



Beyond the Sensationalism:

Professional Responses to Hoarding Disorder

in the
Omaha Community

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Hoarding Disorder

Fact? Or Fiction!

There are plenty of mistruths, myths, and inaccurate assumptions made about people who hoard, hoarding behavior, and hoarded homes. Here are five of the most common myths and the truths that dispel them.

MYTH: Hoarded homes are filthy and the people who live in them are dirty.

TRUTH: The term hoarding refers to the volume of clutter or quantity of objects in a given space. It does not refer to cleanliness. Instead, the term squalor describes filth or the ruin of a space due to neglect. It is possible, and in fact quite common, to have an environment that is filled with clutter but is relatively clean.

MYTH: People who hoard are lazy and choose to live the way they do.

TRUTH: Hoarding disorder is a mental illness recognized by the American Psychiatric Association. People who hoard express shame, sadness, guilt, remorse, and embarrassment at how their illness negatively impacts their lives and those they love.

MYTH: Living through an experience like the Great Depression causes hoarding.

TRUTH: Hoarding is a complex problem with many factors contributing to the onset and course of the illness including: genetic predisposition, neurobiological factors, difficulties with cognitive processing, problematic thinking, and strong emotions. There is no scientific evidence to suggest that deprivation or trauma alone cause hoarding.

MYTH: Hoarding is unique to the United States and is a consequence of American materialism.

TRUTH: Research suggests that hoarding occurs at similar levels in many industrialized countries throughout the world. Clinical treatment and research is taking place in countries such as the United Kingdom, Germany, Italy, and Australia. It is still unclear how common hoarding is in developing nations.

MYTH: A mass clean-out involving garbage bags, shovels, and dumpsters is the best way to solve a hoarding problem.

TRUTH: A large scale, one-time clean-out of a hoarded home will most likely result in feelings of helplessness, violation, and resentment that may lead to further hoarding behavior or serious mental health problems. Instead, the best way to help a person with hoarding disorder is through slow, systematic exposure to sorting and discarding possessions and resisting the acquisition of new items.

Dear Reader,

Thank you for your concern about the complex problems associated with hoarding disorder in the Omaha community. With this document, we seek to reach a variety of professionals as well as people who have a personal interest in hoarding disorder. To that end, we have conducted an in-depth exploration of the problem by area of expertise. Our hope is that this paper serves as the foundation for a collaborative and cohesive response to hoarding in our community.

As graduate students in the field of social work, we are trained to view community concerns systemically and to apply evidence-based practices to alleviate social problems. The purpose of this academic pursuit is to provide practical services in the community. This paper applies national research to the very specific setting of Omaha, Nebraska.

As social workers, we are deeply invested in the care of vulnerable people across many sectors; however we are not experts in most of the fields covered here. We have made a thorough effort to give an accurate overview of services, but acknowledge that we may have missed pertinent information. Still, the purpose of this paper is to ignite a conversation about hoarding in our community and we believe we have achieved that goal.

Please use this document in the way that is most useful to you. As a whole, it serves as a local primer on hoarding; however, each chapter can also stand alone if you are seeking specific information. Our intention is that this information be freely disseminated, so please pass it along as the need may arise.

In the past, hoarding has been sensationalized, misunderstood, belittled, and degraded. As more research becomes available and professional understanding grows, it is apparent that a concerted community effort to provide continuity of care for individuals who hoard is the compassionate and necessary response. We must go beyond the sensationalism and begin to mitigate the suffering associated with hoarding disorder in our community.

Thank you for reading,

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Much of the initial work of identifying and interviewing sources was completed by the students in the 2013 summer seminar on hoarding: Matthew Cook, Katie D'Agosto, Eric Depue, Emilee Doll, Alissa Fay, Rachael Fineran, Alison Frohn, Ashley Frye, Emilio Herrera, Tiffany Moore, Allison Pella, Brittany Waderich, and Alexa Walker.

Annie Driver, graduate assistant, thoughtfully and meticulously helped us prepare for the distribution of our work. Brian Travis generously assisted with graphics. Barbara Prince, J.D., patiently provided hours of editing, formatting expertise and technical support. Alexia Bratiotis deftly addressed our public relation needs. Dr. Gail Steketee kindly reviewed the manuscript. Dr. Christiana Bratiotis not only shared her passion and knowledge for serving individuals with hoarding disorder, but she also coached us through the writing process with humor and grace.

Most importantly, we owe our deepest debt of gratitude to the individuals and families who are suffering because of hoarding disorder. These individuals have allowed us into their lives at difficult moments and shared their deepest secrets. Our hope is that this work honors them and assists individuals in accessing the help they need to live full and joyful lives.

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Methodology

This paper originated as the result of a graduate level seminar on hoarding disorder offered by the Grace Abbott School of Social Work and taught by hoarding researcher, Dr. Christiana Bratiotis, in the summer of 2013. The culmination of a semester of specialized study for eighteen social work graduate students was to choose a professional sector in Omaha that interfaces with hoarding and conduct interviews, review written documentation and shadow professionals to explore available services. Students wrote papers covering mental health, housing, first responders, child protective services, aging services and professional organizers using several questions as a beginning framework.

At the conclusion of the seminar, five students from the course, along with their professor, identified a need in the community for a cohesive report bringing

together the information gathered by the class and adding sections on public health, developmental disabilities and animal welfare. Each section was edited to include a short vignette to illustrate how the sector interfaces with hoarding, a description of the sector, current responses from the sector, and best practices for the sector from the professional literature. A note to families affected by hoarding concludes each section.

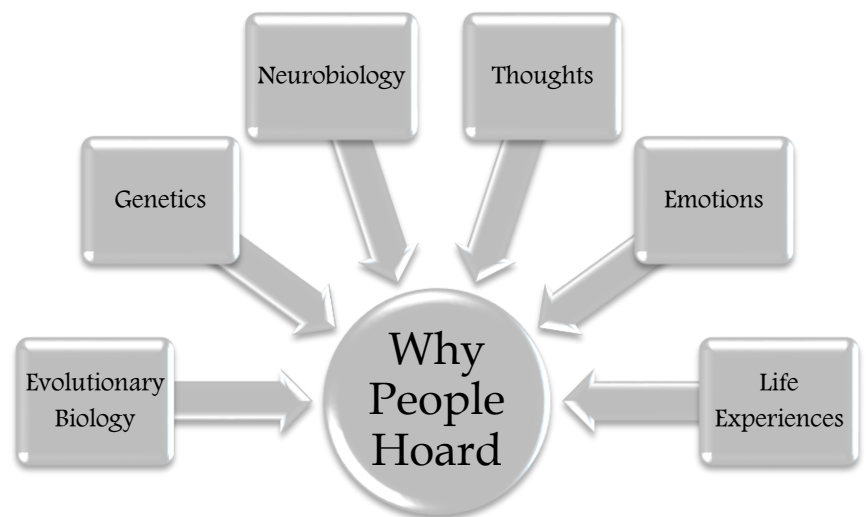
- 1) Do the professionals from this sector currently interface with people who hoard or hoarded homes or both? In what capacity?*
- 2) Do they experience hoarding as a problem for members of the community?*
- 3) Do they view hoarding as a private problem or a public trouble? Describe.*
- 4) Do they have a current response? If so, what is it? Are they satisfied with how they respond? How did they establish the response? How are the efforts paid for?*
- 5) If they are not currently responding – why? What are the obstacles (time, personnel, training, fiscal, etc.)? What would they like to be doing? Where do they refer people who need assistance with hoarding?*
- 6) Are they currently working with any other professional (groups) in the community to address hoarding? Why or why not?*
- 7) Are they aware of or participating in collaborative, cross-disciplinary or community response mechanisms for hoarding (such as coalitions or task forces)? If not, would they be willing/likely to participate in such a group?*

What Is Hoarding?

In recent years, media coverage of hoarding has brought the topic to the forefront of public awareness. However, this attention has not always been accurate or constructive. In order to provide genuine support to those impacted by hoarding in our community, it is important to look beyond the sensationalism. Not every person who hoards reaches an extreme level of accumulation and not every person who collects has hoarding disorder. In fact, there are three specific features that are associated with compulsive hoarding:

- (1) The acquisition of, and failure to discard a large number of possessions that appear to be useless or of limited value;**
- (2) living spaces sufficiently cluttered so as to preclude activities for which those spaces were designed;**
- (3) significant distress or impairment in functioning caused by the hoarding.**¹

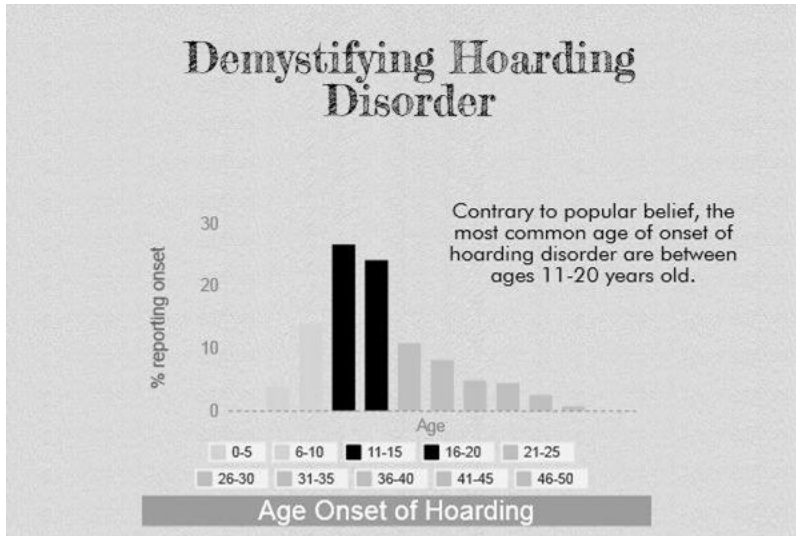
Research in neurobiology and behavioral sciences over the past 20 years has confirmed that hoarding is a distinct disorder with specific symptomology and a complicated etiology. Despite official recognition of the disorder in the *Diagnostic and Statistical Manual of Mental*



¹ Frost, R., & Hartl, T. (1996). A cognitive-behavioral model of compulsive hoarding. *Behaviour Research and Therapy*, 34(4), 341–350.

Disorders (DSM-5), there is still much to learn. Hoarding disorder is a complex problem; and addressing it can require a significant amount of time and resources.

In Omaha, awareness of the problem is increasing and organizations are making efforts to recognize and help those with hoarding disorder. In 2013, more than 30 local agencies came together to create the Omaha Hoarding Task Force. With a population of roughly



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.

421,000, it is estimated that between 12,000 – 21,000 people living in and around Omaha likely have a problem with hoarding.² Unfortunately, specialized training for treatment of hoarding disorder remains scarce. Even when

treatment is available, individuals may not be willing or able to dedicate the time, energy, and financial resources treatment requires. Harm reduction may then become the best solution. Harm reduction is an approach that minimizes the risk posed by accumulated objects by utilizing strategies such as agreed-upon rules to limit acquisition, moving items to clear exit paths in the home, or moving flammable items away from heat sources.³

Hoarding disorder has a chronic and worsening course. Without appropriate intervention, the situation will only become more desperate. A “forced cleanout” of the home may seem like the only option. This is an extreme intervention, which will generate an extreme

² Samuels, J. F., Bienvenu, O. J., Grados, M. A., Cullen, B., Riddle, M. A., Liang, K., Eaton, W. W., & Nestadt, G. (2008). Prevalence and correlates of hoarding behavior in a community-based sample. *Behaviour Research and Therapy*, 46(7), 836-844.

