

**The University of Kansas
School of Social Welfare
Office of Aging and Long Term Care**

**Community Tenure of Older
Adults Who Hoard:
Identifying Risks and
Enhancing Opportunities**

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**Rosemary Chapin, PhD
Sandra McKenzie, JD
Sarah Landry, LMSW
Kimberly Reynolds, MEd
Roxanne Rachlin, MHSA
Terry Koenig, PhD**

**University of Kansas
School of Social Welfare
785.864.3797
kerker@ku.edu**

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I. Executive Summary

Purpose of the Study

The purpose of the “Community Tenure of Older Adults Who Hoard: Identifying Risks and Enhancing Opportunities” project is to 1) develop a profile of older adults with severe hoarding behaviors in three pilot areas in Kansas, and 2) to identify and analyze municipal and/or county codes that impact older adults who hoard’ ability to maintain community tenure. This project will help service providers and policymakers gain a better understanding of hoarding among older adults and develop strategies to help older adults who hoard maintain community tenure. This report describes findings from this project, which was funded from June 1, 2006 through May 31, 2007.

Project Activities

In our proposal, we outlined five separate activities to be completed to address the purpose of the study. First, in order to inform our project activities we comprehensively reviewed the existing hoarding literature. Second, we communicated with key informants from hoarding task forces around the country to identify innovative protocols and state or local codes that have shown to be effective in assisting older adults who hoard to maintain community tenure. Third, we conducted an analysis of relevant city and county codes in each pilot area to examine how provisions of these codes may impact the community tenure of older adults who hoard. Fourth, we created a survey to be disseminated to our three pilot areas in order to develop a profile of older adults with hoarding behavior. Finally, we convened a one-day work session of representatives of relevant state and local agencies to identify barriers and strategies for working with older adults who hoard and their ability to maintain community tenure.

Each of the five project components are described in detail in the full report, followed by a summary and implications section drawn from the study findings. The findings of this report provide pertinent information to state and local policymakers and service providers and will inform future policy, research, and practice in Kansas and nationally.

Key Findings

Key findings include:

- 1. Inconsistent definitions of hoarding limit previous research studies' usefulness.*
- 2. Older adults are not a focus of most existing intervention research.*
- 3. There is a lack of administrative and financial support for multidisciplinary team approach to interventions.*

- 4. Community education about older adult hoarding is needed.*
- 5. Flexibility built into municipal codes can assist older adults in maintaining community tenure.*
- 6. There is a lack of clearly established legal guidelines to address animal hoarding situations.*
- 7. Hoarding negatively affects not only those who hoard, but also those who live with them.*
- 8. Hoarders frequently experience co-existing mental and physical health conditions that may be impacted by hoarding.*
- 9. Hoarders' tendency to isolate may require unique identification and engagement strategies.*
- 10. Higher reported rates of African American older adults who hoard merit further investigation.*
- 11. Lack of funding is a barrier to successful intervention in hoarding situations.*

Through our community based research we have not only completed the project activities as outlined in our initial proposal, but we have become a key player in the dialogue in Kansas about hoarding. Important initial steps to more effectively address hoarding in Kansas have been taken through our research. In addition, public interest has mounted as evidenced by the television and news coverage on hoarding that accompanied release of our findings. The findings of this report can help to guide future policy, research, and practice in Kansas and nationally.

II. Introduction

A. Purpose

The purpose of the “Community Tenure of Older Adult Who Hoard: Identifying Risks and Enhancing Opportunities” project is to 1) develop a profile of older adults who hoard 2) to identify and analyze municipal and/or county codes that impact older adults who hoard ability to maintain community tenure, and 3) identify best practices for interventions. This project will help service providers and policymakers gain a better understanding of hoarding among older adults and develop strategies to help older adults who hoard maintain community tenure in Kansas. This report describes findings from this project, which was funded from June 1, 2006 through May 31, 2007.

Five separate activities were completed to address the purpose of the study. First, in order to inform our project activities we comprehensively reviewed the existing hoarding literature. Second, we communicated with key informants from hoarding task forces around the country to identify innovative protocols and state or local codes that have shown to be effective in assisting older adults who hoard to maintain community tenure. Third, we conducted an analysis of relevant city and county codes in each geographic area to examine how provisions of these codes may impact the community tenure of older adult who hoard. Fourth, we created a survey to be disseminated to three geographic areas in order to develop a profile of older adults with hoarding behavior. Finally, we convened a one-day work session of representatives of relevant state and local agencies to identify barriers and strategies for working with older adults who hoard and their ability to maintain community tenure.

Each of the five project components will be described individually in this report, followed by a summary and implications section drawn from the study findings. The findings of this report provide pertinent information to state and local policymakers and service providers and will inform future policy, research, and practice in Kansas and nationally.

B. Background

Steketee, Frost, and Kim (2001) defined hoarding as, “a debilitating disorder characterized by the acquisition of a large volume of possessions that clutter living areas to such a degree that living spaces cannot be used for their intended purpose”. In addition, animal hoarding is defined by the Minnesota Veterinary Medical Association (2005) as, “a complex disorder characterized by the keeping of an unmanageably large number of companion animals and/or other species”. As no formal epidemiological studies have systematically examined the prevalence rate of hoarding (other than as a characteristic of obsessive compulsive disorder), little is known about the scope of hoarding nationally or at the individual state level. A recent review by the Kansas Association of Code Enforcement and the Kansas Association of Local Health Departments found that member agencies were involved in *more than 700* hoarding cases

throughout the state between 2002 and 2004 (Holland, 2005). An Adult Protective Services worker in Kansas reported 48 hoarding cases in Shawnee and Osage Counties (Shawnee County Hoarding Task Force Monthly Meeting, 2005). This is considered to be a low estimate; however, as only the most severe cases are reported to public health enforcers (Steketee, Frost, & Kim, 2001). In fact, Foster (2002) estimates only one tenth of adults who hoard ever come to the attention of public officials.

While hoarding can occur throughout the lifespan, it is particularly problematic for older adults. Several studies have found that hoarding increases in severity with age. One review of hoarding complaints to local health departments found that more than 40% of hoarding cases involved older adult service agencies (Steketee, Frost, & Kim, 2001). In Kansas, Adult Protective Services staff have reported seeing a recent increase of older adults in “extreme” hoarding situations (Holland, 2005). As the number of older adults is expected to grow exponentially, then, so will the extent of this problem.

Despite the significant costs incurred by individuals who hoard and the community in which she/he lives, little is known about a) the prevalence of hoarding, b) what places individuals at risk for hoarding, and c) how to intervene at different stages of hoarding. The only successful mental health treatment model that has been developed is too costly for most public and private payers (Foster, 2002). Many believe that an interdisciplinary approach, in which “a range of private, municipal, and state agencies dedicated to animal, human, legal, health, and environmental concerns coordinated closely throughout the full scope of the case, from investigation, to resolution, to long-term monitoring” is the only successful solution (Franks, 2004; Handy, 1994; Patronek, Loar, & Nathanson, 2006).

In Kansas, aging stakeholders have recognized the need for additional information about hoarding, and in 2005, pursued funding to present two workshops on hoarding that featured Dr. Gail Steketee, of Boston and Dr. Randy Frost, of Smith College. Kansas aging service providers and other stakeholders involved in hoarding cases have also recognized the need to develop a team approach to address the problem. Service providers in Shawnee County and Sedgwick County have developed hoarding task forces. These task forces have recognized the need for relevant research that can assist service providers and county officials in their efforts to promote the community tenure of older adults who hoard. Members of the Shawnee County Hoarding Task Force contacted the University of Kansas Office of Aging and Long Term Care (OALTC) and began collaborating to identify research needed to understand maintenance of community tenure for older adults who hoard. Community tenure is defined as the length of time an individual remains in the community avoiding institutionalization.

The OALTC, a research arm of the University of Kansas School of Social Welfare, has provided research regarding older adults to state policy makers for over a decade with a major focus on community-based services and the community tenure of older adults. Previous research conducted by the OALTC has demonstrated that community-based services are cost effective and that older adults with a variety of very significant needs can maintain community tenure long term (Chapin, Zimmerman, Macmillan, Rachlin, Nakashima, Hayes, Oslund, Swaim, Burke, Shea, & Reed, 2002). Older adults overwhelmingly prefer community based service over nursing facility care. (Kemper, Applebaum & Harrigan, 1987). Therefore, the partnership between the OALTC

and the Shawnee County Hoarding Task Force focused in large part on what factors might impact the ability of older adults who hoard to maintain community tenure.

After consulting with the local hoarding task forces and examining the literature, it became evident that baseline demographic information was needed about the population. Information about cases of hoarding, the most commonly present characteristics of older adults who hoard, and common responses and outcomes of those cases was also needed. In order to better understand hoarding in local communities and proceed forward with guided interventions, more information about hoarding needed to be gathered. Second, a main goal of both the Shawnee and Sedgwick County Task Forces was to develop a protocol for addressing hoarding cases in their respective communities. Therefore, there was a need to identify other innovative practices or protocols being used in task forces around the country that would be helpful in pursuit of their goal.

Code enforcement and animal control officers often play a critical role in hoarding cases as well as the municipal and county codes which they must follow. Therefore, a thorough analysis of relevant codes was needed to better understand the way in which cities and counties function but also to determine how provisions of these codes may impact older adults' community tenure. Finally, an examination of solutions and next steps to helping older adults who hoard maintain their community tenure by state and local aging stakeholders and service providers was needed to provide direction for further research and practice in Kansas.

In order to address the above needs in an effective manner, the following parameters were created regarding the scope of our research. First, an operational definition of hoarding was identified for this project. A significant subset of people who hoard – animal hoarders was also operationally defined. The definitions of hoarding used for this project were:

- Hoarding: “A debilitating disorder characterized by the acquisition of a large volume of possessions that clutter living areas to such a degree that living spaces cannot be used for their intended purpose” (Steketee et al., 2001).
- Animal hoarding: “A complex disorder characterized by the keeping of an unmanageably large number of companion animals and/or other species” (Minnesota Veterinary Medical Association, 2005).

Second, the OALTC focuses on research relating to older adults and therefore the age group we examined is adults 60 and older. Third, we targeted three geographic areas in Kansas to conduct our data collection and code analysis. These areas included Shawnee County, Sedgwick County, and nine counties that make up the Southeast Kansas Planning Service Area (Allen, Bourbon, Cherokee, Crawford, Labette, Montgomery, Neosho, Wilson, and Woodson). Shawnee and Sedgwick counties were chosen as geographic areas for our study because they are large urban areas with hoarding task forces in place. The third geographic area did not have a working task force but is representative of the more rural areas of Kansas. These parameters provide the context for consideration of the following project activities and findings.

III. Project Components

A. Hoarding Literature Review

“The term ‘hoarding’ originates in an Old English word for ‘collecting.’ Appearing frequently in legends about miserly kings, ‘hoarding’ has connotations of unrewarded effort to conserve

something that is inherently worthless; the kings in the legends end up with straw instead of gold” (R. Frost, Steketee, Youngren, & Mallya, 1999).

Hoarding has also been referred to in the literature as: compulsive hoarding, collecting, Diogenes Syndrome, gross self-neglect, social breakdown, senile breakdown, senile squalor syndrome, and syllogomania (Montero-Odasso et al., 2005) (Rosenthal, Stelian, Wagner, & Berkman, 1999) (Warren & Ostrom, 1988). In Germany, hoarding is referred to as “vermullungssyndrom”, which means “syndrome of complete congestion with garbage”. Germans also use terms such as “refuse hoarding syndrome and litter hoarding syndrome”. Individuals who hoard often refer to themselves as “messies” or “pack rats”. (Maier, 2004). Given that, in recent years, the definition developed by Frost and Hartl (1996) has become the one most commonly cited, for the purposes of our study, we have used it, as well. It is: “the acquisition of, and failure to discard, possessions that appear to be of useless or of limited value” coupled with “cluttered living spaces” and “significant distress or impairment”.

“Hoarding” was first used to mean the type of behavior on which our study has focused by Bolman and Katz (1966), who, in 1966, published a paper describing a woman who began buying and hoarding large quantities of raw hamburger. Prior to that instance, hoarding was used primarily to describe food collecting behavior in animals” (Maier, 2004). Food hoarding has been document in twelve families of birds, 21 families of mammals and many insects (Anderson, Damasio, & Damsio, 2005).

While the term “hoarding” itself has only become common in the psychiatric-related literature in recent years, (Maier, 2004), the behavior that we now recognize as “hoarding” has been mentioned in the works of Freud (1908), Fromm (1947), and other noted early theorists in the field of psychology. Assessments developed as early as 1970 have included items related to hoarding (Frost & Gross, 1993). While, some describe it as a symptom present in many disorders, others describe it as a unique syndrome (Maier, 2004). The syndrome concept was first described by in 1966 by Macmillan and Shaw (1966).

And, though it is commonly described as a mental health problem, not all agree with its being pathological in nature. Those in the self-help movement generally view hoarding as within normal behavior (Maier, 2004).

Whether individuals who hoard view their behavior as pathologic, hoarding has many negative consequences, both for the individuals who hoard themselves and those around them. Those who hoard, and those who live with them commonly experience experience headaches, nosebleeds, respiratory problems and allergies. Clutter increases their risk of falls and other injuries (Neziroglu & Bublick, 2006). Hoarding impacts the structural integrity of the dwelling, and diminishes the value of the home, which in turn, affects the family’s financial security (Franks, Lund, Poulton, & Caserta, 2004). Those who hoard animals may be at increased risk of animal-related diseases such as rabies, ringworm, cat-scratch disease, and parasites. The ammonia level inside the home is often too high (Patronek, 2001).

