

Hoarding Intervention Decision Tree

PERSON OR OTHERS IN THE HOME <u>ARE</u> IN DANGER (SELF OR STRUCTURALLY):

THERE IS CONCERN BUT <u>NOT</u> IN DANGER:

<u>REPORT TO:</u>

PROTECTIVE SERVICES (IF OVER **60**)
DISABILITY COMMISSION (UNDER **60**)
ANIMAL SERVICES (ANIMALS INVOLVED)
DEPT. OF CHILDREN AND FAMILY (CHILDREN)

<u>REPORT TO:</u>

PROTECTIVE SERVICES AND/OR HOARDING PROGRAM AT ASAP/LOCAL TASK FORCE

PROTECTIVE SERVICES/HOARDING PROGRAM

ASSESSMENT MADE ON WHAT APPROACH TO TAKE:

DEMENTIA [SECTION 6]

INSIGHT/MOTIVATION [SECTION 4]

LITTLE INSIGHT AND MOTIVATION [SECTION 4]

NO INSIGHT/ NO MOTIVATION [SECTION 6]

HOME CARE SERVICES SYSTEM OF SUPPORT [SECTION 9]

PREVENTION MODEL CBT METHOD

PREVENTION MODEL CBT METHOD

HARM REDUCTION CRISIS INTERVENTION

POTENTIAL PEER SUPPORT GROUP MEMBER [SECTION 5]

WEEKLY/DAILY IN HOME SUPPORT

WEEKLY OR EVERY OTHER WEEK MEETINGS W/CLIENT

WEEKLY INTENSIVE MEETINGS W/CLIENT

MONTHLY CHECK-IN WITH TEAM OF PROVIDERS MONTHLY CHECK-INS: TO ENSURE SERVICE DELIVERY IS EFFECTIVE/ WORKING MONITORING W/CLIENT

TEAM MEETINGS WITH: ALL INVOLVED (BOH, PROTECTIVE, LANDLORD, HOARDING OUTREACH) TO DISCUSS PLAN OF ACTION AND ROLES/ RESPONSIBILITIES [SECTION 7]

MONTHLY ... OR LESS MONITORING BY HOUSING, HOARDING SOCIAL WORKER, OR

Readiness to Change Questionnaire

Available online [here](#) through HoardingCapeCod.org.

- This 12-item questionnaire helps to assess how ready a person is to change their hoarding behaviors. It's scoring helps to distinguish between "pre-contemplation," "contemplation," and "action," and therefore guides the hoarding informed practitioner with next steps to take (e.g. leave brochures and information sheets).

Readiness to Change Questionnaire

(fill in the blank with the behavior)

	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree
1. My apt. is ok as it is	☐	☐	☐	☐	☐
2. I am trying to collect less than I used to	☐	☐	☐	☐	☐
3. I enjoy saving things but sometimes I collect too much	☐	☐	☐	☐	☐
4. I should cut down on my collecting items	☐	☐	☐	☐	☐
5. It's a waste of time thinking about my collecting items	☐	☐	☐	☐	☐
6. I have just recently changed my collecting habits	☐	☐	☐	☐	☐
7. Anyone can talk about wanting to do something about collecting, but I am actually doing something about It	☐	☐	☐	☐	☐
8. I am at the stage where I should think about collecting less	☐	☐	☐	☐	☐
9. My collecting is a problem	☐	☐	☐	☐	☐
10. It's alright for me to keep collecting as I do now	☐	☐	☐	☐	☐
11. I am actually changing my collecting habits right now	☐	☐	☐	☐	☐
12. My life would be the same, even if I collected less	☐	☐	☐	☐	☐

How to score the Stage of Change questionnaire

- The pre-contemplation items are numbers 1, 5, 10 and 12
- The contemplation items are numbers 3, 4, 8, and 9
- The action 2, 6, 7, 11
- The highest score represents the Stage of Change Designation

Scoring legend:

# of points	Response
-2	Strongly disagree
-1	Disagree
0	Unsure
+1	Agree
+2	Strongly Agree

Scale Scores:

Pre-contemplation _____

Contemplation _____

Action _____

The Highest Score represents the person's level of change

Appropriate response from helper depending on the person's stage of change

Stage	Response from Helper
Pre-contemplation	Leave brochure, information sheets, phone numbers, ask "How would you better off if you "collected" less
Contemplation	Write down pro's and cons of behavior, ask "How would you better off if you "collected" less
Action	Develop an action plan with the consumer immediately, follow up with the person

Socratic Questioning Example

The work on hoarding progressed slowly but steadily as she practiced making faster decisions about discarding information and challenged her own perfectionistic thoughts about needing to review articles thoroughly in case she missed something. Her clinician engaged in Socratic dialogue as Karen evaluated one of several boxes of magazines she was considering recycling:

T: What about this box of magazines? You said these are about 5 years old. What are you thinking about these?

K: They might come in useful sometime—restaurants or advice or whatever.

T: OK, that's a reason to save it. Do you have any reasons to get rid of this?

K: I don't have time to read them. And, I can get the information someplace else. These probably aren't very current anyway.

T: You don't have time and don't really need the information from this source. Any emotional reactions to getting rid of them?

K: Yes, it's like regret. I didn't finish them. That's frustrating.

T: Is it perfectionism related?

K: I don't know, I think so. It's like I didn't give it my all.

T: Is reading all of them something that merits your "all"?

K: That's a good question. I suppose some things should qualify but not others. There's the idea that I spent money on these and have been frivolous with money in the past, although not really with my subscriptions.

T: Does it feel wasteful?

K: Definitely, very wasteful. I used to feel compelled to read every article whether it was interesting to me or not. I'm out of that now, so it is just what's interesting. Some of those articles might be interesting.

T: So, you have succeeded in the past in beating perfectionistic thinking—when you stopped feeling compelled to read everything. Let's review what you've said [looking at the therapy goals]. You feel you should save them because they might be interesting, and you haven't given these your "all" and it seems wasteful. Reasons for getting rid of them are that you don't have time to read them and they are out of date now. Let me also ask if getting rid of them moves you in the direction of your goals; so, let's take a look at that list. What do you think?

K: Yes, this box has been in my study for at least 2 years. I don't have room for it, and it's like a noose around my neck.

T: How will you feel if you get rid of it? Do you think you can handle that?

K: I'm little anxious but I can handle it. OK [with a sigh], it's going into the recycle bin now.

(*Source:* Steketee & Tolin, 2011)

Motivational Interviewing Example

MI

Early in treatment, clinicians encourage clients to articulate their treatment goals (e.g., "be able to cook in my kitchen") and the values that matter most to them (e.g., "I want to be able to have my grandchildren visit"). In addition, therapists use motivational enhancement strategies (Miller & Rollnick, 2002) whenever they judge that motivation is lagging. For example, when clients miss sessions, arrive late, or fail to complete a homework assignment, the clinician asks questions and listens closely to detect ambivalence (uncertainty about whether he or she wants to correct hoarding or acquiring problems).

MI methods require training, because some techniques that work well to reduce reluctance are counterintuitive. For example, playing devil's advocate when the client is afraid to throw something out can prove effective:

Client: If I get rid of this, I might need it the next day. [verbalizes ambivalence]
Therapist: You've got a good point there. Sometimes it just seems like magic—as soon as you decide to toss it out, the very next day you find you need it. You know, maybe it's not a good idea to get rid of any of this. [plays devil's advocate]
C: Well, that might be taking it too far. [pushes back]
T: What do you mean? [asks for elaboration]
C: I know I don't need some of this. I just have trouble figuring out what. [expresses uncertainty]
T: Yeah that makes sense. We talked about the indecision—a real challenge. But if you can't figure it out, it really seems safer to keep it all. [affirms the problem; devil's advocate]
C: But then I have all this stuff I don't want. [pushes back]
T: That's a conundrum. What do you think you want to do with this? [acknowledges concern; asks for a decision]
C: I'm pretty sure I won't need this newspaper. It's really old. [signals residual ambivalence]
T: If you're not sure, maybe you should keep it. [plays devil's advocate]
C: Nah. This is junk. I'm gonna toss it. [expresses change talk]