³ Tompkins, M. A. & Hartl, T. L. (2009). *Digging Out: Helping Your Loved One Manage Clutter, Hoarding, and Compulsive Acquiring*. Oakland, C.A.: New Harbinger Publications.

response in the person who hoards. Forced cleanouts have an adverse effect on mental health and have sometimes been the impetus for suicide. Cleanouts are also expensive and time-consuming – an effort that is frequently wasted. It is not uncommon for the clutter to return worse than before within a few months.⁴

This cycle can leave individuals who hoard, their families, and professionals frustrated and at their limit of their resources. This document provides an alternative – an evaluation of current approaches as well as best practice recommendations for working with people who hoard. Our purpose is to effectively address the public health and safety concerns associated with hoarding in our communities, while at the same time respecting the dignity and self-worth of individuals who hoard and their families.

⁴ Tolin, D. F., Frost, R. O., Steketee, G., Gray, K. D., & Fitch, K. E. (2008). The economic and social burden of compulsive hoarding. *Psychiatry Research, 160*, 200-211.

Mental Health

During her first appointment at the community mental health center, Deborah indicated to her therapist that she was feeling a combination of “really sad and really revved up all the time.” With further prompting and specific questions about her family and living situation, Deborah said, “Well, no, my boys don’t live with me now, none of them – my husband and sons are living with my mother-in-law. They’re there because there isn’t any place for them in our home. We have too many things.” The therapist continued to inquire and learned that Deborah and her family had been separated for four months and that the electricity was turned off about five months ago. When asked how the state of the home and the separation from her family was impacting her, Deborah replied, “If you look in my house and see a mess, well, I’ve got a mess in my head too. A mess of emotions and all kinds of things I’m thinking all the time.”

A variety of mental health professionals across several levels of care encounter hoarding in their work. Service settings include inpatient hospitalization, partial day programs, intensive community support, and outpatient therapy. Treatment providers are typically master’s level social workers or counselors, psychologists, and psychiatrists. However, interventions may also be provided by a myriad of other professionals including nurses, nurse practitioners, bachelor’s level social workers, behavioral service technicians, and case workers. Interactions with health and mental health professionals may take place over a period of several days, such as during a hospitalization, or may occur in briefer encounters such as during appointments or in-home visits. Clients may seek treatment for other co-occurring problems such as depression or anxiety, thus the clinician may not initially detect a hoarding problem.

Current Response

Inpatient and Partial Hospitalization. Acute crisis stabilization is the primary focus of inpatient mental health hospitalization and partial care programs. In Omaha, adult inpatient

hospitalization is available through Alegent Creighton Health, the University of Nebraska Medical Center, and the Douglas County Health Center. Partial programs for all ages are offered through Alegent Creighton Health. The average length of stay ranges from 3 – 5 days for inpatient care and 1 – 2 weeks for partial programs. Due to their acute care focus, inpatient and partial care providers do not use formal assessments for hoarding disorder in the Omaha area. In fact, unless the family brings forward a specific concern regarding hoarding behavior, hoarding is rarely identified as an active problem for acute and sub-acute patients. Instead, treatment focuses on stabilizing suicidal or homicidal behavior. Once the immediate crisis has been resolved, patients are discharged to the community to work on chronic, longer-term problems. In the rare instance that hoarding disorder is identified during a hospitalization, the patient is referred to an outpatient therapist for treatment or is encouraged to contact their community support worker for resources.

Community Crisis Response Team. In cases where the client is in crisis but is able to remain at home, the mobile Community Crisis Response Team at Lutheran Family Services intervenes. Comprised of three full-time licensed mental health professionals (LMHP) and 10 part-time on-call LMHPs, a member of the mobile crisis response team joins law enforcement and the humane society on emergency calls involving behavioral health concerns. Clients with hoarding most often interact with this program if a neighbor calls to report an immediate risk related to excessive accumulation of belongings or animals in the home. The role of the mental health professional is to assist in de-escalation of the crisis and connect clients to services within 24 - 48 hours. These services include therapy, medication management and case management and are provided free of charge for 90 days. While short-term therapy is provided, specific therapy for hoarding disorder does not fit into this timeframe.

Emergency Community Support. The Community Crisis Response Team also collaborates with Salvation Army to provide emergency community support services for clients. Among other things, the emergency community support worker assists the client in resolving the safety issues that led to the initial crisis. This is done using a client-centered approach; treating each client individually and acknowledging hoarding disorder as a mental illness. Interventions focus on harm reduction in the home rather than direct mental health treatment for hoarding disorder.

Intensive Community Support. Hoarding is frequently recognized as a problem when participants become involved with Intensive Community Support and have their first in-home visit. These services usually involve 2 – 4 in-home visits per month. In some instances, the agency rents properties to clients and the organization acts as the landlord. People who have lost housing in the community because of hoarding are then referred to this program, where their untreated problem quickly comes to light. Since hoarding is viewed as a safety issue, a community support case worker collaborates with the client and the property management company to address the specific problems in the unit. The primary goal is to manage the safety of the individual while taking into account the presence of a mental illness.

Community Support Services. Some clients do not need an intensive level of assistance. In these cases, clients can receive community support services through a variety of agencies including Lutheran Family Service, Catholic Charities, The Salvation Army, Friendship Program, and Community Alliance. Community support services are most often funded through the state of Nebraska. The goal of a community support worker is to help the client work toward independence. Depending on the level of need, a client may participate in this type of program anywhere from six months to five years. If hoarding interferes with activities of daily living,

then the community support worker assists the client in problem-solving and harm reduction as a part of a larger plan for reaching independence. While this is not mental health treatment, in some cases support workers have been successful in helping clients discard large amounts of items.

<p style="text-align: center;">Qualifying for Community Support Services⁵</p> <ul style="list-style-type: none">• Must meet criteria for a major mental illness with symptoms that cause severe impairment to functioning. Symptoms must be present for the last 12 months and/or are expected to persist for 12 months or longer• Does not have a primary diagnosis of substance abuse, developmental disorder, or medical condition• Experiences functional impairments in the two of the following areas: Vocational/Educational, Social Skills, or Self Care• Community Support is required for successful functioning in the community• Community support can be expected to reduce inpatient psychiatric hospitalization
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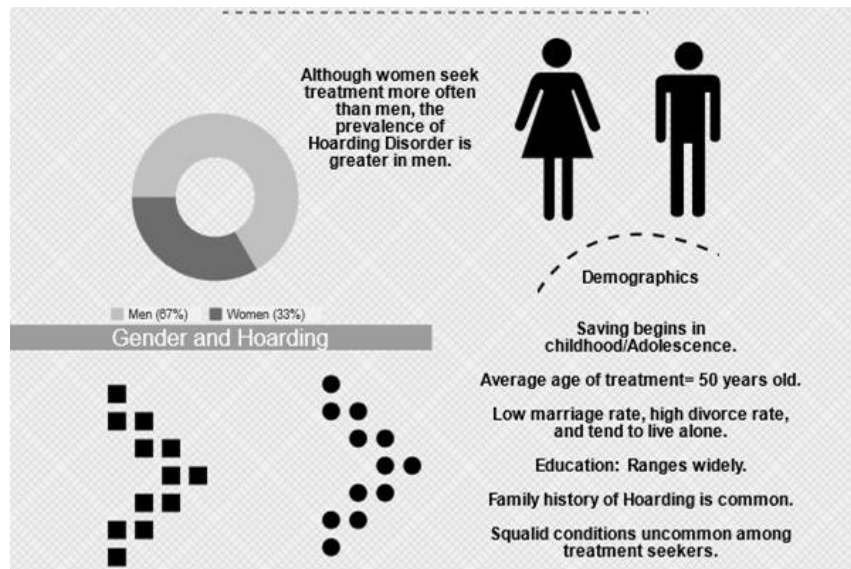
Outpatient Therapy. Although outpatient mental health therapy varies widely, very few Omaha providers offer evidence based therapeutic interventions for hoarding. This is predominantly due to the nationwide lack of training available in hoarding-specific treatment. Perhaps because of scarcity of training and because hoarding disorder is a newly-recognized diagnosis, few outpatient therapists even screen for hoarding disorder. In fact, many may not detect hoarding disorder even after extensive work with a client, due to the client’s avoidance of the topic or lack of awareness of illness. As a result, hoarding frequently goes untreated. Even when hoarding disorder is detected, the client is willing to commit to therapy, and a trained provider is available, payment for therapy may be problematic as third party payers do not yet reimburse for treatment of hoarding disorder.

⁵ Magellan Health Services, Inc. (2013). *Medical Necessity Criteria Guidelines Adapted for Magellan Behavioral Health of Nebraska, Inc.* Retrieved from www.magellanprovider.com/MHS/MGL/about/handbooks/supplements/ne_medicaid/ne_appc_clinguide.pdf

Best Practices

The best way for mental health practitioners at all levels of care to detect hoarding disorder and ensure proper care is to implement screening during intake processes. A number of reliable and valid measures have been designed to measure hoarding disorder. The Saving Inventory-Revised (SI-R)⁶ is a widely-used self-report assessment that measures clutter, difficulty discarding, and excessive acquisition. The Hoarding Rating Scale-Interview (HRS-I)⁷ contains five questions related to clutter, difficulty discarding, and excessive acquisition as well as extent of distress and impairment caused by hoarding. There are also numerous instruments which measure specific aspects of hoarding such as The Clutter Image Rating instrument (CIR)⁸, a pictorial

instrument designed to measure variations in the volume of clutter in a given space, and the Activities of Daily Living for Hoarding (ADL-H) which assesses the impact of clutter on acts of daily living.⁹



Samuels, J. F., Bienvenu, O. J., Grados, M. A., Cullen, B., Riddle, M. A., Liang, K., Eaton, W. W., & Nestadt, G. (2008). Prevalence and correlates of hoarding behavior in a community-based sample. *Behaviour Research and Therapy*, 46(7), 836-844.

⁶ Frost, R. O., Steketee, G., & Grisham, J. (2004). Measurement of compulsive hoarding: Saving inventory-revised. *Behaviour Research and Therapy*, 42, 1163-1182.

⁷ Tolin, D., Frost, R., & Steketee, G. (2010). A brief interview for assessing compulsive hoarding: The hoarding rating scale-interview. *Psychiatric Research*, 178, 147-152.

⁸ Frost, R.O., Steketee, G., Tolin, D., & Renaud, S. (2008). Development and validation of the clutter image rating. *Journal of Psychopathology and Behavioral Assessment*, 30, 193-203.

⁹ Frost, R. O., Hristova, V., Steketee, G., & Tolin, D. F. (2013). Activities of daily living scale in hoarding disorder. *Journal of Obsessive Compulsive Related Disorders*, 2(2), 85-90.

To date, the most commonly studied treatment for hoarding is based on a conceptual model described by Steketee and Frost.¹⁰ This model suggests that a person's genetic, neurobiological and environmental vulnerabilities, combine with deficits in information processing (i.e. attention, categorization, association, perception), contribute to the formation of distorted beliefs about possessions. These distorted beliefs, together with the emotions they evoke, create a cycle of positive and negative reinforcement that maintains and deepens the attachment to objects.

The specialized cognitive and behavioral treatment (CBT) developed to treat hoarding disorder consists of 26 sessions of individual outpatient therapy delivered both in office and at the client's home (every 4th session). The treatment modules include: assessment, case formulation and goal setting; motivational enhancements; skills training—organizing, problem solving, decision making; challenging beliefs about possessions; practice sorting, discarding, and non-acquisition (exposure); and relapse prevention. An open trial of 10 treatment completers demonstrated a strong therapeutic effect, with 50% rated much or very much improved on a clinical global improvement (CGI) scale.¹¹ In a wait-list comparison trial of CBT for hoarding with a sample of 37 treatment completers, CBT was superior to waitlist after only 12 weeks and when all patients completed 26 sessions. In this study approximately 75% of the patients were rated much or very much improved.¹² CBT methods to treat hoarding were also studied in older adult samples (ages 60 and older) with somewhat conflicting

¹⁰ Steketee, G. & Frost, R. O. (2007). *Compulsive hoarding and acquiring. Therapist guide*. New York, N.Y.: Oxford University Press.