One of the most famous cases of hoarding was that of Homer and Langley Collyer, two brothers from a prominent, if somewhat eccentric, New York family. Born in the late 1800s, the brothers both graduated from Columbia University. After both parents died, they remained living in their three story brownstone. Despite their ample

inheritance, the brothers allowed first their phone, then their gas, water, and steam heat to be shut off.

While both brothers were cordial, no one was allowed into their home. After Homer became blind, he was rarely seen in public. The brothers might have continued to live their lives in relative anonymity had they not come to the attention of a reporter for the World-Telegram, who wrote an article citing the many fantastic rumors that been circulating about the brothers and their home, including that the brownstone was full of expensive furnishing and huge amounts of cash. People began attempting to visit them, and schoolchildren began vandalizing the house.

Over the years, Langley was seen visiting his neighbor's trashcans at night and hauling rubbish home with him. He then arranged the materials in such a way as to create tight tunnels through which he traveled about the house. He also constructed traps made of large piles of debris.

During this time, the police received a number of tips from neighbors that the brothers had died. When they responded to a call that they received on March 21, 1947, they were unable to force their way into the first floor of the building. While additional police officers arrived to cordone off the swelling crowd of onlookers (estimated at 600), officers used ladders to access the second floor of the building. The body of Homer Collyer was soon found, emaciated, dressed in a ragged grey bathrobe, dead for ten hours.

Officers began their search for Langley Collyer. Hampered by the clutter, it was nineteen days before they discovered his body, pinned by one of his own booby-traps, only eight feet from his brother's cot. By then, the crowd of several thousand onlookers had seen 103 tons of rubbish hauled from the home, including: a kiddy car, the folding top of a horse-drawn carriage, a Steinway piano, a horse's jawbone, a cavalry saber, 3,000 books, and the chassis of a Model-T Ford (Penzel, 2006).

1. Incidence and Prevalence of Individuals who hoard

There has never been a formal epidemiological study of hoarding; therefore, actual incidence and prevalence is unknown (Frost, Steketee, & Williams, 2000). In their review of the hoarding literature, Stein and colleagues (1999) noted that, while hoarding is probably a common phenomenon, it has received little research attention, and consequently there are many questions about its phenomenology, etiology and management remain unanswered.

There are four studies that provide some indication as to the prevalence of hoarding. In 1985, Snowdon (1987) conducted a survey of community mental health centers in Sydney, and found that, of the 83 individuals identified as "living in a state of uncleanliness", 60 (72%) met their criteria for hoarding. Most of the 83 subjects (85%) were older adults. In a cross-sectional study located in Dublin, Ireland, 10 local human service agencies surveyed reported a total of 79 individuals who hoard on their current caseloads (Scallan, De La Harpe, Johnson, & Hurley, 2000). In their five year study of hoarding complaints to Massachusetts' public health departments, Frost, Steketee and Williams (2000) estimated that hoarding complaints were filed on 26.3 per 100,000 individuals served by health departments. In a survey of 408 residents of a large suburban nursing facility in Maryland and community-dwelling older adults attending

five day-care centers in Maryland, 15% of nursing facility residents and 25% of day-care center participants were found to exhibit hoarding behaviors (Marx & Cohen-Mansfield, 2003).

2. Characteristics of Individuals who hoard

Several researchers have conducted studies to identify the characteristics of individuals who hoard. Steketee, Frost and Kim (2001) interviewed 36 aging service providers and 8 board of health employees who had experience working with older adults who hoard. Providers reported characteristics about 62 hoarding cases that they had been involved with. Most were white, unmarried women living in apartments or single family dwellings. More than one-third (36%) had clutter outside of their homes. Nearly all (91%) received at least one type of service from one of the providers. Service providers reported that most hoarding cases were reported to them by other agencies (73%). Clutter interfered with service delivery in more than half of cases (63%). Nearly half (44%) had a known mental disorder, and a mental disorder was suspected in another 33% of cases. However, more than three-fourths (76%) had no problems with cognitive functioning.

In a study of older adults who either resided in a nursing facility or attended a senior day-care while residing in the community, in comparison to individuals who did not hoard, individuals who hoard: took fewer medications, had fewer medical diagnoses, were more physically functional, had better social functioning skills, and exhibited greater levels of agitation (i.e., pacing, general restlessness, etc.). In the senior day-care, more individuals who hoard were female; however, this was not the case in the nursing facility sample. Also, in the senior day-care, individuals who hoard were more likely to have a diagnosis of dementia than were those in the nursing facility. There were no differences in either sample among individuals who hoard and those who did not with respect to: age, marital status, education level, depression, hearing or vision problems, pain level, hours of sleep, or weight (Marx & Cohen-Mansfield, 2003).

a. Items Saved

Items saved range from those that are potentially useful, to those that are rubbish (Penzel). The most frequently hoarded items include: newspapers and magazines, other paper rubbish, containers, bottles, food and food garbage, and other people's rubbish (Frost, Steketee, & Williams, 2000). Many people who hoard at home also do so at work. Frost and Gross (1993) have noted that, in many cases, those who hoard save the same items as those who do not; however, they acquire greater quantities of those items than those who do not hoard, and, more significantly, they fail to discard items at the same rate as those who do not hoard. Individuals may spend enormous amounts of time and energy acquiring such possessions. Because each item is viewed as unique, it cannot be categorized and therefore, organized (Greenberg, 1987). This focus on the differences rather than similarities of objects contributes to the confusion is known as having under-inclusive categories (Claiborne).

b. Impaired Thoughts and Beliefs

Frost and Hartl (1996) have developed a much cited cognitive-behavioral model of compulsive hoarding that conceptualizes hoarding as a multifaceted problem stemming from: (1) information processing deficits; (2) problems in forming emotional attachments; (3) behavioral avoidance; (4) erroneous beliefs about the nature of possessions. Frost and Hartl identified three types of information processing deficits that were associated with compulsive hoarding: indecisiveness, impairment in structuring and categorization of information, and difficulties with memory.

Several researchers have noted that avoiding organizing and discarding of possessions also allows the people who hoard to avoid making decisions about discarding items that they might then later need; this fear about “wasting” items that might be potentially useful in the future is a commonly held concern (R. Frost, Hartl, Christian, & Williams, 1995). People who hoard also appear to have unique beliefs about the role and meaning of possessions; some appear to attribute human-like status to their belongings (Frost & Hartl, 1996, Frost et al., 1999).

Frost and Gross (1993), in a study of the hoarding scale that they had developed, found that high scores on their assessment tool were associated with elements of perfectionism that they referred to as “maladaptive evaluation concerns” that include concerns about mistakes and doubts about actions. They also noted that high scores were also correlated with indecisiveness, which was a characteristic of hoarders that Frost and Shows (1992) had independently noted. This indecisiveness may be best seen in the behavior known as “churning”. “Churning” involves an attempt to organize that results in an attempt at organizing or discard items; however, because the individual is unsure what to do with them or needs to do something else with them before they are discarded, the items are merely touched, examined, and placed in the same or in new piles (R. Frost, 2004).

Hartl and colleagues (2004) noted that, those who hoard report significantly less confidence in their memories than do those who do not hoard. Frost (R. Frost, 2004) has explained that those who hoard do not actually possess a worse memory than those who do not hoard; but, they are unable to organize items categorically, and instead think spatially and visually, they must remember the exact location of every item. This requirement gives them the misconception that their memories are faulty.

3. Hoarding Causes, Classifications, and Co-Existing Conditions

Frost and Gross (1993) stated that the typical age of onset for hoarding appeared to be childhood or adolescence. Grisham and colleagues (2006) conducted a study of hoarders and found, similarly, that development of hoarding occurred by middle adolescence for many. In contrast, Greenberg (Greenberg, 1987) reported that, in the four hoarding cases that he studied, hoarding behaviors had a specific onset that marked a definite change in the subject’s functioning. Therefore, he determined that hoarding was not a personality trait that had been present since childhood. He stated that it is a condition that begins in the third decade of life.

Zhang and colleagues (2002) remarked that, “Hoarding is likely to be an evolutionarily conserved trait that, in times of adversity, was associated with increased survival and reproductive fitness”. Anderson (Anderson et al., 2005) said that hoarding,

“a behavioural predisposition to acquire caches of food and other potentially useful objects... was possibly selected for in evolution because it increased the probability of survival of the individuals who accumulated such caches prior to times of scarcity.” Damecour and Charron (1998) have said that hoarding most likely has biological, neurological and psychosocial determinants.

Brain scans of hoarders indicated that, “Participants with compulsive hoarding were impaired on specific verbal and nonverbal learning and free recall measures compared to matched control participants. Hoarders also showed significant planning and organization problems when copying a complex figure, drawing disjointed elements of the stimulus rather than its major organizational features.... Hoarders... had difficulties utilizing spatial, but not verbal, encoding strategies” (Hartl et al., 2004). A recent neuroimaging study conducted by Dr. Nicholas Maltby found that, “for people with compulsive hoarding, decisions to discard personal possessions activated brain regions association with processing punishing or unpleasant events. Refusals to discard personal possessions activated regions associated with categorizing, as well as intense emotional processing” (Tolin, 2006).

Frost and Gross (1993) reported that there appears to be a genetic component of hoarding; they found that, more individuals who hoard had first degree relatives who also hoard than did those who did not hoard. Winsberg and colleagues (1999) found that 84% of hoarders reported a family history of hoarding, and 80% grew up in households where someone else hoarded.

Other theories for the causes of hoarding include: emotional deprivation in childhood (Frost, 2004), an unmet need for physical stimulation that is met by touching objects (Marx & Cohen-Mansfield, 2003), loss of a spouse or parent (Greenberg, Witzum, & Levy, 1990), a history of deprivation such as that experienced by Holocaust survivors (Bone, 2005; Greenberg et al., 1990; Wong, 2002), and as a response to the loss of individual ownership due to institutionalization (Stein, 1993).

Hoarding has also been linked to cognitive impairments such as dementia (Hogstel, 1993) or brain injuries (Damasio, Grabowski, Frank, Galaburda, & Damasio, 1994), etc. Hoarding is frequently seen in institutionalized individuals with mental illness or mental retardation (Lane, Wesolowski, & Burke, 1989).

a. Diogenes Syndrome

A significant portion of the literature that focuses on older adult hoarding discusses this behavior using the term “Diogenes syndrome”. Diogenes syndrome was coined in 1975 by Clark (1975) to describe a segment of the older adult population who were self neglectful in terms of the physical appearance, nutrition, and housing. Clark felt that such people were experiencing a unique syndrome that had previously been unacknowledged. While many older adults who met his criteria for Diogenes syndrome exhibited hoarding behaviors, other lived in homes that were almost empty of furniture and other possessions (Clark, Mankikar, & Gray, 1975). Occasionally, multiple members of a household exhibit these characteristics; this has been termed, “Diogenes a deux” (Cole & Gillett, 1992; O’Mahoney & Evans, 1994; O’Shea & Falvey, 1997; Spear, Wise & Herzberg, 1997).

While many researchers have agreed with Clark's concept of a distinct syndrome (Hanon et al., 2004; Reyes-Ortiz & Mulligan, 1996; Rosenthal et al., 1999; Vostanis & Dean, 1992; Wrigley & Cooney, 1992), others believe it to be a set of symptoms linked to a number of mental illnesses and related cognitive disorders (Halliday, Banerjee, Philpot & Macdonald, 2000; Reifler, 1996). In several studies of older adults described by researchers at meeting the criteria for Diogenes syndrome, serious mental illness, dementia, frontal lobe damage, intellectual disability, and other cognitive disorders have frequently been found to be present (Al-Adwani & Nabi, 2001; Beauchet et al., 2002; Lebert, 2005; Grignon, Bassiri, Bartoli, & Calvet, 1999; Sheehan & Geddes, 1998; Turner & Reid, 1997; Van Alphen & Engelen, 2005).

b. Co-existing Conditions

Greenberg (1990) noted that "hoarding is a varied symptom that occurs in a range of clinical conditions. In cases in which hoarding is the main symptom, it is apparently the final common pathway for a spectrum of different processes. At one end of the spectrum lies obsessive compulsive disorder, at the center are the schizophrenic and paranoid disorders, and at the other end are the organic mental states."

Hartl and colleagues (2005) conducted a study to determine the relationship among hoarding, trauma, and attention-deficit disorder. In a study of 26 hoarders and 36 controls, they found that, "PTSD [post traumatic stress disorder] diagnoses were reported more frequently in the hoarding group, and hoarders reported a significantly greater number and frequency of different types of trauma." In addition, "people who hoard report both inattention and hyperactivity symptoms and other cognitive failures to a greater extent than non-hoarders".

Preliminary results of a study comparing individuals with compulsive hoarding to those with obsessive-compulsive disorder and with individuals with no mental health problems has indicated that 57% of people who hoard meet criteria for major depressive disorder, 28% meet criteria for generalized anxiety disorder, and 29% meet criteria for social phobia (Tolin, 2007).