(*Source:* Steketee & Tolin, 2011)

Harm Reduction Approach

5. ALTERNATIVE METHODS

5.1 The harm reduction approach:

Setting targets: Depending on the situation, converse with the landlord (or property standards or fire inspector) to determine, in advance, their expectations. Use these expectations as a guide for planning treatment with the tenant. It is important to have a relationship with the landlord and inform them that hazards could be uncovered as decluttering begins.

1. As a minimum standard, the goal should be a 1 meter clearance from the ceiling to allow air flow. This ensures that the smoke/fire alarm equipment has the air flow to work properly.
2. There should be no freestanding piles of clutter of more than 3-4 feet, to reduce the risk of toppling. Otherwise, items should be placed in secured shelving.
3. Three foot clearance from heat sources.
4. Three foot pathway throughout units, especially leading to exits.
5. There must be clear and easy access to all electrical panels – absolutely nothing in front of them.

Use painters tape to mark the clearances on walls, floors, etc. if needed.

The harm reduction approach can also be used with the client in order to reduce financial troubles or to reduce acquisition. If someone has difficulty controlling their acquiring, a plan can be put in place in order to limit spending or limit shopping trips.

These standards need to be set with the client and proper support needs to be put in place.

(*Source:* Hoarding Toolbox developed by Montfort Renaissance and Options Bytown, March 2016)

Saving Inventory—Revised Tool

©Frost, Steketee, & Grisham, 2004

Available online here through Oxford Clinical Psychology.

- This tool was developed to assess the saving practices and home clutter.
- It has a series of questions on clutter, difficulty discarding and excessive acquisition, all of which can be interpreted using cutoff scores and typical SI-R scores.

Saving Inventory – Revised

Date: _____

For each question below, circle the number that corresponds most closely to your experience DURING THE PAST WEEK.

0 ---------------- 1 -------------------- 2 ------------------ 3 ------------------ 4

| None | A little | A moderate amount | Most/Much | Almost All/ Complete |

1. How much of the living area in your home is cluttered with possessions? (Consider the amount of clutter in your kitchen, living room, dining room, hallways, bedrooms, bathrooms, or other rooms). ○ 0 ○ 1 ○ 2 ○ 3 ○ 4

2. How much control do you have over your urges to acquire possessions? ○ 0 ○ 1 ○ 2 ○ 3 ○ 4

3. How much of your home does clutter prevent you from using? ○ 0 ○ 1 ○ 2 ○ 3 ○ 4

4. How much control do you have over your urges to save possessions? ○ 0 ○ 1 ○ 2 ○ 3 ○ 4

5. How much of your home is difficult to walk through because of clutter? ○ 0 ○ 1 ○ 2 ○ 3 ○ 4

For each question below, circle the number that corresponds most closely to your experience DURING THE PAST WEEK.

0 ---------------------- 1 -------------------- 2 -------------------- 3 -------------------- 4

| Not at all | Mild | Moderate | Considerable/ Severe | Extreme |

6. To what extent do you have difficulty throwing things away? ○ 0 ○ 1 ○ 2 ○ 3 ○ 4

7. How distressing do you find the task of throwing things away? ○ 0 ○ 1 ○ 2 ○ 3 ○ 4

8. To what extent do you have so many things that your room(s) are cluttered? ○ 0 ○ 1 ○ 2 ○ 3 ○ 4

9. How distressed or uncomfortable would you feel if you could not acquire something you wanted? ○ 0 ○ 1 ○ 2 ○ 3 ○ 4

10. How much does clutter in your home interfere with your social, work or everyday functioning? Think about things that you don't do because of clutter. ○ 0 ○ 1 ○ 2 ○ 3 ○ 4