¹¹ Tolin, D. F., Frost, R. O., & Steketee, G. (2007). An open trial of cognitive-behavioral therapy for compulsive hoarding. *Behaviour Research and Therapy*, *45*, 1461-1470.

¹² Steketee, G., Frost, R. O., Tolin, D. F., Rasmussen, J., & Brown, T. A. (2010). Waitlist-controlled trial of cognitive behavior therapy for hoarding disorder. *Depression and Anxiety*, *27*, 476-484.

findings. Additional clinical trials are needed to better understand the specific needs of older adults who hoard and to enhance treatment response.¹³

In addition to individualized therapy approaches, group CBT (GCBT) shows promise for the treatment of hoarding disorder. Twenty sessions of GCBT produced good outcomes, almost at the level of individual treatment, and was more effective when combined with in-home coaching.¹⁴ Groups show efficacy even when conducted via web-cam, creating the possibility of improved accessibility for clients seeking treatment for hoarding. Although there is little research as of yet, mutual-help groups for hoarding also show promise, especially with regard to discarding clutter.

Even when training in specialized CBT techniques is not available to a clinician, community support workers and outpatient therapists can utilize knowledge and principles from the model to aid in simple harm reduction measures such as limiting acquisition, discarding objects, and addressing immediate safety concerns. Implementation of a screening process for hoarding disorder across levels of care increases the likelihood that interventions will reach the client in a timely and compassionate manner. There is a great need in the Omaha community for clinicians to seek the training necessary to deliver these services.

¹³ Ayers, C. R., Bratiotis, C, Saxena, S, & Wetherell, J. L. (2012). Therapist and patient perspectives on cognitive-behavioral therapy for older adults with hoarding disorder: A collective case study. *Aging and Mental Health, 16*(7), 915-921.

¹⁴ 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.

A Special Note to Families Regarding Mental Health

Assisting your loved one with their daily activities of living can be exhausting. Contacting a community support program to inquire if your loved one qualifies for services can help even when therapy is not available. If you have a family member who has hoarding disorder and would like to work on the problem in therapy, help them look for a licensed mental health practitioner who will use cognitive behavioral treatment for hoarding. But remember, not everyone is willing or able to commit the time, energy, and money required for therapy. If your loved one is not interested in therapy, harm reduction techniques can also lead to an improved quality of life.

Public Health

Stella has lived alone her entire life. She enjoys spending time at home more than she likes to be out in the community or with family and friends. She never has visitors to her home because she's embarrassed by how it looks and worries about what other people will think. She finds herself constantly hiding her home life even though it's a comfortable place for her. She feels shame when she tells others that she'd rather meet at a restaurant or the library and not at her home. A friend recently stopped by uninvited. Stella answered the door before she realized what she was doing. The friend forced her way in and observed a house full of objects. The floorboards were sagging, the walls were cracked from water damage and there was a strong smell emanating from behind the closed bathroom door. Several days later Stella received a letter in the mail from the city's board of health. She was being cited and fined for the condition of her home.

The United States system of public health interconnects numerous agencies and professions at the local, state, and federal level in a common effort to minimize health risks to the population. This complex system includes hospitals, clinics, schools, home health care, mental health, corrections, civic groups, and foundations as well as government entities such as national, state, and county health departments. Services include but are not limited to identifying and investigating health hazards, monitoring health status within a community, providing education on health-related issues, and mobilizing community partnerships to identify and resolve health problems.

The Douglas County Health Department and the Sarpy/Cass Department of Health and Wellness share the common goals of promoting the health and safety of the communities they serve. They do this through a wide variety of services including infectious disease monitoring, tracking of vital statistics, laboratory testing, and preventative programs. They also provide education on healthy living, safety, and the management of chronic health conditions. As

government agencies, they are empowered to enforce compliance with the municipal code when there is a danger to public health.

Current Response

The Sarpy/Cass Department of Health and Wellness does not become involved in hoarding cases, nor do they offer educational materials on the subject. All reports of suspected hoarding are referred to the appropriate city official, usually the Housing Inspector or Code Enforcement. Hoarding cases in Omaha are usually brought to the attention of the Douglas County Health Department through neighbor reports of outdoor clutter or odors. In response, the Department conducts a site visit to look for code violations. They also attempt to contact the resident; however, they may not enter the home during this initial visit unless invited.

If evidence of code violations is obvious, such as a noticeable nuisance or a danger to public health, the inspector provides the resident with notice of the violation and a requirement to rectify the situation. The inspector also requests permission to enter the house to look for additional health or safety hazards. If the resident is uncooperative with this request,

¹⁵ Omaha Mun. Code, ch. 12, art. II, § 12-27 (1996).

¹⁶ Omaha Mun. Code, ch. 18, art. I, § 18-2 (1996).

Municipal Codes

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CHAPTER 12¹⁵ Omaha Municipal Code Health and Sanitation

Empowers the health department to enforce the removal of all accumulations of garbage, filth, offal, and similar materials

CHAPTER 18¹⁶ Omaha Municipal Code Nuisances

Defines a nuisance a condition that endangers the comfort, repose, health or safety of others, offends decency, is offensive to the senses, obstructs lawful passage, renders other persons insecure in life or the use of property, or interferes with quiet enjoyment of life and property, or depreciates the value of property of others

the Health Department can obtain an inspection warrant to enter the residence.

Once identified, hoarding cases in Douglas County are referred to law enforcement and addressed through monthly meetings of the Problem Resolution Team (PRT). The PRT is comprised of various agencies including police, fire, code, and public health, which collaborate to resolve hoarding cases using a multi-agency approach with the objective of eliminating any accumulated belongings which pose a safety risk and bringing the residence up to code.

Best Practices

Although the Health Department is mandated to protect public health and safety, there is usually some leeway in the method of enforcement. If the person who is hoarding is at all cooperative, it is best to avoid a court order unless absolutely necessary.¹⁷ Establishing a good rapport from the initial interaction goes a long way to creating a working relationship with the resident. This is essential since hoarding disorder is a chronic mental illness that will progress without intervention, possibly leading to long and/or reoccurring encounters with enforcement agencies.¹⁸ Collaboration with social service agencies can also be helpful, allowing the inspector to focus on enforcement while the other agency focuses on support. The Omaha Hoarding Task Force may also be of assistance, either by providing information on hoarding resources or by assisting with case management.¹⁹

Whenever possible, inspectors should emphasize personal concerns for the resident's safety and well-being. Suggestions for change should be compelling, clear, and directly related to the specific code violations. Although people who hoard save for the same reasons anyone

¹⁷ Bratiotis, C., Schmalisch, C. S., & Steketee, G. (2011). *The hoarding handbook: A guide for human service professionals*. New York, NY: Oxford University Press.

¹⁸ Tolin, D. F., Frost, R. O., Steketee, G., Gray, K. D., & Fitch, K. E. (2008). The economic and social burden of compulsive hoarding. *Psychiatry Research*, *160*, 200-211.

¹⁹ 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.

else does, they often attribute beliefs and meanings to their possessions that go beyond the ordinary. Objects carry the weight of personal responsibility, convey safety or comfort, or even represent the person's identity or potential identity. It will take patience and encouragement to help residents understand the necessity of parting with even a few belongings.²⁰

If possible allow the resident extra time to accomplish goals. Individuals with hoarding disorder frequently have difficulty with organizing, decision-making, perception, insight, and awareness. Provide detailed information on each code violation and the steps necessary to resolve it. Larger tasks should be broken down into smaller, more manageable steps and goals should have a realistic timeline for completion. Provide instructions verbally and in writing. People who hoard often struggle with motivation so schedule return visits with the resident to monitor progress and to provide feedback.²¹

A Special Note to Families Regarding Public Health

The approach taken by the Douglas County Health Department and the Problem Resolution Team is regulatory in nature and rarely includes a support person such as a mental health therapist or caseworker. If possible, seek out this support for your loved one and ask to have them involved in any interventions. At the same time, the presence of a regulatory agency such as public health can be a powerful motivator for change. When health is at risk, the usual intervention in hoarding cases is a mass cleanout. While it is not necessary for you to participate, the PRT typically enlists the aid of family members, friends, and neighbors to assist in the process.

²⁰ Bratiotis, C., Schmalisch, C. S., & Steketee, G. (2011). *The hoarding handbook. A guide for human service professionals*. New York, NY: Oxford University Press.

²¹ Ibid.

Housing

Raul is a 47 year old man who is unmarried and lives alone in a single family home. Raul recently lost his job and is having difficulty paying his rent. He is now three months arrear and his landlord is demanding payment. When his landlord recently stopped by to inquire about the late rent, Raul was home but did not answer the door. Raul has gathered free things and saved too many objects for most of his life. His home contains tens of thousands of miscellaneous objects, especially newspapers, periodicals and parts for electronic equipment. He has every issue of his city's newspaper dating back to the late 1960's. These papers are stacked in narrow rows approximately 10 feet high. He's especially proud of this collection and is certain that it is both monetarily valuable and of interest to many in his community.

Housing professionals in both the public and the private sector will encounter hoarding throughout the course of their careers. Housing inspectors, Omaha Housing Authority employees, landlords, property managers, real estate agents, or neighbors may be the first to notice there is problem in the home and are positioned to intervene for the safety and well-being of the occupant. Code inspectors who work for the city may encounter hoarding when enforcing code regulations. Professionals at Omaha Housing Authority (OHA) encounter hoarding among clients that they serve in subsidized housing. The City of Omaha Planning Department Housing and Community Development Division offers grants for home renovations and interacts with individuals who hoard during the screening process. In the private sector, landlords and property managers encounter tenants with hoarding disorder to varying degrees. Real estate agents are challenged to show and sell overflowing homes. Neighbors and neighborhood associations sometimes take issue with cluttered exteriors and damages to a home that may affect the property value of the area.

Current Response

Code Inspectors for Housing. There are 10 code inspectors employed by the City of Omaha Planning Department Housing and Community Development Division. Their jurisdiction is the city of Omaha and a three mile radius outside of the Omaha city limits. Code inspectors have a background in construction, architecture, or engineering. Each year, the department handles about six to eight cases that involve hoarding behaviors. Some of these cases remain open for decades. Code inspectors are concerned with the structural integrity of dwellings and the stress placed on plumbing, mechanical, electrical, ventilation, and septic systems by excessive accumulation in the home. Additional areas for attention include fire hazards, infestations, and egresses.

In order for a code inspector to work with a private resident, the individual must voluntarily allow the inspector in the home. Without evidence of code violations, the inspector cannot force entry or even apply for a warrant to enter the property. Extreme hoarding cases are a rare exception to this; however, in most instances there must be proof of dangers related to hoarding from outside the home in order to obtain a warrant. Once an inspector's work begins with an individual who hoards, he or she may visit the home once a week to ensure that progress is made toward compliance with building codes. As the process continues, the inspector visits the home less often, although work on hoarding cases can continue for years.

Omaha Housing Authority (OHA). The Omaha Housing Authority also encounters hoarding cases. One of their main concerns related to hoarding is pest infestations that spread from one apartment to another. This can include vermin such as mice, rats, cockroaches, and bed bugs. In particular, infestations of bed bugs in apartment buildings are very difficult to eradicate and a large volume of possessions makes the task even more challenging. After

receiving referrals from the site manager, OHA sends an official to the home to discuss cleaning with the occupant. The tenants do not get assistance paying for cleaning or any other services although OHA occasionally works with a home healthcare agency in cases of hoarding and is open to developing additional partnerships.