Hoarding has also been associated with: anorexia (Crisp, Hsu, & Harding, 1980; Frankenburg, 1984), depression of various types (Abrams, Lachs, McAvay, Keohane, & Bruce, 2002), dementia (D. J. Stein, Laszlo, Marais, Seedat, & Potocnik, 1997), kleptomania, shoplifting, and compulsive buying (Frost, 2004; Frost et al., 1998; Steketee & Frost, 2003)

c. Distinctions Between Hoarding and Obsessive Compulsive Disorder/Obsessive Compulsive Personality Disorder

In a 2007 editorial, Saxena (2007) wrote that, while hoarding is currently categorized in the Diagnostic and Statistical Manual of Mental Disorders (DSM) as a symptom of obsessive-compulsive personality disorder (OCPD), there is evidence that it is, in fact, a unique disorder. Other researchers have agreed, stating that not only is distinct from OCPD, it is also not a symptom of obsessive-compulsive disorder (OCD). Reasons that they have cited for this include that individuals who hoard, as compared with others with OCD: are less likely to respond well to traditional OCD treatment (Saxena); report significantly less anxiety, worry, stress, and depression (Grisham et al., 2005); have

higher educational levels, earlier ages at onset, higher rates of symmetry obsessions, greater frequency of ordering, rituals repetition, counting compulsions, and significantly higher rates of comorbidity with bipolar II disorder and eating disorders (Fontenelle, Mendlowicz, Soares, & Versiani, 2004); exhibit more strongly personality features such as behavioral inhibition and harm avoidance (Fullana et al., 2004); have greater personality disorder symptoms (Frost, Steketee, Williams & Warren, 2000); significantly differ on comorbidity, family history, and response to serotonin reuptake inhibitors, (Saxena, 2005). Also, while classic OCD symptoms such as checking, rituals, and contamination intercorrelated consistently strongly with one another, hoarding related only moderately to them (Frost, Krause & Steketee, 1996; Steketee, Frost, & Kyrios, 2003; Wu & Watson, 2004).

Grisham and colleagues (Grisham, Brown, Liverant, & Campbell-Sills, 2005) believe that, as opposed to being a symptom of OCD, “Pure hoarding may be better conceptualized as an impulse disorders, because many individuals appear to derive pleasure from hoarding behavior.” Also, “Hoarding behavior, like ICDs, is positively reinforcing to the individuals and is associated with a wide variety of emotional states....”

In their study, Hartl and colleagues (2004) found that less than 20% of hoarders met the diagnostic criteria for OCD. In a review of 15 cases of hoarding, 9 met the criteria for obsessive-compulsive disorder, 9 met the criteria for obsessive-compulsive personality disorder, and 6 met the criteria for an OCD spectrum disorder such as Tourette’s, body dysmorphic disorder, or trichotillomania (Seedat & Stein, 2002). Preliminary results of a study comparing individuals with compulsive hoarding to those with OCD and with individuals with no mental health problems has indicated that only 17% of people who hoard also have OCD (Tolin, 2007).

Samuels and colleagues (Samuels et al., 2006) conducted a study to determine whether there were chromosomal regions specifically linked to compulsive hoarding behavior in families with obsessive-compulsive disorder. They found that “a region on chromosome 14 is linked with compulsive hoarding behavior in families with OCD”. These findings suggest that “hoarding behavior may help differentiate a distinct clinical subgroup of people with OCD” (Samuels et al., 2001).

While it appears that most researchers agree that hoarding is not merely a symptom of obsessive-compulsive disorder or obsessive-compulsive personality disorder, but is, in fact, a distinct syndrome, Grisham and Barlow (Grisham & Barlow, 2005) have commented that, “Future research will clarify the diagnostic status of hoarding and its relation to psychopathology in general and OCD in particular.”

d. Animal Hoarders

Animal hoarding is a unique subtype of hoarding. For the purposes of our study, we have utilized the definition of “A complex disorder characterized by the keeping of an unmanageably large number of companion animals and/or other species” (Minnesota Veterinary Medical Association, 2005).

Another of the most utilized definitions of animal hoarding is the one developed by the Hoarding of Animals Research Consortium (The Hoarding of Animals Research Consortium, 2006), which is: “possession of more than the typical number of companion

animals; the inability to provide even minimal standards of nutrition, sanitation, shelter, and veterinary care; and denial of the inability to provide this minimum care; and the resultant impact of that failure on the animals, the household, and human occupants of the dwelling”.

Avery (Avery, 2005) has noted that, “No comprehensive psychological study has been conducted to conclusively determine the causes of animal hoarding. While it appears to be a mental health problem, the exact type is unclear.” The following explanatory models for animal hoarding have been postulated by members of the Hoarding of Animals Research Consortium: a) the delusional model, in which individuals hoard animals because of delusional beliefs such as that they have a special ability “to communicate and/or empathize with animals”, coupled with an inability to see that their animals were unhealthy and neglected; b) the dementia model, in which hoarding is a “warning sign for early states of dementia”; c) the addictions model, in which hoarders exhibit similar characteristics to those who abuse substances, such as, a preoccupation with their possessions, excused for their behavior, isolation from society, claims of persecution, impulse control problems, etc.; d) the attachment model, “in which the individual suffers from early developmental deprivation of parental attachment and is unable to establish close human relationships in adulthood; e) the obsessive compulsive disorder model, which has been discussed earlier in the literature review (The Hoarding of Animals Research Consortium & Frost, 2000).

In their five year study of hoarding complaints to Massachusetts’ public health departments, Frost, Steketee and Williams (2000) found that animals were hoarded in 32% of cases. Health officials rated animal hoarding as a more significant public health threat than was possession only hoarding. And, animal hoarding problems were reported to be significantly more difficult to address than was possession only hoarding. It was also found that significantly less individuals who hoarded animals were willing to cooperate with public officials’ efforts to resolve the hoarding situation than did those who hoarded solely possessions (6.3% versus 43.3%).

Analyses of animal hoarding complaints media reports about animal hoarding cases have found that most individuals who hoard animals are: female, have a median age in the mid 50s, are not currently married, and hoard cats and/or dogs (Arluke, Frost, Luke et al., 2002; Berry, Patronek, & Lockwood, 2005; Patronek, 1999). Vaca-Guzman and Arluke (2005) reviewed 163 media reports during a three year period to determine individuals who hoard animals manage their “adverse labeling”. They found that 56% made excuses about their animal hoarding behavior, 37% saw themselves as rescuing the animals from certain death, and 33% denied their behavior altogether.

The recidivism rate for animal hoarding is estimated at approximately 100% (Allan, 2004). The old adage is that an animal hoarder will “pick up a stray cat on the way home from the courthouse” (Avery, 2005).

4. Assessment Instruments

Several researchers have developed assessment tools to measure hoarding behaviors. The Saving Inventory-Revised assesses the severity of hoarding behaviors. The Saving Cognitions instrument measures hoarding beliefs. In addition, many of the scales developed for OCD and related mental illnesses

have been used, such as the Yale-Brown Obsessive-Compulsive Scale Symptom Checklist and the Obsessive-Compulsive Inventory (Steketee & Frost, 2003).

5. Interventions

Several researchers have stated that “hoarding patients are underrepresented in the treatment outcome literature, in part because they frequently refuse treatment, perhaps due to poor insight, making development of effective treatments difficult” (Steketee & Frost, 2003). Also, “[i]n contrast to the usual pattern of case studies reporting successful outcomes with new treatment methods, hoarding case reports provide negative predictions about treatment refusal and poor outcome. Poor insight, the absence of resistance to hoarding behavior, treatment refusal or drop out, and lack of cooperation during treatment” (Steketee & Frost, 2003). While there are relatively few articles regarding treatment, several researchers have addressed the use of medication, and of therapy. Others have discussed non-clinical interventions.

a. Medication

While, for the most part, medications have not been tested on individuals who hoard (Steketee & Frost, 2003), the use of several different medication regimens have been discussed in the literature. Dr. Sanjaya Saxena, Director of the Obsessive-Compulsive Disorders Program at the University of California, San Diego School of Medicine (Saxena) has noted that, generally, treatment of hoarding begins with serotonin reuptake inhibitors, in part because hoarders may have other symptoms that do respond well to SRIs. For those hoarders whose symptoms do not improve after 12 weeks of SRI treatment, additional medications are often added, including typical and atypical antipsychotics.

However, Saxena (Saxena) noted, hoarders, unlike others diagnosed obsessive compulsive disorder, do not traditionally respond well to the standard pharmacological treatments, which often include serotonin reuptake inhibitors (SRIs) such as Prozac and Zoloft, as well as “standard antiobsessional medications” (Saxena & Maidment, 2004). Recently, however, in his study of the use of paroxetine (Paxil) with participants diagnosed with obsessive-compulsive disorder (OCD) in which nearly half had been identified as compulsive hoarders, he found that both hoarders and non-hoarders “improved significantly” with treatment (Anonymous, ; Saxena, Brody, Maidment, & Baxter, 2007).

Claiborne (Claiborne) explained why many medications that were successful in treating OCD were not useful in treating hoarding. He said that hoarding, unlike OCD is a “successful” compulsion. He noted that, most individuals experiencing OCD “have considerable anxiety in spite of their engaging in both avoidance and compulsive rituals”; however, this is not the case for hoarders, who typically experience “significantly” less anxiety than those with OCD. Those with OCD are assisted by medication that reduces anxiety “by reducing the intensity and frequency of intrusive thoughts. This in turn allows the individual with OCD to engage in formal or informal behavior therapy.... Since hoarders already successfully avoid or manage much of their anxiety and typically have an exaggerated sense of value or importance for their possessions, the medication

doesn't have much impact.... It may be that medication would make CBT [cognitive behavioral therapy] more tolerable but people who are not distressed by a behavior are unlikely to seek help in changing it".

Stein and colleagues (D. J. Stein et al., 1997) reported that five older adults who hoard residing on an inpatient geri-psychiatric unit who were treated with dopamine blockers, which resulted in a significant improvement in both their hoarding and co-occurring psychotic symptoms, and that, upon discontinuation of the medication, the symptoms returned (D. J. Stein et al., 1997). Kaplan and Hollander (2004) also noted that, "Augmentation with stimulants may provide benefits in aspects of hoarding, such as procrastination, which may improve level of functioning, especially if comorbid ADHD [attention deficit-hyperactivity disorder] or severe depression exists".

Conflicting data have been reported regarding the use of risperidone, a frequently prescribed antipsychotic. Chong and colleagues (1996) reported that the addition of risperidone to a clozapine (another widely used antipsychotic) regimen administered to 36-year old woman experiencing schizophrenia significantly increased her hoarding behaviors. Upon removing risperidone, her hoarding behaviors reduced to the level that they had been prior to treatment. In contrast, Herran and colleagues (1999) reported on the case of a 77-year old who, six weeks after receiving 3 mg daily of risperidone, showed improvement in both hoarding behaviors and family relationships. Soon thereafter, however, she began to exhibit confusion and other cognitive deficits. Upon discontinuing risperidone, the woman's impairment decreased, though only temporarily, as she was eventually diagnosed with dementia.

b. Therapy

While hoarding and saving symptoms have traditionally been associated with poor response to cognitive-behavioral therapy (CBT) (Saxena & Maidment, 2004), a CBT intervention that has been developed specifically to treat individuals who hoard appears to show promise (Frost et al., 1999; Steketee, 2000) This protocol "employs exposure (e.g., practice in discarding items), response prevention (e.g., forgoing opportunities to add items to the cache of hoarded items), and cognitive restructuring (e.g., correcting distorted beliefs related to hoarding)" (Reinardy & Mansueto). The primary goals of the intervention are: to assist hoarders, "correct cognitive errors regarding the value of possessions, facilitate the discarding of unwanted items, enhance categorization and organization of kept items, and prevent excessive acquisition and buying" (Cherian, Farchione, & Basden). Preliminary results of a study to examine the efficacy of individual CBT sessions indicate that those treated showed significant reductions in hoarding severity, and that 69% were rated as "much improved" or "very much improved" by their therapist, and 83% rated themselves as "much improved" or "very much improved" (Tolin, 2007).

Cermele and colleagues (Cermele et al., 2001) have found that, mental health clinicians must be involved in assisting their clients in discarding possessions and organizing their homes. Other elements of a therapeutic intervention found to be successful included: role-playing to practice sorting and discarding; discussions regarding which items to discard, recycle, or donate; client-approved removal of items the loss of which caused little or no distress for the client; then, client-approved removal of those

items to which a greater attachment was felt. Aspects of this intervention found to be particularly useful or innovative included: having the client “tell her story” about items to which she had increased emotional attachment; the creation of a scrapbook of photographic “before and after” documentation, as well as photographs of discarded possessions that were particularly significant for the client; use of humor by the clinicians; and participation by the client in physically removing the items and in deciding where they should go.

c. Non-Clinical Interventions

Many older adults who hoard will not seek out the opportunity to participate in treatment with medications and/or therapy. They will not, in fact, pursue any assistance; however, because of a concerned neighbor or family member, an aging service provider, healthcare professional, or legal authority may become involved in their situation. For professionals attempting to intervene, Thomas (Thomas, 1997) made the following recommendations:

1. Observe the condition of the external part of the house.
2. If the older adult will come to the door, try to make at least a cursory assessment of the interior of the home.
3. Talk with neighbors and family member and examine public records in order to determine if bills are being paid.
4. Continue to attempt to develop rapport with the older adult through subsequent home visits – “even if no emergency intervention is needed, it is reasonable to assume that the problem will only get worse in some cases and the community outcry become more intense”.
5. When gaining access to the home, evaluate the situation through non-threatening questions that enable you to determine if the older adult is aware of the content and volume of the clutter, and if she has any plans to discard or organize the material.
6. Avoid making decisions about removal or organization of the clutter that do not include the older adult (even if the individual is cognitively impaired).
7. When removing clutter, examine all items before disposal to ensure that valuables are not hidden among the items.
8. When appropriate, assist the older adult in pursuing mental health treatment, and/or in identifying substitutions for the hoarding behavior.