11. How strong is your urge to buy or acquire free things for which you have no immediate use? ○ 0 ○ 1 ○ 2 ○ 3 ○ 4

Saving Inventory – Revised

For each question below, circle the number that corresponds most closely to your experience DURING THE PAST WEEK:

0	1	2	3	4
Not at all	Mild	Moderate	Considerable/ Severe	Extreme

12. To what extent does clutter in your home cause you distress? ◯0 ◯1 ◯2 ◯3 ◯4

13. How strong is your urge to save something you know you may never use? ◯0 ◯1 ◯2 ◯3 ◯4

14. How upset or distressed do you feel about your acquiring habits? ◯0 ◯1 ◯2 ◯3 ◯4

15. To what extent do you feel unable to control the clutter in your home? ◯0 ◯1 ◯2 ◯3 ◯4

16. To what extent has your saving or compulsive buying resulted in financial difficulties for you? ◯0 ◯1 ◯2 ◯3 ◯4

For each question below, circle the number that corresponds most closely to your experience DURING THE PAST WEEK.

0	1	2	3	4
Never	Rarely	Sometimes/ Occasionally	Frequently/ Often	Very Often

17. How often do you avoid trying to discard possessions because it is too stressful or time consuming? ◯0 ◯1 ◯2 ◯3 ◯4

18. How often do you feel compelled to acquire something you see? e.g., when shopping or offered free things? ◯0 ◯1 ◯2 ◯3 ◯4

19. How often do you decide to keep things you do not need and have little space for? ◯0 ◯1 ◯2 ◯3 ◯4

20. How frequently does clutter in your home prevent you from inviting people to visit? ◯0 ◯1 ◯2 ◯3 ◯4

21. How often do you actually buy (or acquire for free) things for which you have no immediate use or need? ◯0 ◯1 ◯2 ◯3 ◯4

22. To what extent does the clutter in your home prevent you from using parts of your home for their intended purpose? For example, cooking, using furniture, washing dishes, cleaning, etc. ◯0 ◯1 ◯2 ◯3 ◯4

23. How often are you unable to discard a possession you would like to get rid of? ◯0 ◯1 ◯2 ◯3 ◯4

Peer Support Groups

Available online here, Section 5.

- This section of the Hoarding Best Practices Guide includes guidance on establishing a peer support group model.

Hoarding: Best Practices Guide

▶ Sction ⑤

PEER SUPPORT GROUP MODELS, HOW TO FORM AND FACILITATE A SUPPORT GROUP

Support groups have been proven to be an integral part of the intervention and change process. The purpose of a support group for hoarding behavior is to provide a safe and nurturing environment for individuals to share experience, strength, and hope with each other in order to educate and support those who have symptoms of compulsive hoarding. These groups are designed primarily for older adults with hoarding disorder who possess a strong desire to change and manage their hoarding behavior and to improve their quality of life and maintain their living space. According to Jordana Muroff, Ph.D., Boston University, "group interventions are good alternatives that give more people access to clinicians and coaches who can help. Group methods may also be more affordable for hoarding sufferers". Additionally, Muroff reports that a recent study referencing facilitated support groups resulted in "much improvement" of the hoarding behaviors by the group participants (Muroff et. al, 2010).

- Potential group members are interviewed 1:1 to determine fit, ability, and motivation to attend, participate, and progress through entire group session.

- Self-report, including potential participants perspective of their living space based on the clutter image rating tool and HOMES assessment are weighed in addition to interviewer questions and observation.

- Before final determination is made, a home visit will be made to ensure the living space conditions have been reported accurately and that the conditions fall within the qualifying parameters of the clutter image rating tool developed by the International OCD Foundation – [Hoarding Center and the HOMES Multi-disciplinary Hoarding Risk Assessment tool – Appendix 6].

Example: *The group model currently being used at North Shore Elder Services is Psycho-educational.*

- The group is closed (meaning there are no new members after the first meeting) and runs for 15 weeks for 1 ½ hours per group session.

- The integration of Cognitive Behavioral Therapy (CBT) theory with the Conceptual Model, that builds a graphic depiction of the factors contributing to the hoarding behavior, is implemented.