Private landlords and Property Managers. The primary law in Nebraska governing the legal relationship between property owner and a residential renter is known as the Uniform Residential Landlord and Tenant Act (1974). This law attempts to balance the rights of both the property owner and

the tenant. Hoarding cases create unusual circumstances and each landlord or property manager may address the issue as they see fit

Landlord versus Tenant Rights in Nebraska²²	
Landlords	Tenants
<ul style="list-style-type: none"> • May seek monetary compensation for damages • Can evict tenants if they do not comply with legal obligation to maintain the dwelling 	<ul style="list-style-type: none"> • Have the right to possession of the property for the duration of the lease agreement • Have the right to manage objects in the home as they see fit as long as they do not violate housing codes and legal obligation to maintain the dwelling

within the general confines of Nebraska law. While pest infestation and property upkeep is usually considered the legal obligation of the landlord, excessive accumulation is considered outside the normal use of a property. Therefore, costs associated with rectifying the situation are the responsibility of the tenant. In the case of pest infestation, damage to property, or disturbance to the neighbors caused by hoarding (or by any other concern), a landlord can issue a written warning for the situation to be rectified within 30 days. If the problem is not resolved to the landlord's satisfaction, they can seek to end the lease agreement through eviction, a lengthy and expensive legal process.

²² Neb. Rev. Stat. § 76-1401 et seq. (Reissue 2009).

Best Practices

Housing officials who understand hoarding disorder and collaborate with other professionals as well as residents on an agreed upon resolution will be most successful in creating long term solutions.²³ Resolution plans should take into account the presence of a mental illness as well as addressing health, safety, and financial concerns related to housing. The plan should be presented in writing in addition to being discussed. Goals need to be clear and achievable. While time limits for compliance are necessary, be willing to delay eviction or condemnation proceedings if progress toward goals is evident. Utilize flexibility to set time limits that are reasonable in relation the amount of work required to complete a task. Any comorbid physical disabilities must also be taken into account. Many older or disabled individual may find it physically impossible to remove heavy or bulky items from the home without assistance. Whenever appropriate, enlist the resident's family, friends, and community support such as churches or neighbors to help clean the property gradually; reserve large-scale cleanouts for cases of imminent danger only.²⁴

Rectifying the damage caused by long-term hoarding can be costly. The Prospect Village Homeowner Rehabilitation Program, offered through the City of Omaha Planning Department Housing and Community Development Division may provide assistance. The program, which aims to help rehabilitate owner occupied housing in a designated section of North Omaha occasionally receives applications for funds to rehabilitate homes where hoarding has occurred. If resources are present, the planning department official may contact church or neighborhood association groups to help the resident and/or family clean the house

²³ Schmalisch, C. S. (2010). *Hoarding and housing*. Retrieved from http://www.ocfoundation.org/hoarding/housing_services.aspx.

²⁴ Bratiotis, C., Schmalisch, C. S., & Steketee, G. (2011). *The hoarding handbook. A guide for human service professionals*. New York, NY: Oxford University Press.

in order to become eligible for the grant. The planning department collaborates with professionals at the Eastern Nebraska Office on Aging and Visiting Nurses Association when possible, although help from outside sources may be limited because these organizations do not have funds to pay their personnel for hoarding services.

Depending on the condition of the residence, moving may be the only option. Since untreated hoarding is a chronic problem that will continue in any housing situation, relocations should be a last resort due to untenable safety or financial circumstances. Prior to the move, design a harm reduction plan for the new residence that focuses on limiting acquisition of new belongings and establishes safety features from the start such as preserving pathways and open egresses.²⁵ If the hoarded home must be sold, warn prospective buyers about the condition of the house in advance and provide a floor plan of the dwelling.²⁶ During the packing and moving process, seek ways to give the person who hoards as much control as possible. Whenever possible, allow them to make sorting decisions and encourage them to make a list of their most prized possessions which will travel with them to their new home.

²⁵ Bratiotis, C., Schmalisch, C. S., & Steketee, G. (2011). *The hoarding handbook: A guide for human service professionals*. New York, NY: Oxford University Press.

²⁶ Rosenblum, C. (2013, October 11). Selling a hoarder's home: The trouble with stuff. *New York Times*. Retrieved from <http://www.nytimes.com/2013/10/13/realestate/selling-a-hoarders-apartment.html>

A Special Note to Families Regarding Housing

As a family member you may find yourself in the difficult position of negotiating with housing authorities or landlords that may be threatening eviction. You may be worried that your family member will face legal consequences, financial hardship, or even homelessness. The situation is even more distressing if the dwelling is your current or childhood home. Although it may be difficult, try to collaborate with officials in creating a harm reduction plan that meets the needs of your family member and the safety requirements of the housing authorities. Rather than becoming an adversary, housing authorities can be your biggest advocate when dealing with a housing crisis. At the same time, remember that property laws tend to favor landlords, not tenants. Educate yourself and your loved one on tenant rights and responsibilities to ensure fair treatment.

First Responders

During morning roll call, Officer Jenkins reported that yesterday he and his partner were in an unbelievable situation. "Worst I've seen in my 22 year career. It was a medical call; a 54 year old guy – had a heart attack. We responded with EMS and the house was so bad EMS couldn't get their equipment in. Forty-five minutes later, with four of us digging our way through the piles, we finally reached him. We get the guy strapped to the board then we look at each other and realize we have no idea how to get him out."

Firefighters, police officers, and paramedics frequently enter people's homes in order to help them with medical or safety situations. Many times a hoarding case comes to the attention of authorities for the first time due to the safety hazards these professionals encounter during such emergencies. Extensive accumulation of items can trap residents and professionals alike during a fire, contribute to the risk of structural collapse, or make it impossible to provide timely medical intervention during a medical emergency. Thus the extent of the clutter is considered a safety concern for all involved, and influences the extent of first responder involvement in hoarding cases.²⁷

Current Response

Awareness of hoarding as a problem is increasing among most first responders as hoarded homes are more frequently encountered. Still, perceptions about the prevalence and impact of hoarding vary widely. Because of these differences, the current response to hoarding also varies across local municipalities despite their close physical proximity.

Douglas County. The Omaha Police Department (OPD) views hoarding as an individual problem and has no proactive measures to address it. From a legal standpoint, hoarding is not

²⁷ Kirk, S. (2011). Hoarding: A fire prevention and response concern. *Fire Engineering*, 164(3), 231-235.

a criminal matter unless the conditions pose a hazard. Therefore, officers do not actively investigate hoarding cases. Instead, these situations come to the department's attention when they are responding to another matter. Most often, a neighbor or member of the community complains that the hoarded home is negatively impacting them. This most commonly occurs when a foul odor comes from a home or the condition of the yard or exterior of the house is decreasing property values. A hoarded home may also put neighbors at risk for fire and/or infestations by insects and rodents.

Despite the validity of these complaints, there is often little that the police can do about the hoarding. Conditions that do allow for intervention by the police department include homes that do not have running water or electricity, or cases in which an older adult or child may be in danger. In these situations, OPD refers the case to the Omaha Planning Department, Adult Protective Services, or Child Protective Services. The officer may also recruit a mental health crisis response team based on his or her discretion to assist with the immediate situation.

The Omaha Fire Department (OFD) also views hoarding as a private problem, noting that hoarding seems to affect people from all walks of life, but that generally these individuals are not directly bothering anybody. Hoarding does, however, seem to affect a large number of people (family members, neighbors, co-workers, etc.) in indirect ways. At this time the OFD does not have any response specific to hoarding, but rather is prepared to encounter a wide variety of conditions. Hoarded homes present a particular challenge due to the fire load or volume of combustible materials stored in the home. Frequently, the fuel load is so high in a hoarded home that the fire consumes the residence rapidly, making rescues extremely difficult. Smoke also presents a greater risk in hoarded conditions. Under the densely-packed conditions found in a heavily-hoarded home, fires may smolder for hours filling the house with smoke

and endangering the lives of the occupants. Further exacerbating the situation, smoke detectors are frequently inaccessible due to the clutter and may fail to work properly.

Paramedics also frequently encounter hoarded homes while responding to medical emergencies. Although they can use existing paths to make their way to the occupant, even moderate amounts of clutter can make it impossible to bring a stretcher into a hoarded home. In order to remove a person in medical distress, paramedics and EMTs often resort to specialized equipment such as stair chairs or bots. A stair chair is a small, upright chair that has one small pair of wheels and two sets of carrying handles. The patient is strapped into the chair, and is carried or wheeled through a narrow path out of the house. In cases where the paths are too narrow for a stair chair, patients are wrapped in a bot, a reinforced blanket with carrying handles, and carried out of the home. In the most extreme circumstances, paramedics may be forced to break windows in order to remove patients from their hoarded homes. Not only do these methods place additional physical strain on patient and professionals alike, they can take up valuable time in a medical emergency, further risking the patient's life. Aside from training with this specialized equipment, paramedics and EMTs do not receive any specialized training in the area of hoarding.

Sarpy County. The Sarpy County Sheriff's Office (SCSO) recently provided training to their deputies to increase awareness and understanding of hoarding. Because officers are not legally allowed to provide a hands-on intervention in such cases, it can be very difficult for them to assist people who hoard directly. Instead, hoarding-related calls are passed on to the community liaison. The liaison responds by completing a low level scan of the home to understand the severity of the problem. He or she typically conducts a short interview in a non-threatening way in order to get a comprehensive understanding of the situation. If there

is a substantial problem in the home, such as safety issues or squalor, the liaison makes a referral to the appropriate agency. This may include Child Protective Services, the Health Department, the Fire Department, or the Office on Aging. In some instances, a family member may be contacted in order to get the individual some assistance.

Like other municipalities, officers of the La Vista and Bellevue Police Departments primarily focus on the safety of the individual and enforcement of code violations when dealing with hoarding cases. However, these departments rarely receive reports of hoarding, which reinforces the perception that hoarding is not a concern in their communities and therefore, not a police matter. In the rare instance that a hoarding case is encountered and the individual is considered at extreme risk based on the condition of the home, an officer might determine that the individual qualifies for an Emergency Protective Custody (EPC), however, this is not an official department policy but rather at the discretion of the responding officer.

Best Practices

The first responder is often the first outside person to enter a hoarded home in several months or even years. The circumstances surrounding this point of contact are frequently involuntary and stressful for the person who hoards. In such cases, the first responder's reaction plays a critical role in determining the ultimate outcome in a hoarding case. Collaboration with other agencies can lead to increased safety, the primary concern for first responders, as well as an improved quality of life for the individual who hoards.²⁸ For example, the Omaha Police Department utilizes specially trained individuals from the Peer Support Specialist program during cases involving mental health concerns including hoarding.

²⁸ Bratiotis, C., Schmalisch, C. S., & Stekete, G. (2011). *The hoarding handbook: A guide for human service professionals*. New York, NY: Oxford University Press.

Officers are also able to make referrals to the Crisis Response Team to help in situations which may go beyond the officer's scope of expertise.

In addition to collaboration with other community organizations, early intervention, education, and a proactive stance are essential in addressing the problem of hoarding.²⁹

Community hoarding task forces are a means of disseminating training and education about hoarding to first responders. Hoarding task forces have a presence in communities of all sizes and demographics across the country. Often, task forces are initially developed by local agencies as a means of sharing information, expanding knowledge about hoarding, and developing interventions



appropriate for their specific community.³⁰ The Omaha Hoarding Task Force, while relatively new, has already begun to assume this role in the Omaha area.

At times, hoarding task forces become crisis response teams that provide interventions for people who hoard. The city of Arlington, Massachusetts has developed a Hoarding Response Team (HRT) which consists of two Health Department inspectors, a Mental Health Clinician, a designated Police Officer, and the client. The model purposefully limits the size of the team to make it most efficient. In this model each member has a clearly designated role and

²⁹ Bratiotis, C., Schmalisch, C. S., & Steketee, G. (2011). *The hoarding handbook: A guide for human service professionals*. New York, NY: Oxford University Press.