Frost and Steketee (Frost & Steketee, 1999), as with many other researchers, have cautioned against discarding, cleaning, or organizing a hoarder’s possessions without their express consent. They said that, “removal of [a hoarder’s] possessions [without their consent] should be undertaken only if doing so alters a life threatening situation.... It is important to recognize that [an individual’s] hoarding will not be solved until she learns how to make decisions about her possessions. If other people make these decisions for her, her hoarding will continue to be problematic”.

d. Multidisciplinary Team Approach as Intervention

While many researchers agree that responsibility for hoarding cases needs to be designated to an individual or agency, there are many different suggestions as to who should become the designee (Cooney & Hamid, 1995; Nerenberg et al., 1990; Stiegel, 1995). Some recommend that use of a multidisciplinary team (MDT). An MDT has

been described as: A group of diverse professionals who “meet regularly to discuss and provide consultation on hoarding cases and to expand information and community resources. It uses the varied backgrounds, training and philosophies of the different professions to explore the best service plan for the cases involved, to identify and create needed expertise and to develop and coordinate community resources” (Abramson, 2005). MDTs may “address systemic issues, such as investigation processes, provision of protective services, interagency cooperation, funding, and legislative reform.... MDTs also develop and offer community and professional education....” (Stiegel, 1995). They may also “develop screening tools, practice guidelines, and even special programs... based largely upon needs identified through case analysis” (Anetzberger et al., 2005).

Suggested members of MDTs include representatives from:

Adult Protective Services	Child Protective Services
Area Agencies on Aging	Other aging service providers
Police	Sheriff
Fire	Mental health
County corporation counsel	Private practice attorney
Advocates for older persons or persons with disabilities	Physician and/or nurse
Prosecutors	Attorney General’s office
Court personnel	Long-term care ombudsman
Public Housing Authority	Home health agency
Public Health Department	Public guardians
Building Inspectors	City utility companies
Public & private animal care, and control agencies	Veterinarians
Code enforcement	Clergy
Pest control authorities	Local fatality review teams
State department of agriculture	Community leaders

(Abramson, 2005; Allan, 2004; Anetzberger et al., 2005; Chang & Greene, 2001; Dyer et al., 2005; Stiegel, 1995; Teaster & Nerenberg, 2003; The Hoarding of Animals Research Consortium, 2006).

e. Barriers to Treatment and Other Interventions

Barriers to individuals who hoard successfully receiving treatment include that individuals who hoard: 1) only tend to pursue treatment when a significant other has pressured them to do so; 2) often exhibit denial, rationalization, and low motivation for change; 3) are reluctant to complete therapeutic “homework” assignments; and 4) tend to experience significant indecisiveness (Christensen & Greist, 2001). Since those who hoard tend to lack awareness about their hoarding and related mental health problems, if those problems are not severe enough that treatment is obviously required and can be mandated, most will not seek it. Even if individuals who hoard possess some insight about their behavior, similar to someone with an addiction problem, they tend not to be motivated to eliminate their hoarding, but only to “control” it (Shafran & Tallis, 1996).

And, should an older adult who hoards attempt to seek out a cognitive-behavioral therapeutic treatment intervention such as that described in the treatment section above, they will find that few clinicians in the country have been trained to provide it. In

addition, this treatment has been described by the investigators who have developed it as to be so time-intensive as to be prohibitively expensive for most individuals (Hartl & Frost, 1999).

Barriers to non-clinical interventions by public service agencies include prohibitively high costs (The Hoarding of Animals Research Consortium, 2006), difficulty instituting and maintaining regular contact with the individual who hoards (Lauder, Anderson & Barclay, 2005), lack of communication by other service providers who may be involved in the case (Berry et al., 2005), and unwillingness on the part of the court's to support inspectors' actions and impose legal sanctions (Frost, Steketee, & Williams, 2000).

One of the most significant barriers to implementing and sustaining MDTs, specifically, is the paucity of research to guide professionals in working together to address hoarding or other abuse and neglect problems (Lauder et al., 2005). Another barrier is that "there is considerable variation between states in respect to legal definitions of self-neglect and also in the investigative and legal interventions applied in each state (Lauder et al., 2005). And, as has been discussed in an earlier section of this literature review, while "hoarding" remains a commonly used term, others are also used, and "hoarding" has no single legal or clinically recognized definition

Other barriers include:

- Lack of research or ability to "identify warning signs which may trigger earlier but less draconian interventions which may be more satisfactory to all parties involved";
- Current literature diminishes the interpersonal aspect of self-neglect situations, and "clients are normally described in fairly negative terms such as aloof, difficult and resistant" – "whether based on reality or not, seem to act in a way which mitigates against workers adopting a therapeutic stance which places the development of therapeutic relationships at the heart of any effective intervention";
- "[L]imited knowledge... professionals [have] of each other's roles... Liaisons between professions is frequently *ad hoc* and dependent on the commitment of individual workers, rather than through established procedures";
- "Professionals need better training and support in order to cope better with the conflicts, dilemmas and pressures of working with self-neglect";
- MDTs generally lack "long-term evaluations of interventions" that they provide;
- Professionals need assessment tools the use of which are institutionalized throughout all agencies on the MDT (Lauder et al., 2005a). Dyer and Goins (Dyer & Goins, 2000) note that such assessment tools should include "obtaining a comprehensive history and conducting a physical examination, as well as the use of validated instruments to quantify measures of psychosocial health and functional ability";
- Lack of understanding on the part of the court system which leads to legal action being taken that does not support the work of the MDTs (Uekert, Dancy, Peters, & Herman, 2006);
- The lack of a national oversight organization responsible for compiling lists of active MDT groups or facilitating communication and resource sharing among them (Teaster & Nerenberg, 2003);

- In most cases, there is a lack of a local needs assessment to inform an MDT of the prevalence of the problem, the existence of characteristics and problems that may be unique to their community, and the availability of local resources (Schuyler & Liang, 2006);
- “[L]ong-standing agency culture that is wary of outsiders and resistant to interagency cooperation” (The Hoarding of Animals Research Consortium, 2006);
- The lack of funding to enable professionals to perform the work (Schuyler & Liang, 2006) – “Collaborative efforts require significant resources, including having the financial resources to implement new programs and operate the coalition and having access to skilled staff” (Foster-Fishman, Berkowitz, Lounsbury, Jacobson, & Allen, 2001); and,
- Lack of procedures to facilitate coordination between agencies involved (Lauder et al., 2005b).

6. *Legal/Ethical Issues*

The clarity and enforcement of municipal, health and safety, and animal codes is a significant legal issue related to hoarding situations, and a detailed discussion of this issue is included in the following section. There are also other legal and ethical issues that impact professionals attempting to address hoarding situations. Most prominent among them are: (1) conflicting values of autonomy and protection from harm (Nusbaum, 2004), and (2) confidentiality requirements that prohibit providers from sharing information (Stiegel, 1995).

A significant barrier to a multidisciplinary approach of health, aging and other professionals is the requirement of confidentiality. In order to address this challenge, Stiegel (1995) reported that, in many states, Adult Protective Services are authorized to establish a multidisciplinary advisory group to assist them in their efforts. In other states, such teams develop Memorandums of Understanding or other documentation to ensure confidentiality is respected when providers discuss cases (Teaster & Nerenberg, 2003).

With respect to autonomy, Lustbader (1996), has stated that, “The right to self-determination includes the right to exercise bad judgment. Someone may refuse help with removing decomposing piles of magazines from her living room and kitchen, even though the smell of dead mice in the bottom layers of these piles is overwhelming. She may value her magazines more than sanitation or the good will of her landlord and neighbors.”

a. *Legal Issues Specific to Animal Hoarders*

Kuehn (Kuehn, 2003) noted that, “Most states and municipalities do not have laws that specifically address animal hoarding. Law enforcement often must write a separate citation for each offense for each animal. When animal hoarders are charged with many minor citations, such as failing to provide proper nutrition, sanitation, veterinary care, licensing, and vaccinations, more serious charges may be buried and it may seem that law enforcement is being overly aggressive and harassing a well-meaning person....”

In fact, Berry, Patronek and Lockwood (2005), reported that, in only one state (Illinois) has there been passed a law that explicitly defines hoarding in its animal protection statute. The Illinois law, the Companion Animal Hoarding Bill, which has been referred to as “model legislation”, was passed in 2001. It included a legal definition of a “companion animal hoarder”, increased legal penalties for animal abuse, and enabled judges to order a psychiatric evaluation and treatment for those convicted (Avery, 2005; Kuehn, 2003).

Allan (2004) has said that, “Prosecuting animal hoarders is complex, time consuming, and costly. Animal hoarders are often intelligent and experienced in challenging and delaying prosecution and case adjudication. As a result, the costs to care for hoarders’ animals during investigations cause major financial drains for private and public shelters and animal control facilities.... [A]nimal hoarder rescues can double a shelter’s population overnight; large rescues can force shelters into bankruptcy” (Avery, 2005). However, laws can be passed that assist shelters with the cost. “‘Bonding’ laws compel the perpetrator to help with costs of care; other civil citations allow an animal owner to be declared ‘unfit’ to care properly for his animals. Civil ‘unfit’ laws have a lower burden of proof than criminal cruelty proceedings, and require, once the person has been declared unfit, that seized animals quickly become the legal property of the seizing agency; the animals can then be adopted or euthanized instead of languishing in a kennel as the criminal case proceeds through court”.

7. Summary

The review of the literature informed the other elements of our study. In particular, it provided us with valuable information about characteristics of older adults who hoard, interventions commonly employed by service providers and other professionals, and outcomes of older adult hoarding cases. We used these data in the development of our survey, our hoarding task force interview guide, and our stakeholder meeting agenda, as well as to provide context for our analysis of the municipal codes.

The review of the literature indicated that there have been multiple terms and definitions associated with hoarding behavior. Little is known about the incidence and prevalence of hoarding, particularly in older adults. Individuals who hoard experience challenges related to item acquisition, organization, and discarding. They usually experience a heightened sense of responsibility to be prepared for any situation, and need to have their possessions easily accessible for any eventuality. Cognitive difficulties related to categorization impair their ability to organize their possessions, as do perfectionism and indecisiveness. Animal hoarding is a type of hoarding that is particularly difficult to address; it has many negative consequences for the individual who hoards, as well as the animals themselves, and others who live with or near them, and, left untreated, the recidivism rate is nearly 100%.

There is some debate as to whether hoarding is a distinct syndrome, or a symptom related to one or many mental illnesses and cognitive disorders. Traditionally, it has been classified as a symptom of obsessive-compulsive personality disorder, or has been linked with obsessive-compulsive disorder, however, many researchers argue that it is, in fact, a unique disorder requiring the use of specifically tailored treatments. Little is known about the use of medications; however, a specialized model of cognitive behavioral

therapy has shown to be effective. Also helpful is the use of a multidisciplinary team approach, in which various health and human service providers, in partnership with law enforcement and other stakeholders, work collaboratively to successfully resolve a hoarding case. However, multiple barriers exist that impede providers in their efforts; including ethical and legal issues such as confidentiality and the conflicting values of self determination versus public and individual safety.

B. Analysis of City and County Codes

1. Introduction

This section of the project report identifies city and county code provisions relevant to hoarding situations, and discusses how these provisions might impact the community tenure of older adults who hoard. As discussed in the background section of this report data for the project was collected from three geographic areas of the state: (1) Sedgwick County, (2) Shawnee County, and (3) the Southeast Kansas Planning Service Area which includes Allen, Bourbon, Cherokee, Crawford, Labette, Montgomery, Neosho, Wilson, and Woodson counties. This analysis was completed by the Director of the Elder Law Program at the University of Kansas-School of Law.

a. Local Government Jurisdiction

The jurisdiction of local government in Kansas is determined by geographic boundaries. City codes are applicable within the city limits, and are enforced in the city's municipal court. Each city in Kansas is also contained within the geographic boundaries of a county (or counties.) To avoid duplication, county regulations are generally applicable only within the unincorporated areas of the county. County codes are enforced in the district courts, which are part of the county government structure.

Analysis of city and county codes for this project involved contact with local authorities and an independent analysis of the codes. Much of the codification of city ordinances in Kansas is done by the League of Kansas Municipalities, using a standard template. The complexity and number of specific sections varies from city to city. Cities with smaller populations generally have fewer ordinances (shorter codes) and cities with larger populations have more extensive and complex codes.

This analysis covers specific code provisions in the following locations within the geographic areas: the cities of Chanute, Ft. Scott, Iola, Topeka and Wichita, and Crawford, Montgomery, Neosho and Shawnee Counties. Initial analysis of codes showed that they tend to be very similar. These codes were chosen to provide a good representative sample of codes in the geographic areas in terms of population and locality.

b. Legal Basis for Regulation of Hoarding

No specific references to "hoarding" are found in City and County Codes, because the act of hoarding itself is not the subject of the regulations. Instead, local

regulation affecting hoarding is derived from the police power of local government to protect the health, safety and welfare of the public. Participants in the study identified local codes dealing with animals, housing, and public health/safety as those most often applied to hoarding situations. It is important to note here that the application of city and county codes to people who hoard is not limited to “older adults.” Although the overall focus of the study was older adult who hoard, the reader should be aware that local codes apply to all adults, without regard to age.

2. Analysis of Codes – Nuisance Law

The basis for the ability of a city or county to regulate hoarding behavior is the power to require abatement of a nuisance. The legal concept of nuisance is the use of property by an individual in a manner that poses a risk of harm to neighboring property owners or to the public at large.¹

The act of accumulating possessions, even those perceived by others to be of no value, does not become a nuisance until the accumulation poses a risk to the public. This might occur if there is an infestation of vermin, a fire hazard, or other associated problem. The declaration of nuisance sets in motion the city or county code provisions requiring removal, or abatement, of the nuisance. It is the forced clean up, or abatement, that can have devastating consequences for the hoarder.