- The techniques used (Conceptual Model) has members describe and discuss their physical and social environment in order to better understand how both of these aspects affect their hoarding disorder.

- Group members are shown how to work through the thoughts and behaviors associated with their hoarding both through the group process and homework assignments that are then discussed during the group.

Some More Thoughts on Groups:

- The group work guide from the work of Dr. Randy Frost (Maxner, et al. 2010) can be used as a best practice, and then adapted to fit your community and populations unique needs. Groups are a great way to outreach to communities that might be hesitant to discuss "hoarding". Where you host the group can also be an opportunity to *outreach to a new community*. There can be a trickle-down effect where other people who do not choose to participate in the group still gather information and at least start to think about joining in the future. The community also benefits by learning more about hoarding and the services your agency offers. More referrals! Using a non-threatening name such as *The De-Clutter Group* or *Clutter Bug Group* helps people get the assistance they need, while not being labeled as a person who hoards.
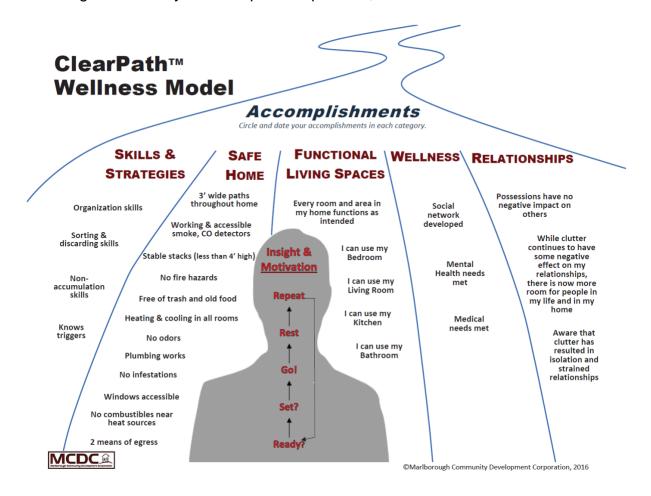
Progress Evaluation
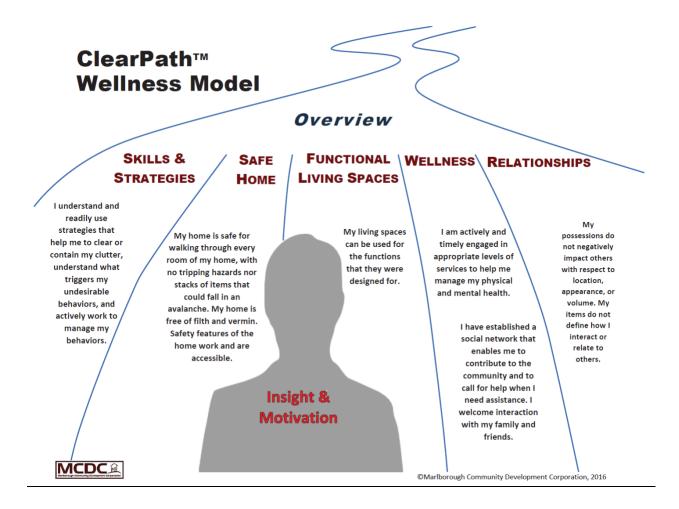
During the evaluation stage, the worker and the client focus on goal attainment, continuing to monitor progress to determine when goals are met, and/or whether new goals should be set. Clients can be directly involved in the evaluation stage through self-monitoring, allowing them to track and reflect upon their own progress. The worker, at this stage, critically evaluates how an intervention is working based on the client's progress. If goals are not being met, it may be necessary to return to the assessment stage to better define the problem.

Source: https://mswcareers.com/generalistinterventionmodel/

ClearPath Wellness Model Accomplishments & Overview Worksheet

Marlborough Community Develompent Corporation, 2016

©Marlborough Community Development Corporation, 2016

ClearPath™ Wellness Model

Overview

SKILLS & STRATEGIES

I understand and readily use strategies that help me to clear or contain my clutter, understand what triggers my undesirable behaviors, and actively work to manage my behaviors.