³⁰ 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.

shared goal. Arlington officials have found that including too many members into the response team limits its effectiveness because “agendas” can be very different. The ultimate goal of the HRT is for the occupant to regain control of his or her life.³¹

A Special Note to Families Regarding First Responders

First responders are often involved with individuals and families in emergency situations and must, as part of their professional responsibilities, assure the safety of all parties involved. It is important to keep this noble goal in mind despite the stressful situation. To prepare for emergencies and potential encounters with first responders, develop a harm reduction plan that includes clear pathways wide enough to accommodate a stretcher, reducing the height and weight of piles, and removing trip hazards. Move flammable items away from heat sources and check smoke detectors regularly. In a hoarded home, the landscape can change rapidly. Carry out regular “fire drills” and monitor accumulated items to maintain two clear routes out of every room.

³¹ Town of Arlington, Massachusetts. (2012). *Hoarding Program*. Retrieved from http://www.arlingtonma.gov/Public_Documents/ArlingtonMA_Health/hoarding/index?textPage=1

Child Protective Services

Mrs. Johnson lives in her hoarded home with three young children. A well-meaning neighbor sees the conditions and is concerned for the safety of the children. She calls Child Protective Services (CPS) to report that the home is dirty and belongings are piled so high they block the window. When CPS investigates, they find unsafe living conditions in the home. To make matters worse, Mrs. Johnson is uncooperative about clearing out her things. Mrs. Johnson's children are immediately removed from her care and placed in the custody of the Department of Health and Human Services. Because there are no suitable family members or friends to take placement, they are placed in a foster home. The children are forced to change schools due to the location of their foster home and are only allowed court-ordered supervised visits with their mother. Mrs. Johnson's caseworker decides to clear out the home with a dump truck in an effort to make the living conditions safe. After the clean out, Mrs. Johnson falls into a major depressive episode. She begins missing visits with her children, stops returning her caseworker's phone calls, and no longer attends court hearings for her case. Twelve months go by and Mrs. Johnson makes no progress toward meeting the court's requirements. Based on this and Mrs. Johnson's inconsistent contact with her children, the county attorney files to terminate her parental rights.

Hoarding is an epidemic that frequently interfaces with the child welfare system. Excessive accumulation poses various safety risks for anyone living in or near a hoarded environment, especially children. The potential risks to children living in hoarded homes include threats to physical and emotional safety as well as to appropriate development.³² Therefore, when children are present, child protection workers and child welfare agencies may become involved. The role of these workers is to assess the home environment for safety and cleanliness, and to determine whether the level of clutter poses a risk of harm to the children, and thus an abuse or neglect concern. Although the primary focus for these workers is the

³² Bratitotis, C., Schmalisch, C. S., & Steketee, G. (2011). *The hoarding handbook: A guide for human service professionals*. New York, NY: Oxford University Press.

health, safety, and overall well-being of the child, they should also be involved with intervention planning and implementation as it relates to the adult individual who hoards.³³

Current Response

There are several ways in which a child protective services agency may become involved in a hoarding case. In some cases, a friend, neighbor, or family member files a formal report when they become aware of a home with adverse living conditions. In other cases, child protection professionals may be the first to discover a hoarded home as part of their work on other family issues. An important task for CPS is to assess

In Nebraska, the Department of Health and Human Services utilizes the following definitions:³⁴

CHILD/YOUTH MALTREATMENT:

Parenting behavior that is harmful or destructive to a child's (age birth through age 17) cognitive, social, emotional, and/or physical development.

EMOTIONAL ABUSE:

Psychopathological or disturbed behavior in a child/youth which is documented in writing by a psychiatrist, psychologist, or licensed mental health practitioner to be the result of continual scapegoating, rejection, or exposure to violence by the child/youth's parent or caretaker.

EMOTIONAL NEGLECT:

The child/ youth is suffering or has suffered severe negative emotional effects due to a parent's failure to provide opportunities for normal experiences that produce feelings of being loved, wanted, secure, and worthy, as documented in writing by a psychiatrist, psychologist, or licensed mental health practitioner.

PHYSICAL ABUSE:

The non-accidental infliction of injury or an act that poses substantial likelihood of bodily injury.

PHYSICAL NEGLECT:

The failure of the parent to provide basic needs, for example food, clothing, shelter, medical care, supervision and a safe and sanitary living environment for the child/youth.

³³ Bratiotis, C., Schmalisch, C. S., & Steketee, G. (2011). *The hoarding handbook: A guide for human service professionals*. New York, NY: Oxford University Press.

³⁴ Division of Children and Family Services Administrative Memo #13-2011, effective November 2, 2011, page 1. Retrieved from http://dhhs.ne.gov/children_family_services/Documents/132011%20SDM%20w%20attachments.pdf

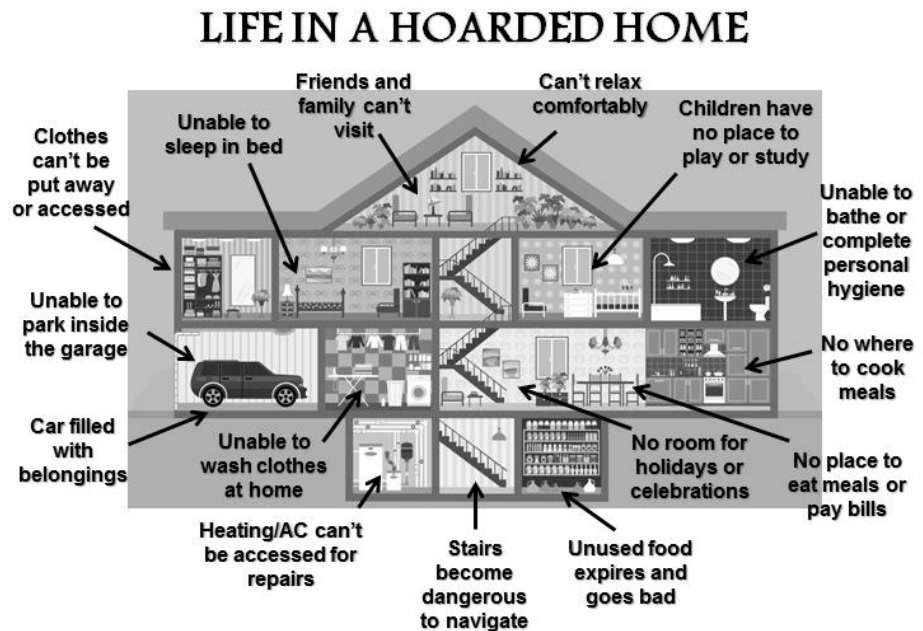
how aspects of hoarding disorder, such as accumulation, difficulty discarding, and acquisition threaten the safety of children in the home.³⁵ In addition to threatening the physical safety of a child, emotional states, educational opportunities, and social ties are threatened as well. It is important for workers to objectively assess the well-being of a child across all of these dimensions.³⁶

Despite these clear objectives, child protection professionals report there is no current standard response to hoarding. Children are often removed immediately. This may exacerbate depression and other

co-occurring mental health concerns in the person who hoards, making it even more difficult for them to remedy the situation.

The lack of an immediate response by the person who hoards

may trigger further concerns on the part of the worker, who may question the parent's ability to ever care for the children properly. Alternatively, workers may address the concern by organizing a group of volunteers or professional organizers to clear the home. Although this might seem like a better option than removing the children, forced cleanouts are extremely devastating for the person who hoards and often do far more harm than good. Furthermore,



³⁵ Bratiotis, C., Schmalisch, C. S., & Stekete, G. (2011). *The hoarding handbook: A guide for human service professionals*. New York, NY: Oxford University Press.

³⁶ Neziroglu, F., Slavin, J. & Donnelly, K. (2010). *How compulsive hoarding affects families*. Retrieved from http://www.ocfoundation.org/hoarding/family.aspx#affects_families

cleanouts do not address the underlying problem. Thus the clutter simply accumulates again, leading to further involvement with CPS.

Interdisciplinary collaboration, as it relates to the CPS sector, is limited. When there is collaboration, oftentimes it is brief and involves a referral to facilitate the aforementioned cleanout. Since the physical appearance of the home is typically the reason for CPS involvement, once this has been resolved there is little attention to the underlying mental health aspect of hoarding. Even when mental health is recognized as a concern, few agencies have enough knowledge or experience about hoarding to make collaboration useful. Over time, the lack of treatment options, ongoing safety concerns, and repeated encounters with CPS may result in the permanent removal of children from their home environment. Given the extreme impact this has on the child and family, there is a great need for services and resources within the community pertaining to hoarding.

Best Practices

Child protective service workers are faced with the challenging task of determining whether the physical manifestation of hoarding creates a risk of harm to the children living in the home. The Nebraska Department of Health and Human Services utilizes the Structured Decision Making model to investigate whether a risk of harm is present.³⁷ During the initial investigation of a hoarded home, it is important to begin with an assessment that targets the history and source of the hoarding. CPS professionals should avoid any language that could elicit shame or embarrassment in the individual who hoards. Instead, use language that builds rapport and promotes motivation to change. If imminent danger makes it impossible for children to remain in the home, CPS professionals should explore alternative options that allow

³⁷ Division of Children and Family Services. (November 2, 2011). Administrative Memo #13-2011. Retrieved from http://dhhs.ne.gov/children_family_services/Documents/132011%20SDM%20w%20attachments.pdf

the family to remain together. This may include relocating the entire family to the home of a friend or relative, or to a shelter, until harm reduction strategies can be implemented in the hoarded home. In instances where the family must be separated, workers should collaborate with the parent or parents about placement options and develop a written timeline for family reunification. Once safety has been ensured, workers should implement strategies of harm reduction to clear out high risk areas. The goal should not necessarily be a beautiful home, but rather a functional home that is a safe place for the family to live. In addition to addressing existing risks, a plan that reduces acquisition and outlines a response to potential relapse is essential to assure ongoing success.³⁸

Though resources are currently limited, collaboration with other disciplines, such as housing inspectors and mental health practitioners with specific knowledge and training in the area of hoarding is critical in reducing the current and future risk inside the home. The benefit of this collaboration could potentially keep families in their homes, assure the safety of the home, and prevent children from entering the child welfare system. Further, involving trained mental health practitioners who specialize in hoarding increases the likelihood that the individual who hoards will receive appropriate assessment and effective treatment. The right therapist can properly integrate elements of harm reduction, teach skills to improve the living conditions, and employ cognitive behavioral therapy to attenuate the underlying cause of hoarding behavior and address problematic family dynamics. Open and frequent communication between professionals is essential. Collaborative wrap-around services by several disciplines provides the best chance for families to remain intact, improve the lives of individuals who hoard and their families, and ensure the overall health of the community.³⁹

³⁸ Bratiotis, C., Schmalisch, C. S., & Steketee, G. (2011). *The hoarding handbook: A guide for human service professionals*. New York, NY: Oxford University Press.

³⁹ Ibid.

A Special Note to Families Regarding Child Protective Services

Facing the prospect of having children removed from the home can be terrifying and overwhelming. However, when CPS becomes involved, there are things you can do to improve the situation. Encourage your loved one to communicate honestly about the situation and to be open to solutions. If they are willing, help them implement elements of harm reduction to eliminate safety risks in the home wherever possible. This may include moving flammable items away from heat sources and clearing a pathway for an emergency exit. However, be respectful of their belongings and their home during this process. Given the high stakes, it is important to allow the individual who hoards to dictate the level of involvement they prefer from their family.

Aging Services

Father Martinez regularly visits his elder parishioners. On a recent visit to Maria's home, he expressed his grave concerns for her safety. "Maria, it's always good to see and to be with you. You're looking a bit thin to me today. I'm worried about you and about how you're managing in the apartment – it's gotten so full lately." Fr. Martinez moved a few things out of the way to clear a path from the bathroom to the bed and from the bed to the kitchen before saying, "I'd like to see if I could get you some help, somebody to be sure you're okay here by yourself. Would it be okay with you if I made a phone call to some people that could come in and see what you need to help you get along better?"