Both housing and public health codes contain nuisance regulations that may be applied to hoarding. Hoarding of animals can affect the safety of housing and present health concerns for the public in the same way as other hoarding, but with the added dimension of concerns for the welfare of the animals. Thus, animal hoarding is treated as a separate category by local officials and researchers. Abatement in the context of animal hoarding includes removal of the animals.²

Individuals working with people who hoard within a specific location should consult local codes to determine which provisions may apply to hoarding. As explained above, the geographic location will determine which city or county code is applicable to a specific situation. This report will discuss common features of the types of regulation, using examples from specific city and county codes.

a. Nuisance Regulation in Housing, Health and Safety Codes

Housing codes establish standards for building construction and also regulate rental housing to ensure that it meets minimum standards for repair and sanitation. For example, the Topeka Property Maintenance Code requires buildings to have a weather tight exterior³, window and door screens⁴, and be in good repair⁵. Public health codes address situations likely to spread disease such as rat and vermin infestation, or other

¹ An example of this is seen in this definition of nuisance as “All articles or things whatsoever caused, kept, maintained or permitted by any person to the injury, annoyance or inconvenience of the public or of any neighborhood.” City of Ft. Scott Code §8.20.010(G).

² Wichita Code §6.04.036

³ Topeka City Code §112-211

⁴ Topeka Code §112-212

⁵ Topeka Code §112-214

sources of filth and sickness. The accumulation of items by people who hoard may present both housing safety and public health issues.

A typical local code provision identifying a housing or public health nuisance lists a number of factors which, in the aggregate, result in a situation that is “unsafe” or “unfit for human habitation.”⁶ Some codes use all inclusive language such as “unsafe, unsanitary, unfit for human habitation or in such a condition that it is likely to cause sickness or disease.”⁷

Vermin, rats, or other insects are covered in both housing⁸ and public health codes.⁹ Garbage, filth, rotting food, feces, and dead animals on the premises contribute to the declaration of a nuisance. The Fort Scott code defines a nuisance to include the accumulation of: “Filth, excrement, lumber, rocks, dirt, cans, paper, trash, metal or any other offensive or disagreeable thing or substance.”¹⁰

Combustible materials or other fire hazards¹¹ are possible factors leading to a finding of nuisance as well as blocked exits and non-working utilities. Wichita’s Housing Code contains language that is particularly applicable to hoarding situations. “Overcrowding,” “inadequate ingress and egress”, and “unsightly stored or parked material, equipment, supplies” are specified as conditions that may contribute to the designation of a dwelling as “unfit for human habitation.”¹²

b. Animal Regulations Applicable to Hoarding

Animal regulation by cities tends to focus on cats, dogs, and other companion animals, while county regulations address livestock. Survey reports of animal hoarding were more likely to occur in cities than in unincorporated areas. There are two categories of regulations that apply to animal hoarding: 1) regulatory provisions that limit the number of animals in one location, and require licenses and vaccination; and 2) provisions addressing animal cruelty.

Cities typically require pets to be vaccinated against rabies, and may require other licensing. The Topeka Animal Code requires permits and rabies vaccination for both dogs¹³ and cats.¹⁴ The Wichita City Animal Code, requires vaccination of dogs over 5 months of age,¹⁵ and requires a kennel license for a location that contains more than four (4) dogs.¹⁶

Animal hoarding typically involves more than just a large number of animals and includes situations in which the health and safety of the animals is compromised. These

⁶ Iola Property Maintenance Code, allows condemnation of structure deemed unsafe (§108.1.1) or unfit for human habitation. §108.1.3

⁷ Crawford County Abatement Regulations §2-02-01.

⁸ Topeka Property Maintenance Code §112-213 structures must be free of rats, rodents.

⁹ Wichita Code §7.40.040 Public Health Nuisance includes the presence of dead animals, feces, rats, and other conditions offensive to the senses as factors creating a public health nuisance.

¹⁰ Ft. Scott Code §8.20.010(A)

¹¹ Fire hazards are specifically mentioned in the Wichita City Housing Code §20.40.070.

¹² Wichita City Code §20.04.180

¹³ Topeka Animal Code §§18-101, 18-103 and 18-106

¹⁴ Topeka Animal Code §§18-216, 18-217 and 18-220

¹⁵ Wichita Animal Code §6.04.040

¹⁶ Wichita Animal Code §6.04.110

situations fall under code provisions dealing with animal cruelty. Cities and counties often work with the local Humane Society or other group in identifying and addressing animal cruelty.¹⁷

Animal cruelty is a crime in Kansas.¹⁸ Prior to 2006, animal cruelty was a non-person misdemeanor.¹⁹ City code provisions dealing with animal cruelty were often patterned after the state animal cruelty statute. Chanute's ordinance is an example of this.²⁰ Other codes incorporate portions of the state statutes by specific reference; e.g. animal cruelty as defined in K.S.A. §21-4310.²¹

The animal cruelty statute was amended effective July 1, 2006 to add the element of intent, and to increase the severity of the offense.²² The most serious form of animal cruelty, "intentionally and maliciously" injuring an animal²³ is now a non-person felony.²⁴ A first conviction of other intentional acts constituting cruelty to animals²⁵ is a non-person misdemeanor, and a second or subsequent conviction is a non-person felony.²⁶

Codes which incorporate the state statutes by reference automatically reflect the statutory amendments. Other codes are not updated unless specific action is taken by the city or county to do so.²⁷ The changes made in 2006 are significant because municipal courts have jurisdiction over misdemeanor crimes, but not over felonies. An individual charged in municipal court with an instance of animal cruelty that would be considered a felony under K.S.A. §21-4310 could raise lack of municipal court jurisdiction as a defense.²⁸ Lesser offenses, such as animal neglect, could still be subject to municipal court prosecution.²⁹

The 2006 changes in the state statute which increased penalties for animal cruelty are likely to limit the ability of cities to prosecute animal cruelty. While this is probably an unintended consequence, it could result in fewer convictions. Shifting animal cruelty cases to the district courts means that they must share limited prosecutorial resources with more serious offenses. This is similar to the situation regarding prosecution for OUI; first and second offenses are misdemeanors, and subject to municipal court

¹⁷ The Topeka Helping Hands Humane Society is specifically mentioned in the Shawnee County Code §5-57(A).

¹⁸ K.S.A. §§21-4310, 21-4311

¹⁹ See Kara Gerwin "There's (Almost) No Place Like Home: Kansas Remains in the Minority in Protecting Animals From Cruelty" 15 Kan. J. L. & Pub. Policy 125 (2005)

²⁰ Chanute Code defining animal cruelty §6.04.040(A).

²¹ Shawnee County Code §5-201 prohibits animal cruelty as defined in K.S.A. §21-4310(a)(1).

²² L. 2006, ch. 126, §1; July 1.

²³ K.S.A. §21-4310(a)(1); prior version did not include "maliciously."

²⁴ K.S.A. §21-4310(d)(1)

²⁵ K.S.A. §21-4310(a)(2) – (5); prior versions did not include "intentionally."

²⁶ K.S.A. §21-4310(d)(2)

²⁷ The Wichita Code definition of animal cruelty includes the intentional/malicious elements added to the statute in 2006, but retains classification as a misdemeanor. §6.04.035. Chanute's code matches the pre-2006 statutory language.

²⁸ *Junction City v. Cadoret*, 263 Kan. 164, 946 P.2d 1356 (1997.) Municipal court lacked jurisdiction to prosecute third OUI offense. City ordinance treating offense as a misdemeanor conflicted with state law making the offense a felony.

²⁹ Chanute Code §6.04.045

jurisdiction. Third offenses are felonies, which are much less likely to be prosecuted in district court.³⁰

The Kansas Animal Health Department (KAHD) also assists with animal cruelty cases when at least 20 animals are involved.³¹ Premises containing more than 19 dogs, cats, or both must be licensed and inspected by the K.A.H.D. under the Kansas Pet Animal Act.³² The additional licensing and inspection requirements enforced by the K.A.H.D. are valuable in dealing with animal cruelty cases involving people who hoard. As noted above, many instances of animal hoarding would also be likely to be deemed a nuisance under health and safety codes if premises are found to contain animal excrement and dead or dying animals.³³

3. Enforcement of Local Codes

Enforcement of the city and county code provisions applicable to hoarding situations is essentially complaint driven. City and County governments lack the resources to address these problems proactively, and must deal with them in response to a citizen report of a possible violation. People who hoard themselves do not perceive their behavior as problematic, and thus reporting must be done by someone else. People who hoard are often reclusive and reluctant to invite others into their homes, making detection of hoarding situations more difficult. Even when the hoarding is reported, a shortage of code enforcement personnel may preclude, or severely limit, investigation.

Criminal penalties attach to some city code violations, and can result in a misdemeanor conviction, a fine, and/or jail time.³⁴ Animal control officers participating in this study reported that the threat of jail was effective in some cases in encouraging clean-up, with the animal control officer acting as the “bad cop” and the social worker being the “good cop.”

When the violation involves the declaration of a nuisance, or finding of animal cruelty, the court may require abatement of the nuisance (or removal of the animals.) This remedy can be devastating to the hoarder, and have a negative impact on his/her community tenure.

The enforcement process begins when a complaint is made and directed to the appropriate city or county office; e.g. Animal Control, Housing, Code Enforcement or other department. The owner of the property in question is contacted, and the complaint is investigated by the designated local official.³⁵ Some conditions may be

³⁰ Junction City v. Cadoret, 263 Kan. 164 (1997)

³¹ <http://www.kansas.gov/kahd>

³² K.S.A. §§47-1701 through 47-1721; 47-1723 through 47-1727; 47-1731; 47-1732 through 47-1736.

³³ Wichita Code §7.04.040(b) dead or dying animals and excrement. Ft. Scott Code also refers to dead or dying animals as a nuisance. § 8.20.010(B)

³⁴ City code violations fall under the jurisdiction of municipal courts; county code violations are handled by district courts. District courts have jurisdiction over felonies as well as misdemeanors. Municipal courts only handle misdemeanors.

³⁵ The Montgomery County Director of Environmental Health is authorized to examine all “sources of filth and causes of sickness” affecting the health of county inhabitants. Montgomery County Sanitary Code §3-1.1.

readily observed from the exterior of the structure such as broken windows, deteriorating structural integrity, porches or yards full of litter, animals, old vehicles, or other obvious problems.

Other conditions associated with hoarding will only be apparent from the inside: blocked exits, narrow pathways, severely reduced living space, odors. If the occupant does not cooperate with the investigation by permitting access to the property, enforcement is more difficult. Without permission, an investigating officer would need to obtain an administrative search warrant to enter the property. Scarcity of resources in code enforcement offices may preclude obtaining the necessary search warrant, and effectively end the investigation.

If the inspecting official finds that the conditions constitute a nuisance a notice of the violation is issued. Notice is sent to the property owner of record, and is posted at the site.³⁶ The Notice identifies the property location and describes the conditions constituting a nuisance. The property owner is given a period of time to remedy the violation. The amount of time is variable, 30 days is typical, and may include provision for extensions.³⁷

The notice of violation also triggers the property owner's right to request a hearing on the matter. Again, the time period for making the request varies and is set by local codes.³⁸ This is an administrative hearing, and offers an opportunity to provide information about the nature of hoarding and its underlying causes. In some cases, the hearing officer has the authority to grant variances.³⁹ Grounds for granting a variance include practical difficulties with compliance, and unnecessary hardship, both of which could be useful in working with people who hoard.

Once the time period for compliance has passed the property is re-inspected. If there has been no voluntary compliance, the city can perform the needed clean up, and bill the costs to the property owner.⁴⁰

If the hoarder is renting, the violation can also lead to eviction, which has obviously detrimental effects on maintaining community tenure.

3. Possible Strategies for Addressing Hoarding

As noted above, local codes do not regulate hoarding directly. Local codes may be applied to hoarding if they pose a threat to the health and safety of the public. Whether the results of code enforcement prove helpful or harmful to an individual's community tenure depends on the individuals (hoarder, code enforcement officer, social worker, judge) involved in the process. The goal of code enforcement is to require clean up (abatement), which in turn should help allow the hoarder to remain in the community.

³⁶ Topeka Code §112-61

³⁷ For nuisances related to property maintenance, the compliance period is 30 days in Crawford County. §3-03(3). The Topeka Code allows a maximum of 60 days, plus one extension of 60 days. §112-44. Ft. Scott Code §8.20.080 allows extension of time as long as good faith effort at abatement is being made.

³⁸ Crawford County §3-03(3) allows ten days from receipt of notice of violation in which to request a hearing.

³⁹ Topeka Code §112-72.

⁴⁰ Ft. Scott Code §8.20.090; Topeka Code §§112-91, 112-92.

There is however significant risk posed by a forced clean-up because of its potentially devastating effect on the hoarder.

Individuals who hoard need time and support services in order to comply with notices to clean up nuisance situations. Local animal, housing and public health codes do provide a period of time for compliance, but this is often too short for the hoarder. In some instances, it may be possible to gain additional time by requesting a hearing following a notice of violation. The hearing is an opportunity to present information about hoarding, and the consequences of a forced clean-up. The hearing must be requested within a specified time of receipt of the notice; failure to do so results in forfeiting the hearing. Some codes also specifically allow the hearing officer to grant variances in individual cases.

A broader solution might involve changing the enforcement system to include recognition of a need for an extended time for compliance. Issues that would need to be explored in this regard would be defining hoarding, and educating code enforcement personnel about the problem. Mechanisms to provide support to individuals who hoard, and benchmarks for successful compliance will be needed as well. Local officials will also want to be careful that the public health and safety are not compromised by allowing additional time for compliance.

