

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

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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.



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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 force 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 Winthrop 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 be 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, Bratton, & 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.

References - Best Practices for Hoarding

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders*. Washington, D.C.
- Broncaccio, D. (2018, April 13). State Task Force, Workshops Help Hoarders Cut the Clutter. *Greenfield Recorder*.
- Bratiotis, C. (2013). Community hoarding task forces: a comparative case study of five task forces in the United States. *Health and Social Care in the Community*, 21(3), 245-253.
- Gilliam, C., Hannan, S. E., Norberg, M. M., Morrison, S., Villavicencio, A., & Dufresne, D. (2009). Group cognitive behavioral therapy for compulsive hoarding: An effectiveness study. Paper presented at the Association of Behavioral and Cognitive Therapies, New York, NY.
- Grcevich, S. (2018, April 11). How the church can make mental illness a topic of conversation. Retrieved from <https://erlc.com/resource-library/articles/how-the-church-can-make-Mental-illness-a-topic-of-conversation>.
- Hogstel, M. (1993). Understanding Hoarding Behaviors in the Elderly. *The American Journal of Nursing*, 93(7), 42-45. doi:10.2307/3464334
- Hurley, M (2019). Winthrop Department of Public Health and Clinical Services [PowerPoint Slides].
- Hurley, M. (2019, December 2). Email with [M Hurley].
- Hoarding Best Practices Committee. (2012). *Hoarding: Best Practices Guide*. Retrieved from <https://umassmed.typepad.com/files/best-practice-hoarding-guide-final-.pdf>.
- Is it Hoarding, Clutter, Collecting, or Squalor? (n.d.). Retrieved December 5, 2019, from <https://iocdf.org/>.
- Koenig, T. L., Leiste, M. R., Spano, R., & Chapin, R. K. (2013). Multidisciplinary team perspectives on older adult hoarding and mental illness. *Journal of Elder Abuse & Neglect*, 25, 1-20. doi: 10.1080/08946566.2012.712856

- Kress, V. E., Stargell, N. A., Zoldan, C. A., & Paylo, M. J. (2016). Hoarding disorder: Diagnosis, assessment, and treatment. *Journal of Counseling & Development, 94*(1), 83-90.
- Lilienfeld, S., Arkotiz, H. (2013). Clutter, Clutter Everywhere. *Scientific American Mind, 24*(4), 68-69. Retrieved from www.jstor.org/stable/24942483
- Muroff, J., Steketee, G., Rasmussen, J., Gibson, A., Bratiotis, C., & Sorrentino, C. (2009). Group cognitive and behavioral treatment for compulsive hoarding: a preliminary trial. *Depression and Anxiety, 26*(7), 634-640. doi: 10.1002/da.20591
- Muroff, J., Bratiotis, C., & Steketee, G. (2010). Treatment for Hoarding Behaviors: A Review of the Evidence. *Clinical Social Work Journal, 39*(4), 406-423. doi: 10.1007/s10615-010-0311-4.
- Muroff, J., Steketee, G., Himle, J., & Frost, R. (2010). Delivery of internet treatment for compulsive hoarding (DITCH). *Behaviour Research and Therapy, 48*(1), 79-85.
- Sampson, J., Yeats, J. & Harris, S. (2012). An Evaluation of an Ambiguous Loss Based Psychoeducational Support Group for Family Members of Persons who Hoard: A Pilot Study. *Contemporary Family Therapy, 34*(4), 566-581. doi: 10.1007/s10591-012-9214-6
- Singh, S., & Jones, C. (2013). Compulsive hoarding syndrome: engaging patients in treatment. *Mental Health Practice, 17*(4), 16-20.
- The Town of Winthrop Massachusetts. Retrieved from <https://www.town.winthrop.ma.us>
- US Census Bureau. (n.d.). Census.gov. Retrieved December 5, 2019, from <https://www.census.gov/>.
- US Census Bureau. (2017). Census.gov. Retrieved December 15, 2019, from <https://www.census.gov/>.
- Whitfield, K. Y., Daniels, J. S., Flesaker, K., & Simmons, D. (2012). Older adults with hoarding behavior aging in place: Looking to a collaborative community-based planning approach for solutions. *Journal of Aging Research, 2012*, 1-8. doi:10.1155/2012/205425
- Yeats, J. (2013). The Impact of Hoarding Disorder on Individuals, Families and Communities. [PowerPoint Slides]. Retrived from <http://www.napsa-now.org/wp-content/uploads/2013/10/The-Impact-of-Hoarding-Disorder-on-Individuals-Families-and-Communities.pdf>

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 elderly 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.