SAFE HOME

My home is safe for walking through every room of my home, with no tripping hazards nor stacks of items that could fall in an avalanche. My home is free of filth and vermin. Safety features of the home work and are accessible.

FUNCTIONAL LIVING SPACES

My living spaces can be used for the functions that they were designed for.

Insight & Motivation

WELLNESS

I am actively and timely engaged in appropriate levels of services to help me manage my physical and mental health.

I have established a social network that enables me to contribute to the community and to call for help when I need assistance. I welcome interaction with my family and friends.

RELATIONSHIPS

My possessions do not negatively impact others with respect to location, appearance, or volume. My items do not define how I interact or relate to others.

MCDC

©Marlborough Community Development Corporation, 2016

Saving Cognitions Inventory (SCI)

©Steketee, Frost & Kyrios, 2003

Available online here.

- The SCI is a tool that helps to assess saving cognition along 4 sub-scales: emotional attachment, control, responsibility and memory. The score on all 24 questions is added to generate a score.

SCI Scoring

Subscales:

Emotional Attachment (10 items): 1, 3, 6, 8, 9, 10, 13, 16, 22, 23

Control (3 items): 5, 18, 24

Responsibility (6 items): 2, 7, 11, 12, 15, 19

Memory (5 items): 4, 14, 17, 20, 21

Total Score = Sum of all items

Steketee, G., Frost, R.O., & Kyrios, M. (2003). Cognitive aspects of compulsive hoarding. *Cognitive Therapy and Research, 27,* 463-479.

ID#:_____   Date:_____

Saving Cognitions Inventory

Use the following scale to indicate the extent to which you had each thought when you were deciding whether to throw something away **DURING THE PAST WEEK**. (If you did not try to discard anything in the past week, indicate how you would have felt if you had tried to discard.)

1	2	3	4	5	6	7
not at all			sometimes			very much

1.	I could not tolerate it if I were to get rid of this.	1 2 3 4 5 6 7
2.	Throwing this away means wasting a valuable opportunity.	1 2 3 4 5 6 7
3.	Throwing away this possession is like throwing away a part of me.	1 2 3 4 5 6 7
4.	Saving this means I don't' have to rely on my memory.	1 2 3 4 5 6 7
5.	It upsets me when someone throws something of mine away without my permission.	1 2 3 4 5 6 7
6.	Losing this possession is like losing a friend.	1 2 3 4 5 6 7
7.	If someone touches or uses this, I will lose it or lose track of it.	1 2 3 4 5 6 7
8.	Throwing some things away would feel like abandoning a loved one.	1 2 3 4 5 6 7
9.	Throwing this away means losing a part of my life.	1 2 3 4 5 6 7
10.	I see my belongings as extensions of myself; they are part of who I am.	1 2 3 4 5 6 7
11.	I am responsible for the well-being of this possession	1 2 3 4 5 6 7
12.	If this possession may be of use to someone else, I am responsible for saving it for them.	1 2 3 4 5 6 7
13.	This possession is equivalent to the feelings I associate with it.	1 2 3 4 5 6 7
14.	My memory is so bad I must leave this in sight or I'll forget about it.	1 2 3 4 5 6 7
15.	I am responsible for finding a use for this possession.	1 2 3 4 5 6 7
16.	Throwing some things away would feel like part of me is dying.	1 2 3 4 5 6 7
17.	If I put this into a filing system, I'll forget about it completely.	1 2 3 4 5 6 7
18	I like to maintain sole control over my things.	1 2 3 4 5 6 7
19.	I'm ashamed when I don't have something like this when I need it.	1 2 3 4 5 6 7
20.	I must remember something about this, and I can't if I throw this away.	1 2 3 4 5 6 7
21.	If I discard this without extracting all the important information from it, I will lose something.	1 2 3 4 5 6 7
22.	This possession provides me with emotional comfort.	1 2 3 4 5 6 7
23.	I love some of my belongings the way I love some people.	1 2 3 4 5 6 7
24.	No one has the right to touch my possessions.	1 2 3 4 5 6 7

Activities of Daily Living—Hoarding (ADL-H)

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Available online here.