C. Hoarding Task Force Interviews

1. Introduction

Policymakers and practitioners who collaborate with us on our research have indicated a need for additional information about how service providers around the country are addressing hoarding situations. To gather this information, we conducted interviews with current hoarding task forces that had been identified primarily through a list on the Children of Hoarders' website, www.childrenofhoarders.com. This website is well known as one of the most comprehensive sources for information about current information related to hoarding.

Of those task forces listed on the website, two are no longer functioning. The task forces in Dane County, Wisconsin and New York City, New York no longer meet; however, both continue to maintain their websites. Task forces that were listed as active but were, in fact, either on hiatus or had not yet begun meeting, were located in: Erie, New York, San Mateo, California, Sacramento County, California, and San Francisco, California.

2. Methodology

There remained seven current hoarding task forces that we were able to conduct interviews with: Fairfax County, Virginia, Ft. Wayne, Indiana, L.A. County, California, Orange County, California, Princeton, New Jersey, Seattle, Washington and St. Louis County, Minnesota. Two of the hoarding task forces (in Ft. Wayne and Princeton) no longer hold regular meetings; however, as they characterized themselves as remaining a cohesive group who continue to work together on hoarding issues, they were included in

the interviews. The Ft. Wayne task force typically meets on a quarterly basis. And, the Princeton task force has a shared email list that they use to discuss hoarding situations, and they call meetings as needed, such as when there are personnel changes in key agencies.

Interviews were conducted by telephone in early April, 2007 with the following representatives from the seven current hoarding task forces. The interview guide developed for this element of the study was informed by the literature review and through our participation in the two local hoarding task forces. We received input from our project's methodologist, as well as from Christiana Bratiotis, a doctoral student at Boston University who has been awarded a fellowship to write her dissertation about hoarding task forces. Key interview questions were developed to inform our study specifically about municipal codes that were particularly useful or innovative, and, emerging best practices for intervention.

3. Findings

a. Please tell me about the history of your task force - how long it has been functioning, the impetus for establishing it, etc.?

The oldest task force had been functioning since the early 1990s. Another had been in operation since 1999. One task force had been functioning for seven years, and another for four years. One had been a task force for two years, but the same group was part of a larger coalition that had addressed the issue since 2003. Another had been functioning for two years, as well. And one had been meeting for a year and a half.

In regard to the impetus for their community initiation of a task force, all responded that community agencies had been frustrated by not knowing how to handle situations, and some spoke of a lack of knowledge by some agencies such as the health department or code enforcement about knowing what to expect from the social service agencies involved. One task force was created by the mayor's office, which had been receiving the same complaints about the same properties and people for many years, and wanted some way to respond to them. One task force was mobilized after some well publicized events in which individuals who hoard died, children were found living in squalid conditions, or individuals who hoard with very large numbers of animals were investigated. Two task forces started in part because of the interest that they discovered when holding workshops for the community. For one task force, the impetus for its inception was when one of their older adult mental health staff was asked to speak about hoarding to a senior center group. They expected an audience of about 25, and instead, 250 people representing many different organizations in the community attended her presentation. Something similar was involved in the creation of another task force. Providers had decided to look at the issue of hoarding more closely, and to do so, to conduct a workshop. They asked the a University if they could use their 225 seat auditorium. They anticipated that about 125 people would attend; instead, 300 people registered, and they had to turn away 75 people. So, three months later, they held another workshop at a larger venue, and again, 300 additional people registered.

b. What would you describe as the primary purpose(s) of your task force?

Answers included:

- To combine the resources of county agencies to provide a coordinated response to residential hoarding when it threatens life, safety, and property
- To intervene early enough to assist individuals who hoard to continue to live independently and with a manageable number of pets
- To provide education and develop assessment tools and identify interventions that work
- To increase interdepartmental awareness and education
- To satisfy residents of area neighborhoods
- To keep people in their homes living in a clean, safe and sanitary environment
- To identify and understand the issues, difficulties and causes of human hoarding behavior, to educate the public of these behaviors, and to develop humane options and innovative interventions

c. What types of organizations are represented on your task force?

They responded with a list of providers similar to those recommended by authors of many of the articles discussed in the literature review section of this report:

Public Health Dept	Mental Health	Building Safety
Sanitation	Adult Protective Services	Animal Control
Police Dept/Sheriff	Local Hospital	Child Protective Services
Fire Dept	Property Inspectors	Area Agency on Aging
District Attorneys	Judges	Environmental Health
Senior Centers	Organizer/Cleanup Agency	Private Attorneys
Code Enforcement	Housing/Zoning	Hospice
Vector Nuisance		

Some discussed the challenges of attempting to have representation from their city and county agencies; for example, LA County covers 64 small cities and the city of LA.

Three task forces had identified key agencies that they said must be involved in hoarding situations. For one task force, there are four: police, Adult Protective Services, mental health, and animal control. For another task force, there are also four: fire departments, health departments, Adult Protective Services, and animal control. For

another task force, there are five: mental health, a professional organizer or cleanup organization, the fire department, the defense attorney, and the prosecuting attorney.

One theme that was consistently discussed as part of answering this question, was about how task forces addressed the issue of confidentiality in working together on a hoarding case. One task force said that, for example, a social service provider could contact an inspector with a concern about a house that a client lived in, and, so long as the condition of the house was what was discussed, no confidentiality issues arose, because the provider was not even confirming that the person received services from their agency. And, further, they felt that confidentiality issues did not preclude them from informing a professional who would be visiting or inspecting the property if there were potential hazards to the professional or to the consumer; for example, if the consumer had a history of violent behavior or suicide attempts which the provider felt that the professional's visit might trigger. Another task force said that their state's welfare act allowed their Adult Protective Services to use a multidisciplinary team of licensed staff representing agencies such as mental health to staff cases with them. They added that this included sharing identifying information about the individual in order to help APS better understand the case and to handle it. And, another task force said that they had a unique county funded geriatric mental health team to respond to situations, and that, for continuity of care purpose, they were allowed to involve other agencies without the permission of the older adult.

d. Has your task force noticed any local trends in hoarding since your task force was formed, such as increase in the numbers of individuals who hoard, or a change in the types of hoarding that you are seeing?

All said that they had noticed an increase in the number of hoarding cases, but felt it was primarily because of the community education that they had been doing, and in the case of the one task force, because of all of the publicity that several of the more serious cases had received. However, several responded that there had been changes in their relationships with service providers. For example, one task force said that, in the past, their community mental health providers had been unwilling to assist with hoarding cases, because they only served the chronically mentally ill. But, after they received some education from the task force, as well as some community pressure, they were willing to at least provide evaluations.

Two task forces said that, in the past, inspectors were reluctant to pursue hoarding cases, because they felt that individuals who hoard living in dangerous housing was still better than being homeless, but, after the task force formed, they learned that child and adult protective services would become involved, and they would help get them resources such as other services, housing, and in some cases, guardianship, and, so, consequently, they were more willing to do something about hoarding cases. And two responded that, since the task force involvement, the chronic, more severe hoarding cases had been addressed, and they were now better able to intervene sooner, before cases became so problematic.

e. What percentage of the individuals who hoard seen by your task force is over the age of 60?

One reported that almost all are above 50, that only 10-15% are younger than 50, and there has been no one in their 30s. Another said that the typical hoarder is “middle to advanced age”. One said that, because their task force was affiliated with their older adult mental services, 100% of individuals who hoard seen by their task force were older adults, and, that, if younger adults were referred, they encouraged them to seek treatment from one of the local therapists who had experience in serving the population. Another said that, even though they technically only served older adults, they did include those who they considered as “functioning as an older adult”, for example, if a disability limited their functioning. In those cases, they would definitely assess the person, but they might not continue to serve them, in which case they would give them information about hoarding and local support groups. One also said not quite 100%. However, another said that only a little more than 50% were older adults, and one said that only about 20% of the individuals who hoard were older adults.

f. Are there particular housing, health and safety, or animal control-related codes that help your hoarding task force in assisting individuals who hoard (please give examples)?

In general, they responded that all of the codes they worked with were helpful, because they could use them to get the hoarder to allow the providers to help them. One also commented that code violation situations could provide them with useful information when they needed to pursue an involuntary commitment. They also discussed the usefulness of having codes that were city specific, such as animal codes. One also mentioned that it was helpful that animal control could enter a house without a warrant if they had reasonable cause to suspect that an animal was in danger. Another said that requiring that animals be registered, have rabies shots, be spayed or neutered, was helpful, and that requirements clearly defining what a kennel was, also helped.

g. Are there particular housing, health and safety, or animal control-related codes that hinder your hoarding task force in assisting individuals who hoard (please give examples)?

Two task forces responded that, because their codes don't address home interiors, inspectors can't inspect until there is a health and safety hazard, at which time, one person said, things are “really awful”. Another said that this caused their health department not to be invested in hoarding situations unless hoarding was present outside of the house, as well. Two task forces said that all of the steps of notifications, warrants, fines, etc. were frustrating in that they slowed down the process. And two task forces commented that it wasn't so much the codes that were the problem, it was the lack of funding to actually condemn and bulldoze the property that kept the codes from being effective.

h. Without giving us any identifying information, please describe a hoarding case that was resolved successfully, and explain why you think that the case was successful?

A successful case involved a 78 year old man who had inherited the house that he lived in, and the task force also suspected that he inherited some of the clutter in the house, as well. He had 900 bicycles and bike parts in his yard. The inside of his house was falling down around him; the sink had gone through the kitchen floor, the roof was collapsing. There were boxes of books and papers everywhere. He slept on top of a baby grand piano. For eight years, code enforcement and other regulators had been involved in the case, and he had had multiple forced clean outs. Finally, after being cited for three years, a lien had been placed on his house, and, people showed up with a dumpster yet again to clean him out, and he got into an argument with them and shoved them and ended up in court.

The judge was going to sentence him to jail, but, one of the mental health court liaisons alerted the task force, and they contacted the attorney, who said that what the county really wanted was not jail time for the man, but a conservatorship on him. However, he didn't lack capacity, so, the task force members knew that he didn't need someone to become his conservator. They advocated for the man with the attorney, who not only kept him out of jail, but, contacted a friend of his who was a professional organizer to come in and help. The man liked the organizer and he let her sell his bike parts online. The task force asked Habitat for Humanity to repair the house. At some point, the man realized that he needed socialization, and began attending Clutterer's Anonymous meetings. He eventually married. The organizer and the task force continue to monitor his progress.

For one task force, their first case involved 37 dogs and two cats in a one bedroom house that had been flooded seven years previously, and never cleaned. They became involved because of a complaint of odor by a neighbor, and when someone was sent to follow up on the complaint they found urine leaking out of foundation, newspapers on windows, the front door nailed shut, and no power or water.

Initially, they were unable to view the inside of the property, as the woman was "very leery of law enforcement"; consequently, when animal control staff would visit, they would not wear their uniforms. Once they had enough information, they were able to obtain a warrant. They knew that they would have only the one opportunity to go inside of the house, so, they arranged for many different providers to accompany them: a veterinarian, the fire department, code enforcement, mental health, and adult protective services. The woman was sent to a psychiatric hospital for a 72 hour stay, while the animals were impounded. All of the dogs were inbred or cannibalized, and there were three dogs in basement who had lived their entire lives there - the stairs had rotted, so she was unable to visit them, and lowered them food and water. She put newspapers on the floor every time that she or the animals ever urinated, which, over time, made the height of floors so high that they had to duck under the door jams. The small dogs dug through

these newspaper layers to get under furniture to have their litters; the fire department had to tear apart the furniture so that the animals could be rescued. In addition to hoarding animals, she also hoarded: suitcases, purses, milk jugs, unopened mailers, and newspapers.

Upon being discharged from the hospital, she was assisted in moving to living independently in a trailer park, and was allowed to keep one favorite pet that had been vaccinated and spayed. She has not hoarded animals since. The reason attributed to this successful outcome was that the service providers took the time to engage her, and that the person who had developed the best relationship with her took a lead role in the interactions with her.

One task force representative described a case in which Meals On Wheels reported a hoarder to Adult Protective Services because she did not have working appliances and was unable to ambulate safely or to prepare food safely. Over time, they were able to persuade her to “temporarily” move to an assisted living facility. They said that this was a successful case because “we got her safe”, and that, in the end, “she was glad [to move] but it was hard to leave her home.”

Another task force representative told of a hoarding situation in which the neighbors had learned that when the hoarder was not “safe”, she would not pick up her mail or her newspaper. They noticed that this was occurring, and contacted the police. The woman did not answer the door, and when they looked in her window, they saw her lying on the floor, and broke into her house. She was merely sleeping, and, when they attempted to commit her, she was found competent. Finally, her community and her attorney convinced her to move into a rehabilitation center to address some health problems. At the center, she became very socially active and began to care for her physical appearance. Upon leaving the center, the positive changes that she had begun continued, and her hoarding problems decreased.

One task force representative answered that they have a hoarding team at their mental health center consisting of a case manager, an outreach worker, and various clinical staff. The involvement of this team as well as representatives of Adult Protective Services ensures that individuals who hoard are more likely to be identified early and receive effective interventions.

One responded that they have not had any hoarding cases that were not resolved successfully in terms of the home remaining in the condition that it was, but that this is because they only intervene in the most serious of hoarding situations, in which the person must bring the house up to code or not be allowed to remain in their home. Their inspectors do attempt to work with individuals who hoard by allowing them to clean and organize areas of their home incrementally; however, any problems with blocked egress, unsafe heat source, or lack of smoke detectors must be able to be resolved quickly.