Hoarding Coalition - References

Address Our Mess. About Us. Retrieved from <https://www.clutterhoardingcleanup.com/about-us>

American Psychiatric Association (2019). What is hoarding disorder? Retrieved from <https://www.psychiatry.org/patients-families/hoarding-disorder/what-is-hoarding-disorder>

Butterfoss, F., Goodman, R., & Wandersman, A. (1993). Community coalitions for prevention and health promotion. *Health Education Research: Theory and Practice*. 8 . 3. 315- 330.

Butterfoss, F., & Kegler, M. (2009). The community coalition action theory. In R.J DiClemente, R.A.

Crosby, M. Kegler (Eds). *Emerging Theories in Health Promotion Practice and Research*. (pp. 238-243). San Francisco, CA: Jossey-Bass.

Children of Hoarders. (2014). About Children of Hoarders, Inc. Retrieved from <http://childrenofhoarders.com/wordpress/>

City of Arlington. (2019). Hoarding Response Team. Retrieved from <https://www.arlingtonma.gov/departments/health-human-services/health-department/housing/hoarding-response-team-hrt>

City of Newton. (2019). Newton's Hoarding Task Force Members. Retrieved from

http://www.newtonma.gov/gov/health_n_human_services/humansvcs/hoarding/members
City of

Somerville. (2019). Somerville committee for suicide prevention and mental health. Retrieved from: <https://www.somervillema.gov/departments/programs/somerville-cares-about-prevention-scrap/somerville-committee-suicide-prevention-and-mental-health>.

Cromer, K., Schmidt, N., & Murphy, D. (2007). Do traumatic events influence the clinical expression of compulsive hoarding? *Behaviour Research and Therapy*, 45(11), 2581-2592. Doi:10.1016/j.brat.2007.06.005

Data USA. (2019). Lynn, MA. Retrieved from: <https://datausa.io/prfile/geo/lynn-ma/#about>
Elder

Services of Merrimack Valley, Inc. (2019). About Our Services. Retrieved from <https://nselder.org/about-us/>

Frank, C., & Misiaszek, B. (2012). Approach to hoarding in family medicine: Beyond reality television. *Canadian Family Physician Medecin De Famille Canadien*, 58(10), 1087-91, e542-7.

Frost, R., Steketee, G., & Tolin, D. (2011). Comorbidity in hoarding disorder. *Depression and Anxiety*, 28(10), 876-884. Doi:10.1002/da.20861

Hoarding Cape Cod. (2019). Cape Cod hoarding task force: education, collaboration, & support. Retrieved from <https://www.hoardingcapecod.org>.

Community Health Needs Assessment Data Placemats 2. (n.d.). Retrieved from: https://learn.bu.edu/bbcswebdav/pid-7435728-dt-content-rid-34221705_1/courses/19falls
[swwp705_a1/iCHNA%20Data%20Placemats%20%5B7759%5D.pdf](https://learn.bu.edu/bbcswebdav/pid-7435728-dt-content-rid-34221705_1/courses/19falls)

International OCD Foundation (2019). About IOCDF. Retrieved from <https://iocdf.org/about/>

MassHousing. (2018) Local Hoarding Task Force Initiative Grants FY2018 Final Report: August 2018. Retrieved from https://www.masshousing.com/portal/server.pt/document/14231/fy%2718_local_hoarding_task_force_awards%2C_final_report

U.S. Census Bureau. (2018). *QuickFacts: Winthrop, MA*. Retrieved from <https://www.census.gov/quickfacts/winthroptowncitymassachusetts>

Worldanimal.net (2017). Advantages and disadvantages of working in coalitions. Retrieved from <http://worldanimal.net/our-programs/strategic-advocacy-course-new/module-4/networking-and-alliances/advantages-and-disadvantages-of-working-in-coalitions>.

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) (Massachusetts 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, Prader-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 providers, 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.

Hoarding Toolkit - References

About Hoarding. (n.d.). Retrieved from <https://hoarding.iocdf.org/about-hoarding/>

Almendarez, J. (2015, December 16). Cornell vet: Recidivism in animal hoarding is nearly 100 percent. Retrieved from <https://ithacavoices.com/2015/12/cornell-vet-recidivism-in-animal-hoarding-is-nearly-100-percent/>

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). American Psychiatric Publishing.