- This test is designed to assess the extent to which hoarding behaviors and clutter in the home interfere with the activities of daily living. Questions are structured around three areas: activities of daily living, living conditions, and safety issues. An average score in the range of 3 is likely to indicate substantial problems with functioning due to clutter.

Activities of Daily Living for Hoarding (ADL-H)

Date: _____

Sometimes clutter in the home can prevent you from doing ordinary activities. For each of the following activities, please circle the number that best represents the degree of difficulty you experience in doing this activity because of the clutter or hoarding problem. If you have difficulty with the activity for other reasons (for example, unable to bend or move quickly due to physical problems), do not include this in your rating. Instead, rate only how much difficulty you would have **due to hoarding**. If the activity is not relevant to your situation (for example, you don't have laundry facilities or animals), circle Not Applicable (NA).

Activities affected by clutter or hoarding problem	Can do it easily	Can do it with a little difficulty	Can do it with moderate difficulty	Can do it with great difficulty	Unable to do	Not Applicable
1. Prepare food	1	2	3	4	5	NA
2. Use refrigerator	1	2	3	4	5	NA
3. Use stove	1	2	3	4	5	NA
4. Use kitchen sink	1	2	3	4	5	NA
5. Eat at table	1	2	3	4	5	NA
6. Move around inside the house	1	2	3	4	5	NA
7. Exit home quickly	1	2	3	4	5	NA
8. Use toilet	1	2	3	4	5	NA
9. Use bath/shower	1	2	3	4	5	NA
10. Use bathroom sink	1	2	3	4	5	NA

11. Answer door quickly	◯ 1	◯ 2	◯ 3	◯ 4	◯ 5	◯ NA
12. Sit in sofa/chair	◯ 1	◯ 2	◯ 3	◯ 4	◯ 5	◯ NA
13. Sleep in bed	◯ 1	◯ 2	◯ 3	◯ 4	◯ 5	◯ NA
14. Do laundry	◯ 1	◯ 2	◯ 3	◯ 4	◯ 5	◯ NA
15. Find important things (such as bills, tax forms, etc.)	◯ 1	◯ 2	◯ 3	◯ 4	◯ 5	◯ NA

Gail Steketee, Randy O. Frost
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Termination, Maintenance, & Follow-Up

The ultimate goal of any therapeutic intervention is that a time will come when the client is able to maintain progress on their own. Termination is thus the last stage of the generalist intervention model. During this stage, the client reflects on their accomplishments, and the client and worker work together to identify resources and supports in place to help the client should problems re-emerge.

Source: https://mswcareers.com/generalistinterventionmodel/

More sample documents are needed for this section on termination and follow-up. We were not able to find examples of toolkits that address termination and follow-up in our research to incorporate into this toolkit, but as this document evolves and grows to best suit the needs of the Winthrop community, more information and documents from other hoarding resources can be added as seen fit by those who share ownership of this document.

Winthrop Community Asset Map

https://www.google.com/maps/d/u/0/edit?mid=1JZf5PTYJRaH8sh23sG1cvhJrW6OxH8Ve&ll=42.37 7348180041096%2C-70.98447209603268&z=16

Many community organizations focus on the needs or deficits of the community. Every community has needs and deficits that ought to be attended to.

But it is also possible to focus on assets and strengths—emphasizing what the community does have, not what it doesn't. Those assets and strengths can be used to meet those same community needs; they can improve community life.

To draw upon a community's assets, we first have to find out what they are. In this map, we've begun to identify community assets and resources of the Winthrop community, with the intention that this map can be changed and added to by those who share ownership of this toolkit.

(*Source:* https://ctb.ku.edu/en/table-of-contents/assessment/assessing-community-needs-and-resources/identify-community-assets/main)