Older adults are the fastest growing segment of the population and currently comprise 13% of all people living in the United States. By 2030, the U.S. Census Bureau projects that nearly 1 in 5 Nebraskans will be 65 years of age or older.⁴⁰ Local services for older adults include in-home health services such as home health care and hospice, state and federally-funded organizations such as the Eastern Nebraska Office on Aging (ENOA), Adult Protective Services (APS), and facilities associated with the long-term care continuum such as independent living centers, assisted living facilities, and nursing homes. Together, these organizations provide a wide array of services geared toward helping older adults remain independent, active, and healthy.

Hoarding is most frequently associated with older adults. Although research shows that 80% of those who hoard exhibit hoarding behaviors by age 18⁴¹, it can take decades for the accumulated clutter to reach the clinical levels we associate with hoarding disorder. Older adults are particularly vulnerable to hazards associated with a hoarded home including fall

⁴⁰ United States Census Bureau (2012). *Projections of the Population by Selected Age Groups and Sex for the United States, 2015 to 2060 (NP2012-T2)*. Retrieved from <http://quickfacts.census.gov/qfd/states/310001k.html>

⁴¹ Grisham, J. R., Frost, R. O., Steketee, G., & Hood, S. (2006). Age of onset in hoarding. *Journal of Anxiety Disorders, 20*, 675-686.

risks, fire hazards, impaired ability to care for oneself, and social isolation.⁴² It is frequently these health-related or quality-of-life circumstances that lead professionals working with older adults to encounter hoarding.

Current Response

In-Home Health Services. The overarching goal of home healthcare services is to allow people to remain in the privacy and comfort of their own home by attending to their non-medical and medical needs. These can range from assistance with meals, housekeeping, errands, and acts of daily living to skilled nursing care or hospice. No matter what the service, agencies providing home healthcare and hospice care seek to preserve their client's dignity and sense of autonomy. The accumulation of possessions; however, often interferes with this goal. Clutter often makes it difficult to bring necessary equipment into the home and may necessitate the transfer of the client from the home to an inpatient facility. Additionally, the condition of a client's living environment may pose safety risks to the staff providing in-home services. If services can be provided in-home despite these obstacles, the agency staff will frequently utilize harm reduction techniques to ensure the comfort and safety of the patient without directly addressing the hoarding. They may also engage family members and friends to accommodate the hoarding behavior by reducing or removing some of the clutter. In some cases, a referral might be made to ENOA for additional services or an APS report might be filed.

State and Federally-Funded Organizations. Government agencies such as ENOA provide myriad resources and programs designed to meet the needs of older adults living independently. Many of these services occur in the home, where hoarding quickly becomes a problem. These include the bath aide program, the homemaker program, and Meals on

⁴² Ayers, C. R., Bratiotis, C., Saxena, S., & Wetherell, J. L. (2012). Therapist and patient perspectives on cognitive-behavioral therapy for older adults with hoarding disorder: A collective case study. *Aging & Mental Health, 16*(7), 915-921.

Wheels. In addition, ENOA is often the first agency contacted by concerned families and other agencies seeking assistance for older adults who hoard. Although ENOA has provided extensive training to their staff on the topic of hoarding, resources for hands-on interventions remain limited in the Omaha area. Frequently, ENOA’s ability to assist in hoarding situations is limited to referrals to professional organizers, contract companies who can provide a forced cleanout, or advise family members on out-of-home placement or guardianship.

Adult Protective Services. APS becomes involved in hoarding situations when someone from the community suspects abuse, neglect/self-neglect, or exploitation of a vulnerable adult and makes a report. If an investigation is warranted, APS will collaborate with the county attorney and local law enforcement to determine if intervention is required. They will also determine what services are necessary to address the situation. These may include referrals for medical, mental health, or case management needs, assistance with basic resources such as food, clothing, shelter, or utilities, as well as support for caregivers such as respite care.

Cases of hoarding frequently fall under the “denial of essential services or self-neglect”

category. If the client is capable of making choices in their own best interest, they are given the necessary assistance to remain in their

Denial of Essential Services or Self-Neglect⁴³	
Living Environment	Victim Conditions
<ul style="list-style-type: none"> • Unsafe – shelter • Lack of food, clothing, medicine, or edible food • Human or animal feces on floors/ furniture • Rotting floors, ceilings • Housing does not protect from weather 	<ul style="list-style-type: none"> • Activities of daily living being neglected • Untreated medical conditions or injuries • Advanced bed sores • Lack of needed prosthetic devices – glasses, dentures, walkers, hearing aids • Poor personal hygiene such as untrimmed nails, matted hair, soiled clothing, and odors • Improperly clothed for winter or no clothing • Person shows signs of not enough food or water for no good cause • Lack of proper supervision

⁴³ Nebraska Department of Health and Human Services. (2014). Retrieved from http://dhhs.ne.gov/children_family_services/Pages/nea_aps_apsindex.aspx

homes whenever possible. However, resources to address hoarding are limited and frequently the only recourse for remaining in the home involves a forced cleanout.

In cases where the individual appears to suffer from a substantial mental impairment that impedes their ability to live independently, such as poor insight and an inability to resolve the situation, a court order may be sought to remove the person from their home involuntarily or have them declared legally incompetent. While obtaining guardianship over the person who hoards may allow for a more rapid response to the hoarding conditions, it may cause additional harm by disempowering the person who hoards and forcing unwanted interventions on them. Furthermore, a guardianship does nothing to rectify the limited resources available for hoarding. The pros and cons of such an extreme intervention must be carefully weighed.

Long-Term Care Continuum. When an individual who hoards is no longer able to live in their own home, they may move to an independent or assisted living facility. Nursing homes may also provide care to people who hoard. Since a change in the living situation does not eliminate hoarding behaviors, such facilities learned to cope with the clutter. In independent living facilities, the ability of the agency to intervene in hoarding situations is quite limited. Frequently, the only intervention available to them is to ask the client and/or their family to reduce the clutter based on health and fire code regulations. If the individual is unable to reduce the clutter, the agency may have no choice but to require the client to move.

In assisted-living or skilled-nursing facilities, the staff may have more ability to limit acquisition through close monitoring of the client. They may also attempt to reduce the amount of clutter by removing acquired objects when the resident is not present. This can damage the rapport between the client and the staff, and lead to feelings of frustration and intolerance. If these smaller attempts at accommodation cannot keep pace with the hoarding, facilities may resort to a larger forced cleanout. As with cleanouts done in a private home, this

intervention can elicit strong emotional reactions in the client such as anxiety, depression, and feelings of betrayal or suspicion, and frequently prove to be a temporary solution at best.

Best Practices

Just as older adults have special risks in relation to hoarding, treatment and harm reduction efforts also require modification to meet the needs of this special population. Older adults often have more physical limitations than the general population, making the process of sorting and removing items from the living space more physically challenging. Moreover, they may not have access to transportation or may not have recycling or garbage pick-up available to them. Those working with older adults should plan in advance to accommodate these logistical concerns in a harm reduction or cleanout situation.⁴⁴

Neurocognitive changes in executive functioning combined with the low insight and limited motivation of hoarding disorder can make cognitive-based interventions less effective for older adults. In addition to assessing for hoarding disorder, a thorough neurocognitive assessment should be obtained and interventions tailored accordingly. Based on cognitive ability, harm reduction may be more appropriate than CBT for many older individuals. In either case, clinicians should emphasize behaviorally-based strategies such as dividing tasks into small, time-limited parts, scheduling harm reduction tasks on calendars, and placing written reminders such as post-it notes in highly visible locations. Linking new behaviors to pre-existing, automatic tasks can also be helpful. For example, place a recycling bin next to the mailbox and encourage sorting and discarding every time the client collects their mail.⁴⁵

⁴⁴ Ayers, C., Najmi, S., Howard, I., & Maddox, M. (2014). Hoarding in older adults. In R.O. Frost & G. Steketee (Eds.), *Oxford handbook of hoarding and acquiring*. New York, NY: Oxford University Press.

⁴⁵ Steketee, G. & Ayers, C. R. (n.d.). *Challenges in treating hoarding in midlife and older adults*. Retrieved from http://www.adaa.org/sites/default/files/Steketee_Master-Clinician.pdf

A lifetime of attachment to their belongings as well as any history of deprivation can contribute to client fears of not having necessities and reinforce the need to save. In addition, older adults are more vulnerable to the social isolation that accompanies hoarding, making involvement from supportive friends and family invaluable to recovery. Those working with older adults should pay special attention to rapport-building. A strong relationship with the person who hoards will increase client confidence as well as their motivation to change. Encouragement and nonjudgmental support can be critical to successfully decreasing hoarding behaviors.⁴⁶

A Special Note to Families Regarding Aging Services

Accumulation of clutter can often go unnoticed for years by family members who are separated from the person who hoards by distance or obligations. Whether the hoarding is a recent discover or an ongoing concern, the current system can be frustrating and ineffectual to families who are seeking help for their loved ones. As in all hoarding cases, it is essential to evaluate immediate threats and develop a harm reduction plan that ensures safety while preserving as much dignity and autonomy for your family member. Keep the big picture in mind and remember that harm reduction strategies can be as effective if not more so than CBT treatment for older adults.

⁴⁶ Ayers, C. R., Bratiotis, C., Saxena, S., & Wetherell, J. L. (2012). Therapist and patient perspectives on cognitive-behavioral therapy for older adults with hoarding disorder: A collective case study. *Aging & Mental Health, 16*(7), 915-921.

Developmental Disabilities

At a recent staff meeting, Michelle, the manager of a six bed group home shared her concern for a particular resident. "Robert is a very sweet man. He's kind and always helping everyone else in the house. He especially likes to help them clean their rooms." The staff laughed, recalling how Michelle had previously indicated that Robert helped his housemates in order to take the items they were throwing away back to his room. "Now there's so much stuff in there, I can barely open the door. And Robert can't sleep in the bed. He's placed a mat on top of the piles and is sleeping on that." Another staff commented, "We could be in trouble with the fire marshal." Michelle asked the group, "Does anyone have any suggestions? Each time I suggest he get rid of anything he gets really angry and sometimes even violent."

In Nebraska, the Department of Health and Human Services Division of Developmental Disabilities (DDD) oversees services to individuals with intellectual disability or severe, chronic disability such as conditions resulting from genetic disorders or traumatic brain injury. When present, hoarding disorder is considered secondary to these disabilities. The goal of the DDD is to "provide an array of services to meet the needs of individuals with developmental disabilities in finding the greatest amount of independence with the right supports in the most inclusive environment possible."⁴⁷ All services emphasize the client's individual choice, individual legal rights, confidentiality, dignity, and respectful interactions.

Specialized services are available for both children and adults. They include day programs, vocational programs, residential services, respite services, and retirement services. Residential services can take a number of forms. Intermittent support may be provided in the family home or in a companion home, where 2 – 3 developmentally disabled individuals live independently. Individuals may also live in an extended family home, with an unrelated

⁴⁷ Department of Health and Human Services. (2013). Retrieved from http://dhhs.ne.gov/developmental_disabilities/Pages/developmental_disabilities_ddservices.aspx

“foster” family, or in a group home setting. In any of these residential situations, hoarding behavior may pose a serious threat to health and safety, and must be addressed.⁴⁸

Current Response

Many individuals with developmental disabilities have a legal guardian and/or family members who are responsible for making decisions for them. Most often, the legal guardian works in conjunction with the Individual Program Plan (IPP) team to direct care for the individual. The IPP team also consists of the individual’s DHHS service coordinator as well as representatives from service providers such as residential services or vocational services. In the case of hoarding behaviors such as excessive acquiring and the accumulation of excessive clutter, the IPP team addresses the behaviors through a habilitation program. Habilitation programs are designed to acquire, retain, and improve the skills necessary to ensure as much independence as possible, enhance the client’s choice and self-management, and to ensure participation in the rights and responsibilities of community membership.