Bratiotis, C., Woody, S., & Lauster, N. (2019). Coordinated community-based hoarding interventions: Evidence of case management practices. *Families in Society: The Journal of Contemporary Social Services*, 100(1), 93–105. doi: 10.1177/1044389418802450

Braun, J. D., Strunk, D. R., Sasso, K. E., & Cooper, A. A. (2015). Therapist use of Socratic questioning predicts session-to-session symptom change in cognitive therapy for depression. *Behaviour research and therapy*, 70, 32–37. doi:10.1016/j.brat.2015.05.004

Chapter 8.40-Rental property registrations and inspection. (n.d.) Retrieved December 15, 2019 from https://library.municode.com/ma/winthrop/codes/code_of_ordinances?nodeId=TIT8HESA_CH8.40REPRREIN

City of Gloucester Health Department. (2013). 2013 annual report [PDF file]. Retrieved December 8, 2019 from <https://www.gloucester-ma.gov/documentcenter/view/2856>

Donnelly, K. (2012, February 29). How many hoarders in the US?: Hoarders in the US. Retrieved from <https://www.clutterhoardingcleanup.com/resources/hoarding/how-many-hoarders-us>

- Davis, T.H., & Edsell-Vetter, J. (2015). Rethinking hoarding intervention: MBHP's analysis of the Hoarding Intervention and Tenancy Preservation Project. Retrieved December 15 from http://www.metrohousingboston.org/wp-content/uploads/2015/07/Hoarding-Report-2015_FINAL.pdf
- General Court of the Commonwealth of Massachusetts. (2019). Section 4: Unlawful practices. Retrieved December 15, 2019 from <https://malegislature.gov/Laws/GeneralLaws/PartI/TitleXXI/Chapter151B/Section4>
- Girodat, J. (2019, August 29). North Shore hoarding task force awarded MassHousing grant. Retrieved December 15, 2019 from <https://nselder.org/blog/north-shore-hoarding-task-force-awarded-masshousing-grant/>
- Gloucester Health Department. (2015). Health department annual report [PDF file]. Retrieved December 8, 2019 from <https://www.gloucester-ma.gov/documentcenter/view/3747>
- Hurley, M. (2019). Winthrop Department of Public Health & Clinical Services [PowerPoint slides]. Retrieved from https://learn.bu.edu/webapps/blackboard/content/listContent.jsp?course_id=_58058_1&content_id=_6956570_1&mode=reset
- International OCD Foundation. (n.d.). Who gets hoarding disorder? Retrieved from <https://hoarding.iocdf.org/about-hoarding/who-gets-hoarding-disorder/>
- Ivanov, V. Z., Mataix-Cols, D., Serlachius, E., Lichtenstein, P., Anckarsäter, H., Chang, Z., ... Rück, C. (2013). Prevalence, comorbidity, and heritability of hoarding symptoms in adolescence: A population-based twin study in 15-year-olds. *PLoS one*, 8(7), e69140.
- Kessler, R. C., Brown, R. L., & Broman, C. L. (1981). Sex differences in psychiatric help-seeking: Evidence from four large-scale surveys. *Journal of Health and Social Behavior*, 49–64.
- Kyrios, M., Frost, R. O., & Steketee, G. (2004). Cognitions in compulsive buying and acquisition. *Cognitive Therapy and Research*, 28(2), 241–258.
- Mass.gov. (2019a). Overview of fair housing law. Retrieved December 15, 2019 from <https://www.mass.gov/service-details/overview-of-fair-housing-law>
- Mass.gov. (2019b). The Attorney General's guide to landlord and tenant's rights. Retrieved December 15, 2019 from <https://www.mass.gov/guides/the-attorney-generals-guide-to-landlord-and-tenant-rights>
- Massachusetts General Hospital. (2019). *Community health needs assessment report. Community Health Needs Assessment Report.*