And, one responded that elements of a successful resolution included: “a good team effort” by “a number of different agencies and organizations working together”;

involvement on the part of both code enforcement and a helping professional; involvement of professional organizers; when code enforcement and the city manager and/or city council agree to be more flexible than how the code is written and are willing “to weather the ongoing complaints from the neighbors”.

The final question that we asked was:

i. Without giving us any identifying information, please describe a hoarding case that was not resolved, and explain why you think that the case was not successful?

One task force described a current case involving “Howard”, who believes that no one can take care of animals as well as he can. He takes in stray animals; he also hoards pots and pans, dishes, clothing (not his own), and items that are recyclable (but he never recycles them). He has been prosecuted for the animal hoarding, and has been required to submit to follow up inspections to ensure that he adheres to a limited number of animals, but, then they just fine him, and, because of a mental illness, he isn’t his own payee, so, he doesn’t pay. He has had three previous homes that had to be demolished because of the condition they were in. In a few years, the task force member said, the house he is living in will be condemned, and he will be found competent, so he will not receive treatment, and it will happen again.

Another task force described a current case of a 69 year old woman who has lived in her house for 40 years. Five years before they became involved with her, she had several “mini strokes” that made her unstable on her feet. Her house is full of bird droppings from a pet bird, and there are trash bags everywhere, as well as soiled paper from instances when she had been unable to get to the bathroom before having an accident. The odor from her house can be noticed by someone standing on the sidewalk.

While they believe her to be cognitively impaired, whenever they have attempted involuntary commitment, she presents well enough that she is not committed. The task force member commented that, “She’s gonna slip and fall, and break a hip, and then she’ll be out of the house.”

One responded, “When regulations don’t support intervention or some authority moves too fast and too strongly”. For example, they had a situation in which the hoarder was jailed for a week for not complying with a judge’s order to clean up, and while he was in jail, his son cleaned his house without his permission. This resulted in his being “more dead set than ever” about not addressing his hoarding.

One task force responded that hoarding situations in which funding for needed services is not available are less likely to be successful. Examples of services needed ranged from renting a dumpster to mental health case management.

Also, two task forces noted that there are times when a report about hoarding is received, but, when the inspector visits, there is no odor, the inspector cannot see

anything, and the suspected hoarder will not let them into the house. And, the person who made the report is unwilling to become more involved, such as by being willing to be identified.

The multidisciplinary approach described by the task forces seemed to be a key element in successful resolution of hoarding cases. Benefits of this approach included that: a) there were multiple opportunities for service providers and other professionals to intervene; b) the community and other service providers were educated about the availability of the group, which ensured that the case was brought to the attention of someone who could intervene; c) it appeared to increase the likelihood that there would be someone available with the time and commitment needed to engage the person who hoarded; and d) it appeared to increase the likelihood that there would be resources available to assist the person who hoarded in addressing the situation.

An additional information element appeared to be the existence of municipal, health and safety, and animal codes that allowed professionals' access to the homes of older adults who hoard. Codes that required action on the part of older adults who hoard, or enabled professional intervention, were also useful (i.e., codes that enabled animal control staff to remove an excessive number of animals from a home, codes that required individuals to live in homes without blocked egress, etc.).

D. Service Provider Survey

1. Design and Study Population

This survey was designed to use quantitative research methods to develop a profile of older adults who hoard in Kansas. The survey participants included service providers who represented three geographic areas: (1) Shawnee County task force; (2) Sedgwick County task force; and (3) Southeast Kansas Planning Service Area which includes Allen, Bourbon, Cherokee, Crawford, Labette, Montgomery, Neosho, Wilson, and Woodson counties. The Southeast Kansas area was identified through contact with agencies similar to those represented in the Shawnee and Sedgwick county task forces. Agencies participating typically included Adult Protective Services (APS) Area Agencies on Aging (AAA), Code Enforcement, Animal Control, City Police Department, Meals on Wheels, Kansas Animal Health Department (KAHD), mental health agencies, and other aging service providers. Survey participants were asked to complete surveys on any new cases from August 1, 2006 through April 1, 2007 involving adults age 60 and over who are hoarding.

Our survey was constructed in order to address our research questions and was informed by our review of hoarding literature and screening tools. The survey underwent extensive review by members of the Shawnee and Sedgwick County Hoarding Task Forces, as well as providers in our third geographic area. In addition, Dr. Gail Steketee, Interim Dean of Boston University's School of Social Work, and one of the foremost authorities on hoarding, also reviewed and provided feedback on the survey. The survey can be found in the appendix of this report.

We developed our survey instrument addressing the following research questions:

1. What is the occurrence of reported hoarding cases among older adults in our geographic areas over a nine month period?
2. What are the demographic characteristics of older adults who hoard?
3. What are the common hoarding characteristics, responses, and outcomes of hoarding cases among older adults?
4. What are differences and similarities between older adults who hoard and move from their home and those who remain in their home?
5. What are the difference and similarities between older adults who hoard animals and those who do not?

2. Methodology for Survey Dissemination

After development of the survey, with assistance from local service providers in the 3 geographic areas, we developed a methodology for dissemination of the survey. Due to time and funding constraints, we determined that data could be collected for a nine month period.

In order to disseminate the survey to the survey participants we established a point of contact for each agency, and that person was sent our introductory letter, instruction guide, and a survey. They were asked to distribute that information to relevant staff in their agency. Consent to participate as well as a confidentiality statement were also provided in the introduction letter.

We asked that service providers return surveys by the last day of each month for each new case opened during the previous month. For example, if a new case was opened in March of 2007 we would ask that the survey participant complete and return a survey on that case by the end of April of 2007. We collected surveys monthly in order to increase accuracy of responses. The data were used to identify and occurrence rate over the nine months. At the beginning of collection we also requested participants return surveys on cases that were already open on the date data collection started in order to capture the characteristics and interventions for as many older adults who were hoarding as possible. Surveys were provided in three forms: a) electronic form to be filled out and emailed back; b) on-line format accessed through our website and submitted directly from that site; c) hard copies to be mailed back in self-addressed stamped envelopes. Each month a reminder email with the survey was sent to each point of contact asking them to disseminate the survey to staff.

3. Findings

a. What is the occurrence of hoarding among older adults?

To answer our first research question we calculated how many new cases were reported over a nine month period. On average 4.1 new cases occurred per month in our 3 geographic areas. This number was determined by averaging new cases (n= 37) over nine months and does not include the surveys that we received on cases that were already open at the start of data collection. The open cases are included in the rest of our analysis. We

wanted to be sure we provided an accurate occurrence rate of new cases so we limited it to only those new cases. We received a total of 57 surveys on 52 individual people. In a few instances more than one survey from different service providers was completed on an individual. Of the 57 surveys we received, 30% (17) of the surveys came from Area Agency on Aging (AAA) case managers and 25% (14) came from Adult Protective Services (APS) social workers. The majority of other agencies reporting to us included 11% (6) from other aging service providers, 12% (7) from Kansas Animal Health Department (KAHD), 7% (4) from public housing authorities, and others including 9% (5) from animal control officers. Table 1 portrays the distribution of surveys by county of occurrence by geographic area, which highlights the fact that there are hoarding cases in the more urban and rural areas of Kansas. In addition, most cases came from Sedgwick, Shawnee, and Montgomery counties, which is not surprising since these counties have the highest proportion of older adults among our three geographic survey areas. We did not receive any cases from Woodson or Cherokee counties.

Table 1

County of Occurrence by Geographic Area

	<u>N</u>	<u>%</u>
Sedgwick County Geographic Area	16	31
Sedgwick County	16	31
Shawnee County Geographic Area	12	23
Shawnee County	12	23
Southeast KS Geographic Area	24	47
Montgomery	9	19
Bourbon	4	8
Labette	4	8
Allen	3	6
Crawford	1	2
Neosho	1	2
Wilson	1	2
Woodson	0	0
Cherokee	0	0

b. What are the demographic characteristics of older adults who hoard in Kansas?

The mean age of older adults was 74.4 ranging from 60 to 95 years of age. There was a much larger proportion of females in our sample (73%) compared to males and also compared to the overall population of adults 60 and over in Kansas. In comparison,

57% of adults 60 and older in Kansas are female (U.S. Census Bureau, 2000). In addition, in our sample 75% (39) were White and 17% (9) were African American. The percentage of African Americans is disproportionately higher than in the 60 and older population in Kansas. African Americans 60 and older only make up 4% of the population 60 and older and Whites make up about 93% (U.S. Census, 2000). Also, in our sample, 4% (2) were Asian, and 2% (1) were Native American. Although these are small numbers it shows that older adults identified as people who were hoarding in our sample were much more diverse than the general population of adults 60 and older in Kansas.

Sixty-nine percent of the sample was single, either widowed, divorced or never married. Although at least 69% of our sample was not married almost half of the sample lived with someone else and half were reported as living alone. Thus, it is important to note that even though a large proportion were single, 48% (25) were also living with someone and either impacting or being impacted by another person living in the home. In addition to the above demographics we attempted to capture older adults' level of education, monthly income, and occupation through our survey. However, we were not able to measure these variables for our findings because significant portions of these survey categories were either reported as unknown or had missing data. In addition, 3 of the 52 surveys analyzed did not identify an approximate age for the older adult and therefore the mean age is calculated based on 49 cases.

Table 2

Demographics of Sample Population

	<u>N</u>	<u>M</u>	<u>Range</u>
Age	49	74.4	60-95
<hr/>			
	<u>N</u>	<u>%</u>	
Gender			
Male	14	27	
Female	38	73	
Ethnicity			
African American	9	17	
Asian	2	4	
Native American	1	2	
White	39	75	
Missing	1	2	
Marital Status			
Single, never married	9	17	
Widowed	15	29	
Divorced	12	23	
Married/Partnered	10	19	
Unknown	6	12	
Living			
Alone	26	50	

With Spouse/ Partner	16	31
Relatives	9	17
Other	1	2
Residence		
Apartment	13	25
Single Family Dwelling	34	65
Other	5	10

In addition to demographics we also asked how many individuals may have had a suspected mental illness, physical disability, and/or illness/injury. We use the word suspected because we knew that not all service providers for this population are mental health or health care professionals and thus would not be able to provide a definitive diagnosis. However, generally speaking, providers dealing with these cases would be able to tell if symptoms of these conditions were present. Of the 52 individual cases, we found that 35% (18) of older adults who hoard had a suspected mental illness. Mental illnesses most commonly reported were Alzheimer’s/dementia, Schizophrenia, and Depression. Fifty-four percent (28) of the sample had a suspected physical disability. Disabilities most commonly reported were related to arthritis or difficulty ambulating. Seventeen percent (9) had a suspected illness/injury due to hoarding with asthma and injuries related to falling most commonly reported.

c. What are the common hoarding characteristics, responses, and outcomes in hoarding cases among older adults?

In order to address our third research question, we reviewed the literature to develop a list of hoarding characteristics which were used in our survey instrument. In the literature, the kinds of things people hoard as well as structural effects are examined under the topic of hoarding characteristics. Participants were asked to identify all characteristics that applied to their cases. The most common characteristics, reported for over 80% of cases were: acquiring a large volume of possessions cluttering areas to the extent that use of space was inhibited, acquiring possessions that appeared to be of useless/limited value, having difficulty discarding those possessions, accumulating combustible materials (such as newspapers, magazines), having narrow pathways in the home due to clutter, and having belongings perceived by others as bothersome/dangerous.

In 60% of the cases, older adults who hoard were upset or defensive when cleaning was suggested, and/or were socially isolated or reclusive. Over 50 % of the cases involved structural problems such as broken windows or rotting floors, blocked exits due to clutter, and/or useful living space that had been confined to one room or area. Finally, about a third of the sample had non-working utilities, rat or insect infestation, rotting food and/or used food containers, human and/or animal waste, and/or an unmanageably large number of companion animals.

Table 3

Common Hoarding Characteristics

	<u>N</u>	<u>%</u>
Acquisition of possessions that appear to be of useless/limited value	46	89
Acquisition of a large volume of possessions cluttering living area to the extent that use of space is inhibited	45	87
Others perceive belongings as bothersome/dangerous	44	85
Accumulation of combustible material	43	83
Difficulty discarding possessions that appear to be of useless/limited value	42	81
Narrow pathways in home	42	81
Useful living space has been confined to one room/area	34	66
Blocked exits	33	65
Socially isolated/ reclusive	31	60
Upset/defensive when cleaning is suggested	31	60
Structural problems	27	52
Rat/Insect infestation	22	42
Rotting food and/or used food containers	20	39
Human and/or animal waste	19	37
Non-working utilities	19	37
Unmanageably large number of companion animals	16	31
Presence of dead/dying companion animals	3	6
Other	0	0

*categories are not mutually exclusive

Second, during survey development we received help from both the Shawnee and Sedgwick county task forces on most common responses and outcomes to hoarding cases. We asked participants to identify all of the responses that applied to their case (see Table 4). In 65% of cases some kind of referral was made to another agency including APS, aging services, professional cleaning services, code compliance, mental health, and environmental health. Most referrals were made to APS and other aging service providers. In 44% of cases a home visit was completed to investigate further. In some cases, the older adult was removed from the home and in others the older adult did not allow entry into their home. In a few cases no referral was made. In addition to the categories listed survey participants provided additional information in the ‘other’ category. Some of these responses included making contact with family to address the situation, removing pets, and beginning clean-up.