Best Practices

Although there is little empirical research relating to hoarding disorder among developmentally delayed individuals, methods of reducing the clutter such as mass cleanouts, sneaking items out of the living space when the client is absent or asleep, or trying to force the client to “clean up their room” will most likely prove ineffective at best and may provoke extreme distress at worst. Instead, develop habilitation programs which focus primarily on limiting acquiring. Depending on the individual’s specific behaviors and cognitive abilities, this may include working with the client to differentiate between needs and wants, developing a budget, or making lists of what items are already owned. Goals should be clear, measurable,

⁴⁸ Nebraska Department of Health and Human Services. (2012). Fast facts about eligibility for developmental disabilities. Retrieved from http://dhhs.ne.gov/developmental_disabilities/Documents/Fast_Facts_6_12.pdf

and achievable, draw on client strengths and include personally-motivating rewards. Token economies, a system of behavior modification that relies on reinforcing positive behavior with rewards, can be effective. Tokens can be as simple as earning stars on a chart that can be later exchanged for a coveted reward such as eating out or seeing a movie.⁴⁹

The use of Positive Behavioral Support techniques may also be useful in working with a developmentally disabled individual who hoards. The goal of Positive Behavioral Support is to

respect and promote self-determination by seeking to understand the person within the context of their life and helping them to attain a life that they value.”⁵⁰ The philosophy takes a behavioral approach to behavior – that consistent behaviors

Key Positive Behavioral Support Strategies⁵¹

- Changing the circumstances surrounding the occurrence of the behavior such as being aware of and avoiding acquiring situations.
- Identifying and avoiding antecedents (early warning signs preceding a behavior) such as providing a preferred activity when the individual exhibits churning behavior.
- Teaching a skill that serves the exact same function as the problem behavior but is more effective and socially acceptable. An example of this could be recycling instead of accumulating items.
- Teaching coping skills such as relaxation and anger control.
- Finding ways to prevent the desired outcomes of the hoarding behavior.

serve some purpose for the individual, either by helping them obtain something they want or avoid something they don't want. By determining the function that a behavior serves, unhelpful behaviors can be replaced with helpful ones. Key Positive Behavioral Support strategies are particularly helpful in relation to hoarding behavior.

⁴⁹ Bratton, C., Schmalisch, C. S., & Steketee, G. (2011). *The hoarding handbook: A guide for human service professionals*. New York, NY: Oxford University Press.

⁵⁰ Missouri Division of Mental Retardation and Developmental Disabilities. (2008). Positive Behavior Support Guidelines. Retrieved from <http://www.nasddd.org/RestrictiveProcedures/MO%20Pos%20Behav%20Support%20guide08.pdf>

⁵¹ Ibid.

A Special Note to Families Regarding Developmental Disabilities

As mentioned above, there is limited research on individuals who have both developmental disabilities and hoarding behaviors. Many best practice recommendations are non-specific to hoarding disorder but may still be effective, especially when focusing on acquiring behavior. Families should work closely with residential providers and caseworkers to create rehabilitative programing to help address the hoarding behaviors, while still respecting the individual's rights and dignity. Emphasis should be on guiding the individual's choices and allowing the individual to make their own decisions so long as safety can be simultaneously maintained. Use a harm reduction approach, which emphasizes quality of life rather than a perfectly organized environment, as a foundation for program development.

Professional Organizers

Brenda is a 67 year old recently retired elementary school teacher who is concerned about her already cluttered house and all the boxes, totes and bags of items she brought home from her classroom seven months ago. The teaching supplies and classroom items are stacked in the front entrance and hallway of Brenda's home, making it nearly impassable. During a conversation with a friend, Brenda commented, "My house was too crowded before and now it's really overflowing." In response, her friend recommended that she reach out to a professional organizer. "I heard that Suzy is really helpful – she'll work with you to sort and organize your items."

Professional organizers work with clients in residential or business settings to create personal systems for managing all aspects of day-to-day life.⁵² They come from a wide variety of professional backgrounds and bring diverse skill-sets and past experiences to their organizing work. Certification or licensure is not required; however, many professional organizers are certified through the National Association of Professional Organizers (NAPO).

Chronic Disorganization is characterized by the following:⁵³

- The accumulation of a large number of possessions "beyond apparent necessity or pleasure";
- Difficulty parting with things;
- Many uncompleted projects;
- The need for visual reminders;
- Easy distractibility;
- Poor time management skills.

Some professional organizers choose to work with special populations such as people who hoard or experience "chronic disorganization". The terms chronic disorganization and hoarding seem to be used interchangeably by many professional organizers, although hoarding

⁵² Bratiotis, C., Schmalisch, C. S., & Stekete, G. (2011). *The hoarding handbook: A guide for human service professionals*. New York, NY: Oxford University Press.

⁵³ Institute for Chronic Disorganization. (2010). *Common characteristics of chronically disorganized individuals (ICD Fact Sheet – 003)*. Retrieved from <http://www.challengingdisorganization.org/content/fact-sheets-public-0>

is often reserved for more severe cases involving larger amounts of amassed objects or individuals who seem incapable of making any progress due to their acquiring or inability to discard. While professional organizers are not required to obtain special training to work with chronically disorganized individuals or people who hoard, many choose to pursue certification through the Institute for Chronic Disorganization (ICD). ICD training may take anywhere from eight months to two years to complete and includes required readings, numerous teleclasses, and a certification exam.

Current Response

Most professional organizers work independently with clients in their homes. Whether the initial referral is made through the client themselves, a family member or, infrequently, an agency, the profession's code of ethics requires that the client themselves must agree to services. Collaboration with other professionals appears to increase as the severity of the case increases and is only pursued with the client's permission. Other members of this multi-disciplinary approach may include therapists, physicians, social service agencies, eldercare attorneys, clergy, housing inspectors, and even realtors.

The only formal tool utilized by Professional Organizers is the Clutter-Hoarding Scale, which is employed in suspected cases of hoarding or chronic disorganization. The Clutter-Hoarding Scale⁵⁴ uses a multi-level system to assess the interior of a home in the areas of structure and zoning, animals and pests, household functions, health and safety, and personal protective equipment. While the Clutter-Hoarding Scale can be used to assess aspects of clutter and residential safety, it is limited as an assessment for hoarding since serious health and safety concerns may not be related to the accumulation of clutter.

⁵⁴ Institute for Chronic Disorganization. (2011). Clutter – hoarding scale (CHS) quick reference guide. Retrieved from <http://www.challengingdisorganization.org/content/fact-sheets-public-0>

Best Practices

Approaches for working with all clients, whether chronically disorganized, hoarding, or “ordinary clients” are fairly similar among local professional organizers. After the initial phone call, the professional organizer meets the client in their home for an assessment. Often, the area of concern, or preferably the entire home, is toured together with the client. Following the tour, the professional organizer collaborates with their client to determine what bothers them most about the current state of disorganization and to establish personal goals for their work together. Compassionate listening and empathy is essential. Respectful language and a positive attitude are also pivotal. The ICD provides tips for communicating with chronically disorganized individuals, which highlight approaches such as acceptance, focusing on strengths, and positive reinforcement. “Nagging” and quick fix suggestions such as “just do it” are discouraged.⁵⁵

Honesty is also an essential part of communication between the professional organizer and the client. Each professional organizer seeks to provide their client with a forthright appraisal of the time, effort, and expense involved in achieving the identified goals. This is a priority from a financial standpoint as well as an ethical one since clients pay privately for services. Depending on how much hands-on assistance a client needs and other factors such as whether the client is participating in therapy, work with a professional organizer can span years in a heavily-hoarded home.

Professional organizers have a number of skills which would benefit them in working with people who hoard as well as the ethics required to work with this vulnerable population. Many of the techniques employed by professional organizers such as sorting piles and Only

⁵⁵ Institute for Chronic Disorganization. (2010). Tips for communicating with chronically disorganized individuals (ICD Fact Sheet – 007). Retrieved from <http://www.challengingdisorganization.org/content/fact-sheets-public-0>

Handle It Once (OHIO) are effective with clients who hoard.⁵⁶ Furthermore, local professional organizers recognize that it is ideal for the client to make the decision on each object during the sorting process. However, many clients are unable to make decisions about objects, leading to frustration for both the client and the professional organizer. Clients may also experience escalating anxiety and even panic attacks during the sorting or discarding process, in which case referral to a mental health professional is recommended. Education in decision-making techniques, harm reduction strategies to minimize risk, and collaboration with other professionals within the community would further enhance their ability to address this serious problem and make them valuable members of a case management team.

A Special Note to Families Regarding Professional Organizers

The professional organizer's goal is to organize the disorganized. Many organizers express that the personal satisfaction they gain from working with ordinary clients is simply not found in the seemingly endless chaos of someone who hoards. Things to consider when deciding whether to work with a professional organizer include the level of client motivation and readiness to change, the size/duration of the job, ability to pay, whether there is an ongoing problem with acquiring, and the experience and training of the professional organizer. Even a moderately hoarded home can take long periods of time to organize and professional organizer services are an out of pocket expense that can quickly become difficult to afford.

⁵⁶ Bratiotis, C., Schmalisch, C. S., & Steketee, G. (2011). *The hoarding handbook. A guide for human service professionals*. New York, NY: Oxford University Press.

Animals

A complaint of foul odors coming from a home was phoned into the local animal control division hotline. When the officer responded to the report, he was greeted on the porch of the home by an older adult woman wearing soiled clothing and appearing generally unkempt. As the officer explained the reason for his visit, the home owner indicated she was well intentioned in her efforts to care for the 60 - 65 cats in her home. "I love them all so much. Each one is a special gift. I just recently ran out of food and didn't have money to get more litter, but we're fine. I get my check soon and then we'll be all set. I can probably even welcome in one or two more."

Although there is much less research on animal hoarding compared to object hoarding, clear distinctions between the two disorders have already come to light. Most notably, animal hoarding is not solely defined by a large number of animals in the home. For example, breeders may have a large number of animals in the home, but provide appropriate care for the animals and humans in the environment. Frequently, the lack of proper care in animal

ANIMAL HOARDING
Defined by the presence of large numbers of animals kept in homes in conjunction with four main characteristics:⁵⁷

- Failure to provide minimal standards of sanitation, space, nutrition, and veterinary care for the animals;
- Inability to recognize the effects of this failure on the welfare of the animals, human members of the household, and the environment;
- Obsessive attempts to accumulate or maintain a collection of animals in the face of progressively deteriorating conditions; and
- Denial or minimization of problems and living conditions for people and animals.

hoarding cases raises concerns about animal mistreatment. In addition, hoarding of animals creates a public health concern due to the accumulation of animal urine and feces in the home,

⁵⁷ Bratiotis, C., Schmalisch, C. S., & Steketee, G. (2011). *The hoarding handbook. A guide for human service professionals*. New York, NY: Oxford University Press.

which poses serious health risks for humans in the environment. The presence of a large number of animals and animal waste may also contribute to housing code violations.

The city of Omaha contracts with the Nebraska Humane Society (NHS) to provide animal control and cruelty investigation services throughout the city and to areas within three miles of Omaha city limits. These services are also provided to all areas of Sarpy County, and statewide assistance is available upon request. In Omaha, NHS Field Department addresses cases of animal hoarding. The NHS Field Department is comprised of two investigators, twenty animal control officers, and eight dispatchers. Hoarding complaints are generally addressed by investigators, who have the necessary training and experience in dealing with animal hoarding cases. Investigators are able to obtain search warrants and impound orders, as well as misdemeanor and felony arrest warrants. Additionally, animal control officers are authorized to issue criminal citations for any violations of animal control ordinances.