- MassHousing. (2012, Winter). Hoarding: Best practices guide. Retrieved from https://www.masshousingrental.com/portal/server.pt/community/community_services/330/hoarding_resources
- MassHousing. (2019). Massachusetts local hoarding task forces [PDF file]. Retrieved December 15, 2019 from https://www.masshousing.com/portal/server.pt/document/2697/massachusetts_local_hoarding_task_forces
- MetroHousing Boston. (n.d.) Fair housing & civil rights: Hoarding & sanitation fact sheet. Retrieved December 15, 2019 from <https://www.metrohousingboston.org/what-we-do/fair-housing-civil-rights-help/hoarding-and-sanitation-fact-sheet/>
- Metropolitan Area Planning Council. (2017). Gloucester housing production plan. Retrieved December 8, 2019 from <https://www.gloucester-ma.gov/DocumentCenter/View/5443>
- Metropolitan Boston Housing Partnership. (n.d.). Housing and homelessness: A year of candid, community-based conversations about housing trends, challenges and resources in Greater Boston [PDF file]. Retrieved December 15, 2019 from <http://www.metrohousingboston.org/wp-content/uploads/2017/10/Community-Meetings-Brochure-FINAL.pdf>
- Muroff, J., Bratiotis, C., & Steketee, G. (2011). Treatment for hoarding disorders: A review of the evidence. *Clinical Social Work Journal*, 39, 406–423. doi: 10.1007/s10615-010-0311-4
- Muroff, J., Steketee, G., Rasmussen, J., Gibson, A., Bratiotis, C., & Sorrentino, C. (2009). Group cognitive and behavioral treatment for compulsive hoarding: A preliminary trial. *Depression & Anxiety*, 26(7), 634–640. Retrieved from https://onlinelibrary.wiley.com/doi/full/10.1002/da.20591?casa_token=4-Zc6PLGiAYAAAAA:v8OmOdhttyNuy_6eyxTUpOIkGHBP0sRIPRcoPL4HEZ_EmAQhVFJUs62lerloq9g_XyyGu-CmhMbR
- North Shore Center for Hoarding & Cluttering. (n.d.). Retrieved December 15, 2019 from <https://nselder.org/wp-content/uploads/2015/08/program-pamphlet.pdf>
- North Suffolk Community Health Needs Assessment Community Survey. (2016). *North Suffolk community health needs assessment community survey*.
- Parekh, R. (2017, July). *What is hoarding disorder?* Retrieved from <https://www.psychiatry.org/patients-families/hoarding-disorder/what-is-hoarding-disorder>
- Rodriguez, C. I., Levinson, A., Patel, S. R., Rottier, K., Zwerling, J., Essock, S., ... Simpson, H. B. (2016). Acceptability of treatments and services for individuals with hoarding behaviors. *Journal of Obsessive-Compulsive and Related Disorders*, 11, 1–8. doi:10.1016/j.jocrd.2016.07.001

- Roman, J. (2010, October 12). Elder Services responds to hoarding issues. *The Salem News*. Retrieved December 15, 2019 from <https://www.salemnews.com/>
- Saltus, L., Andrews-Semler, K., Conlin, M., Dixon, L., Gousseynoff, F., & Lozyniak, T. (n.d.) [PowerPoint slides]. Retrieved from https://www.masshousingrental.com/portal/server.pt/document/10847/hoarding_presentation_hampden_county_hoarding_task_force
- Steketee, G., & Frost, R. O. (2007). *Compulsive hoarding and acquiring: Therapist guide*. Oxford University Press.
- Sweeten, G., Sillence, E., & Neave, N. (2018). Digital hoarding behaviours: Underlying motivations and potential negative consequences. *Computers in Human Behavior*, 85, 54–60.
- Tolin, D. F., Meunier, S. A., Frost, R. O., & Steketee, G. (2010). Course of compulsive hoarding and its relationship to life events. *Depression and Anxiety*, 27(9), 829–838.
- Tompkins, M. A. (2011). Working with families of people who hoard: A harm reduction approach. *Journal of Clinical Psychology*, 67(5), 497–506. Retrieved from https://onlinelibrary.wiley.com/doi/pdf/10.1002/jclp.20797?casa_token=7d1vQnV_FecAAA:AA:rjAkyB82xgjDxLyTvjnt_fbZalYgSjIV4RTxMt6EIM8u63qA1fjy1uGQe72vlgX-Zy9xXBK4ommw
- Treatment of HD - Motivational Interviewing (MI). (n.d.). Retrieved from <https://hoarding.iocdf.org/professionals/treatment-of-hoarding-disorder/treatment-of-hd-motivational-interviewing-mi/>
- United States Department of Housing and Urban Development. (n.d.a). Housing discrimination under the Fair Housing Act. Retrieved December 7, 2019 from https://www.hud.gov/program_offices/fair_housing_equal_opp/fair_housing_act_overview
- United States Department of Housing and Urban Development. (n.d.b). Reasonable accommodations and modifications. Retrieved December 15, 2019 from https://www.hud.gov/program_offices/fair_housing_equal_opp/reasonable_accommodations_and_modifications
- United States Department of Housing and Urban Development & United States Department of Justice. (2015). Joint statement of the Department of Housing and Urban Development and the Department of Justice: Reasonable accommodations under the Fair Housing Act. Retrieved December 15, 2019 from <https://www.justice.gov/crt/us-department-housing-and-urban-development>
- Weiss, K. J., & Khan, A. (2015). Hoarding, housing, and DSM-5. *The Journal of the American Academy of Psychiatry and the Law*, 43(4), 492-498. Retrieved from <http://jaapl.org/content/43/4/492>

Worcester Fair Housing Project. (n.d.) Hoarding and reasonable accommodation: A guide about tenant's rights [PDF file]. Retrieved December 15, 2019 from https://www.masshousing.com/portal/server.pt/document/8667/worcester_fair_housing__Hoarding_and_reasonable_accommodation

Appendices

Appendix A: Handout on Hoarding for the Religious Community

Appendix B: Guide on Building a Community Task Force

Appendix C: Hoarding Toolkit