Current Response

City of Omaha ordinance limits the number of adult dogs and cats per residence. Residents may keep no more than three dogs and five cats; although dogs and cats under six months of age are not counted in this number. Citizens may obtain a Pet Avocation license that allows a maximum of five dogs, six cats, or any combination of the two species up to eight pets per household for a fee. Omaha ordinances do not limit the quantity of other species an individual may keep as pets. This can make it difficult to regulate the number of reptile, birds, and other species that someone who hoards animals may acquire.

NHS utilizes several interventions in situations involving animal hoarding. In cases involving non-regulated species, the NHS investigator will evaluate the health and living conditions of the animal to determine if the animals are in immediate danger. If there is no

imminent risk to animals or humans, the investigator will work with the owner to improve the living conditions. Even in cases involving large numbers of unlicensed cats and dogs, NHS does not immediately remove the animals as long as they are in good health and living conditions are appropriate. Instead, NHS offers assistance to the owner to voluntarily reduce the number of animals by rehoming or adopting out some of the animals. In cases complicated by the presence of breeding animals, the NHS Lied Spay & Neuter Center offers discounted spay and neuter services which will prevent future litters in the home. Owners may also obtain pet food and other care supplies at no cost from the NHS Pet Food Pantry.

If conditions in the home are found to be poor and present a real risk to health and/or safety, investigators may remove the animals from the home. NHS investigators will explain the dangers to the owner and ask them to voluntarily surrender the animals. If the owner is uncooperative, NHS investigators will seek a search warrant and impound order to remove the animals. During these situations, NHS works closely with other organizations including the Health Department, Code Enforcement, APS, CPS, and police and fire departments to ensure the safety and well-being of both animals and humans. Once animals have been involuntarily removed and impounded, they are held at NHS pending a judgment from the court. During this time period, the owner is legally responsible for all costs associated with the care and feeding of the animals, including any necessary medical care.

Best Practices

It is important that the presence of animal hoarding is properly identified and addressed to reduce recidivism and treat the underlying hoarding behaviors. A coalition of animal welfare, law enforcement, public health workers, housing inspectors, legal aid, and human services professionals is essential to provide coordinated services in animal hoarding scenarios.

Engaging and coordinating such a large number of agencies can be difficult. Care must be taken to identify common goals that accommodate each agency's mission while meeting the needs of the humans and animals involved in the hoarding.

Once collaboration has been reached between the involved agencies, it is important to understand the relationship the person who is hoarding has with their animals. Three "types" of people who commonly hoard animals: overwhelmed caregivers, rescuers, and exploiters. Overwhelmed caregivers often began with a few, well-cared for pets; however, over time passive acquisition of animals and a decline in their health or resources leads to an inability to provide proper care. Rescuers actively acquire animals in an effort to protect them. Although they are not providing adequate care, their belief that they have a special responsibility toward the animals makes them blind to poor conditions. Exploiters, thought to be the rarest group, collect animals to serve their own purposes such as dog fighting. Lack of empathy for animal and humans may suggest sociopathic personality characteristics in the case of the exploiter.⁵⁸

Once the dynamics driving the animal hoarding are understood, it is possible for professionals to tailor interventions to the needs of the individual. Although interventions should be individualized based on the specifics of the case, three overall approaches can be utilized. These include persuasion/verbal agreements, threats of legal action, and prosecution. Overwhelmed caregivers frequently respond well to persuasive offers of help and are frequently open to downsizing the number of animals they own. Threats of legal action may be sufficient to prevent recidivism and prosecution is often unnecessary and counterproductive. Rescuers, on the other hand, are unlikely to respond to persuasion and frequently require threats of legal action to reduce their rescue efforts. When threats fail, prosecution may be

⁵⁸ Hoarding of Animals Research Consortium (2006). *Animal Hoarding: Structuring Interdisciplinary Responses to Help People, Animals, and Communities at Risk*. Retrieved from <http://vet.tufts.edu/hoarding/pubs/AngellReport.pdf>

necessary. Unfortunately, prosecution is usually essential to curtail people who exhibit exploiter-type animal hoarding. Persuasion and threats are frequently ineffective in these circumstances.⁵⁹

Although these interventions are useful in resolving existing cases of animal hoarding and in reducing recidivism, they do little to provide mental health treatment for the person who hoards animals. Research indicates that animal hoarding is different from object hoarding. As of yet, there is no recommended standard treatment for people who hoard animals. Therapeutic interventions that focus on motivation, such as Motivational Interviewing, as well as treatments that address any co-occurring mental health diagnoses are frequently helpful.⁶⁰ Regardless of the treatment approach, a thorough assessment must be completed that evaluates the mental and physical health of the animal owner/caretaker, any previous history of animal collecting and animal cruelty, past interventions, and an in-home assessment.⁶¹ As is true for those who hoard objects, ongoing support and monitoring from professionals, family members, and friends are essential to reducing recidivism.

⁵⁹ Hoarding of Animals Research Consortium (2006). *Animal Hoarding: Structuring Interdisciplinary Responses to Help People, Animals, and Communities at Risk*. Retrieved from <http://vet.tufts.edu/hoarding/pubs/AngellReport.pdf>

⁶⁰ Ibid.

⁶¹ Bratiotis, C., Schmalisch, C. S., & Steketee, G. (2011). *The hoarding handbook: A guide for human service professionals*. New York, NY: Oxford University Press.

A Special Note to Families Regarding Animals

The person who hoards animals faces a number of difficulties. Frequently, they may perceive their actions as kind and helpful, rather than maltreatment or neglect. They may fear legal ramifications. Or they may fear that their animals will be taken from them. However, animal hoarding frequently gives rise to conditions that pose a serious health and safety risk to humans and animals alike. This often necessitates the involvement of professionals and frequently leads to forced cleanouts. This can be highly traumatic for your loved one. The ongoing support of family and friends is essential. If you are unable to provide your support, seek community support through neighbors, volunteers, social service agencies, and clergy.

HOMES[®] Multi-disciplinary Hoarding Risk Assessment

Instructions for Use

- HOMES Multi-disciplinary Hoarding Risk Assessment provides a structural measure through which the level of risk in a hoarded environment can be conceptualized.
- It is intended as an initial and brief assessment to aid in determining the nature and parameters of the hoarding problem and organizing a plan from which further action may be taken-- including immediate intervention, additional assessment or referral.
- HOMES can be used in a variety of ways, depending on needs and resources. It is recommended that a visual scan of the environment in combination with a conversation with the person(s) in the home be used to determine the effect of clutter/hoarding on Health, Obstacles, Mental Health, Endangerment and Structure in the setting.
- The Family Composition, Imminent Risk, Capacity, Notes and Post-Assessment sections are intended for additional information about the hoarded environment, the occupants and their capacity/strength to address the problem.

© Bratiotis, 2009. [The HOMES Assessment was developed in conjunction with the Massachusetts Statewide Steering Committee on Hoarding. Information about the assessment can be found in Bratiotis, C., Schmalisch, C. S., & Steketee, G. (2011). *The hoarding handbook: A guide for human service professionals*. New York, NY: Oxford University Press.]

HOMES[®] Multi-disciplinary Hoarding Risk Assessment

Health

- | | | |
|---|---|--|
| <input type="checkbox"/> Cannot prepare food | <input type="checkbox"/> Cannot use bathtub/shower | <input type="checkbox"/> Cannot locate medications or equipment |
| <input type="checkbox"/> Cannot access toilet | <input type="checkbox"/> Presence of spoiled food | <input type="checkbox"/> Presence of feces/Urine (human or animal) |
| <input type="checkbox"/> Cannot sleep in bed | <input type="checkbox"/> Presence of insects/rodents | <input type="checkbox"/> Presence of mold or chronic dampness |
| <input type="checkbox"/> Garbage/Trash Overflow | <input type="checkbox"/> Cannot use stove/fridge/sink | |

Notes: _____

Obstacles

- | | |
|---|---|
| <input type="checkbox"/> Cannot move freely/safely in home | <input type="checkbox"/> Unstable piles/avalanche risk |
| <input type="checkbox"/> Inability for EMT to enter/gain access | <input type="checkbox"/> Egresses, exits or vents blocked or unusable |

Notes: _____

Mental health (Note that this is not a clinical diagnosis; use only to identify risk factors)

- | | | |
|--|--|--|
| <input type="checkbox"/> Does not seem to understand seriousness of problem | <input type="checkbox"/> Defensive or angry | <input type="checkbox"/> Anxious or apprehensive |
| <input type="checkbox"/> Does not seem to accept likely consequence of problem | <input type="checkbox"/> Unaware, not alert, or confused | |

Notes: _____

Endangerment (evaluate threat based on other sections with attention to specific populations listed below)

- | | |
|--|---|
| <input type="checkbox"/> Threat to health or safety of child/minor | <input type="checkbox"/> Threat to health or safety of person with disability |
| <input type="checkbox"/> Threat to neighbor with common wall | <input type="checkbox"/> Threat to health or safety of animal |
| <input type="checkbox"/> Threat to health or safety of older adult | |

Notes: _____

Structure & Safety

- | | | |
|--|---|--|
| <input type="checkbox"/> Unstable floorboards/stairs/porch | <input type="checkbox"/> Electrical wires/cords exposed | <input type="checkbox"/> Leaking roof |
| <input type="checkbox"/> No running water/plumbing problems | <input type="checkbox"/> Flammable items beside heat source | <input type="checkbox"/> Caving walls |
| <input type="checkbox"/> Blocked/unsafe electric heater or vents | <input type="checkbox"/> Storage of hazardous materials/weapons | <input type="checkbox"/> No heat/electricity |

Notes: _____

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

Household Composition

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

Ages of adults: _____ Ages of children: _____

Person who smokes in home Yes No

Person(s) with physical disability _____

Language(s) spoken in home _____

Assessment Notes: _____

Risk Measurements

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

Threat of Eviction: _____

Threat of Condemnation: _____

Capacity Measurements

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

Awareness of clutter

Physical ability to clear clutter

Psychological ability to tolerate intervention

Willingness to accept intervention assistance

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

Capacity Notes: _____

Post-Assessment Plan/Referral

Client Name: _____

Assessor: _____

Date: _____

National Resources

BOOKS

Bratnotis, C., Schmalisch, C. S., & Steketee, G. (2011). *The hoarding handbook: A guide for human service professionals*. New York, NY: Oxford University Press.

Muroff, J., Underwood, P., & Steketee, G. (2014). *Group treatment for hoarding disorder: Therapist guide (treatments that work)*. New York: Oxford University Press.

Steketee, G. & Frost, R.O. (2010). *Stuff: Compulsive hoarding and the meaning of things*. Boston, MA: Houghton Mifflin Harcourt.

Steketee, G. & Frost, R.O. (2013). *Treatment for hoarding disorder: Therapist guide (treatments that work)*. New York: Oxford University Press.

Steketee, G. & Frost, R.O. (2013). *Treatment of compulsive hoarding: Workbook (treatments that work)*. New York: Oxford University Press.

Tolin, D., Frost, R.O., & Steketee, G. (2013). *Buried in treasures: Help for compulsive acquiring, saving, and hoarding (treatments that work)*. New York: Oxford University Press.

Tompkins, M.A. & Hartl, T.L. (2009). *Digging Out: Helping Your Loved One Manage Clutter, Hoarding and Compulsive Acquiring*. Oakland, CA: New Harbinger Publications.

WEBSITES

Association for Behavioral and Cognitive Therapies (ABCT)
<http://www.abctcentral.org/xFAT/>

International OCD Foundation (IOCDF) Virtual Hoarding Center
www.ocfoundation.org/hoarding

SELF-HELP

Clutterers Anonymous (CLA)
<http://sites.google.com/site/clutterersanonymous>

Messies Anonymous
www.messies.com

Messies Anonymous self-help group
<http://health.groups.yahoo.com/group/Messiness-and-Hoarding>

Moderated self-help group
<http://health.groups.yahoo.com/group/H-C>

The International Obsessive Compulsive Foundation self-help information
www.ocfoundation.org/hoarding/self_help.aspx

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