Table 4

Responses to Hoarding Cases

	<u>N</u>	<u>%</u>
Referral made	34	65
Home visit to investigate further	23	44
Remained/arranged removal from home	6	12
Not allowed entry/contact refused	6	12
No referral made	2	4
Other	19	37

*categories are not mutually exclusive

Finally, to determine the most common outcomes of hoarding cases we asked participants to mark all of the following outcomes that applied to their case (see Table 5). Twenty-three percent (12) of the entire sample moved from their home for various reasons including nursing facility placement, the home was demolished, they were evicted, they moved to another home in the community, they moved to an assisted living facility, or local government seized possession of the home. However, forty-six percent (24) remained in their home with little or no change to their environment. A much smaller percent remained in a home that had been cleaned, repaired, or organized. Although referrals were made in many cases, in 23% of cases services were refused. And in 15% of cases providers reported that older adults utilized some or all of the referrals. In 12% of cases the older adult either had codes enforced, were being charged with animal cruelty, or were fined or in the process of being fined. And in 6% of cases the older adult was hospitalized. Fortunately, no older adults in this sample died or committed suicide during the time period of our study. Additional information provided in the ‘other’ category included seeking guardianship for the older adult, initial compliance with services followed by a reoccurrence of hoarding characteristics, and seizure of animals.

Table 5

Outcomes of Hoarding Cases

	<u>N</u>	<u>%</u>
Remained in home with little or no change to the environment	24	46
Refused services	12	23
Moved	12	23
Utilized some/all of referrals	8	15
Charged with animal cruelty, fined/in process of being fined, or codes enforced	6	12
Remained in home that had been cleaned/repaired/organized	5	10
Hospitalized	3	6
Suicide attempt	0	0
Died	0	0
Other	20	39

*categories are not mutually exclusive

d. What are the differences and similarities between older adults who hoard who move from their home and those who remain in their home?

In order to address our fourth research question we compared people who moved and those who remained in their home. A move includes people who left their home because they moved to a nursing facility, an assisted living facility, another home in the community, their home was demolished, they were evicted, or the local government seized possession of the home. We did not receive information on whether or not the person stayed at home or moved in every case, thus the sub-sample of those who moved or remained at home consists of 42 cases. Of all those who reported to have moved or stayed at home (n=42), 29% moved and 71% remained at home. As represented in Table 6 a much higher proportion of people who moved were female compared to those who did not. In addition, the people who moved seemed to be slightly older. Also, a higher proportion of African American and Asian older adults moved compared to those who stayed at home.

A higher proportion of older adults who lived in apartments were able to remain in their homes. A slightly higher proportion of people who moved were single, widowed or divorced. Finally, a much higher proportion of people who moved were hoarding animals compared to those who remained at home.

Table 6

Demographics of Older Adults Who Moved or Remained at Home

	Move		Not Move	
	<u>N</u>	<u>%</u>	<u>N</u>	<u>%</u>
Gender				
Male	2	17	10	33
Female	10	83	20	67
Age				
60-74	4	33	16	53
75+	7	58	12	40
Missing	1	8	2	7
Ethnicity				
African American	3	25	5	17
Asian	2	17	0	0
Native American	0	0	1	3
White	7	58	24	80
Residence				
Apartment	2	17	11	37
Single Family Dwelling	10	83	16	53
Other	0	0	3	10
Living				
Alone	6	50	16	53
With Spouse/Partner	4	33	10	33
Relative	2	17	4	13
Marital Status				
Single, never married	1	8	5	17
Single, widowed	5	42	7	23
Single, divorced	4	33	7	23
Married/Partnered	2	17	6	20
Unknown	0	0	5	17
Animal Hoarder				
Yes	5	42	7	23
No	5	42	19	63
Missing	2	17	4	13

In comparing the two groups we were also able to find some significant associations among certain variables. By conducting a Pearson Chi-Square we found the following to have a significant association at the .05 level. Those who refused services were more likely to remain at home. This finding warrants further investigation as to the types of services refused and how it relates to remaining at home. However, what is known is that older adults coming into contact with the legal system through codes being enforced, fines, or being charged with animal cruelty were more likely to move.

e. What are the differences and similarities between older adults who hoard animals and those who hoard other items?

In order to answer our final research question, we completed a comparison of the older adult who were hoarding animals and those who hoard other items. Again, not every survey clearly captured animal hoarding activity, thus due to some missing data, the following statistics are on a sample of 45 cases. A larger proportion of women hoarded animals compared to those who did not. There was not much of a difference in age between individuals who were hoarding animals and those who were hoarding other items. A higher proportion of the individuals who were hoarding animals were White than of those not hoarding animals and 6% of people who were hoarding animals were Native Americans. More people who were hoarding animals lived in single family dwelling, but similar proportions of both groups lived alone. A higher proportion of older adults who hoarded animals lived with a spouse/partner, 31% compared to 21%. Finally, a higher proportion of older adults who did not hoard animals were single. Thus, it appears that there was a higher rate of animal hoarding among those that were partnered at some point.

Table 7

Demographics of Animal Hoarders and Non-Animal Hoarders

	Animal		Non-Animal	
	<u>N</u>	<u>%</u>	<u>N</u>	<u>%</u>
Gender				
Male	3	19	8	28
Female	13	81	21	72
Age				
60-74	8	50	15	52
75+	8	50	12	41
Missing	0	0	2	7
Ethnicity				
African American	2	13	6	21
Asian	0	0	2	7

Native American	1	6	0	0
White	12	75	21	72
Missing	1	6	0	0
Residence				
Apartment	2	13	10	35
Single Family Dwelling	12	75	16	55
Other	2	13	3	10
Living				
Alone	9	56	16	55
With Spouse/Partner	5	31	6	21
Relative	2	13	6	21
Other	0	0	1	3
Marital Status				
Single, never married	1	6	8	28
Single, widowed	6	38	8	28
Single, divorced	4	25	7	24
Married/Partnered	3	19	3	10
Unknown	2	13	3	10

We did not find statistically significant associations between any of the hoarding characteristics, responses, or outcomes of older adults who were hoarding animals and those who were not, but there were some trends in the data worth reporting. A slightly higher proportion of older adults who were hoarding animals had a suspected illness or injury due to hoarding compared to those who were not hoarding animals, 25% and 17% respectively. A much higher proportion of people who were not hoarding animals refused services. And a higher proportion of people who were hoarding animals had codes enforced upon them, were fined, or were charged with animal cruelty.

Table 8

Comparison of Animal Hoarders and Non-Animal Hoarders on Select Variables

	Animals		No Animals	
	<u>N</u>	<u>%</u>	<u>N</u>	<u>%</u>
Do you suspect illness/injury due to hoarding?				
Yes	4	25	5	17
No	12	75	24	83
Refused Services				
Yes	1	6	9	31
No	14	88	20	69
Missing	1	6	0	0
Codes enforced, fined, charged w/ animal cruelty				
Yes	3	19	2	7
No	12	75	27	93
Missing	1	6	0	0

4. Limitations

Due to time and funding constraints we were only able to reach out to targeted providers within three geographic areas for the purpose of participation in our study. Consequently, we were not able to capture all hoarding cases in the state of Kansas during the data collection period. Further, we were not able to examine cases longitudinally. Research studies indicate that hoarding is a lifespan issue. Further, members of the task forces identified individuals under 60 that we were not able to include in our sample. The problem of hoarding appears to begin for some before the age of 60. Consequently, our findings need to be interpreted with caution and we are limited in being able to generalize to the entire population of individuals who are hoarding in Kansas. Finally, our sample was too small to complete many formal statistical analyses. However, in a few areas we were able to determine statistical significance. In addition, our data shows interesting trends that will be informative for people that work with this population and that can be examined in future research studies.

5. Conclusions

This study was exploratory in nature and does begin to help us understand older adults who hoard in Kansas. One area for future research includes examining differences

among older adults who hoard and move and those who do not move. Examining older adults who hoard moving patterns may help in identifying risk and protective factors for those older adults who are still at home in order to avoid premature loss of community tenure. Also, we now know that in many older adult hoarding cases the older adult remains at home with little or no change to his/her environment which may validate the complexity and difficulty of these cases. There is clearly much more research that needs to be done on this issue but we have taken the first step toward helping to improve practice in Kansas , and to develop the hoarding research agenda.

E. Stakeholder Work Session

1. Introduction

The purpose of the stakeholder work session was to identify solutions and next steps in helping older adults who hoard maintain their community tenure. State and local aging stakeholders and service providers were invited to provide feedback in regard to our project findings as well as identify next steps for Kansas. After presentation of our preliminary findings, participants were broken up into small groups and asked to discuss a series of questions. Participants signed consent forms in order to be tape recorded during their discussions. Forms and transcripts from this event can be found in the appendix. The following is a summary of those discussions organized around the key questions asked of the stakeholders.

2. Findings

a. How are you involved in working with older adults who hoard?

Participants were involved with hoarding in a number of ways including case management, animal control officers, public health nurses, task force members, Adult Protective Services workers , mental health center service providers, , and at the state level as staff in the Department on Aging. All participants had either personal and/or work experience with people who hoard or were invested at the local community and state level to make change.

b. Describe interventions in hoarding cases among older adults where you've been involved. What were some of the agencies you referred to, if any? What were some of the outcomes of your interventions?

Agencies that were commonly referred to included APS, Gatekeepers, Meals on Wheels, Animal Control/Code Enforcement, Mental Health, and cleaning agencies. Participants noted that in some instances referrals to these agencies were successful. However, it can be difficult for an agency to get an initial “foot in the door” to begin working with the older adult. Some suggested helping the older adult who hoards with small things as well as making several visits to build rapport. Others mentioned using the health department as leverage. When time is available, participants note the following

interventions can be successful: sharing follow-up task with other agencies, involving mental health agencies, developing a multidisciplinary approach and involving family to address situations before they escalate. At other times, no matter who is involved the case, there is no resolution. Quite often the outcome in animal control cases is most severe including removal of animals and prosecution.

- c. Are the demographics of the sample discussed in the survey presentation representative of the cases you see in your practice? Are the responses similar? Are the outcomes similar?**

Participants noted that the demographics presented in the survey findings were similar to their experience in the field. In particular, they noted that they mostly work with White elderly women from all sorts of socio-economic backgrounds. In addition, some participants mentioned that they did not see a higher proportion of African Americans in the hoarding cases in which they participated. Finally, most agreed that it is common for older adults who hoard to refuse services.

- d. In your experience in dealing with people who hoard, what primary factors do you believe influenced whether they moved or remained at home?**

Primary factors mentioned that may influence whether or not an older adult who hoards moved included: the house was condemned, landlord evicted the individual, a crisis forced the older adult to move, and the older adult had financial issues regarding whether or not he/she can afford to take proper measures to remediate the problem.

- e. What are the primary barriers to older adults who hoard remaining in their homes?**

Participants named a number of barriers for older adults who hoard to remaining in their homes. These barriers can be categorized as health and safety, financial, support and service, and emotional. Examples of health and safety barriers include problems with homes leading to possible falls, asthma, rotting floors, caving in roofs, and feces. Some participants named lack of finances for affordable mental health services, or limited travel for getting help as other barriers. Support barriers include lack of family and community support along with professionals unwilling to travel to provide services to rural individuals. Embarrassment, fear, and stigma of reaching out for help were also named as emotional barriers.

- f. Identify three potential solutions that address these barriers.**

Participants were asked to name potential solutions that may help to address the barriers people who hoard have to remaining in their homes. One solution participants named is to increase education and awareness among families, professionals, and the communities where these individuals live in order to increase understanding of what hoarding is and why these individuals hoard. Participants mentioned hoarding becoming

a DSM diagnosis to help professionals better understand what is occurring with these individuals. Another solution put forward was to develop multidisciplinary teams to triage services for individual who hoard. Participants suggested a phone tree to increase communication among organizations once a hoarder is found. Mental health services, home care services, cleaning services, and animal control were some of the community organizations mentioned that might be involved. Finally, some participants mentioned identifying evidence-based practice for working with adults who hoard and designing clear cut programs for assisting these individuals.

g. Describe necessary steps for putting these solutions into action.

Funding, education, and awareness were the three big steps needed to put these solutions into action. The discussion focused around getting individuals involved at University and community levels to increase awareness and interest in the issue of hoarding, which could lead to increased funding. Developing pamphlets and websites were discussed as educational tools. Participants also suggested trainings for professionals and community members interested in the topic of hoarding. They also suggested more task forces should be developed to focus on finding solutions for hoarding in more rural communities. Finally, one group suggested immunizations for individuals going into the homes as a health and safety precaution for providers.

h. In thinking about the information presented today, how could it influence your direct practice or your agency?

After hearing the information presented at this conference, some participants mentioned they will now be more aware of health and safety issues regarding interventions with individuals who hoard. Others mentioned it will now be helpful to have an increased awareness of other professionals and services in the community that also work with individuals who hoard. Finally, individuals agreed that it is helpful to be knowledgeable of the codes, rules, and regulations that apply when working with the hoarding population.

3. Summary of Work Session

Participants attending the work session came from a variety of backgrounds and all had a vested interest in helping older adults who hoard. Many of the agencies that are commonly referred to in hoarding cases were represented. Participants did describe some interventions that they had found useful. However, they also identified a number of barriers to older adults maintaining community tenure as well as solutions and next steps for communities and service providers. Most often, factors that may influence an older adult who is hoarding to move and barriers to their maintaining community tenure include health and safety issues regarding the home. In addition, a lack of financial resources and community support can play a role in the ability of an older adult who hoards to maintain community tenure. Therefore, solutions and next steps to addressing

these concerns requires education and awareness of hoarding issues among all parties involved in these cases including older adults, family members, service providers, and the general community. In addition, the local hoarding task forces have taken many steps toward developing protocols and systems in which agencies represented can communicate and support one another on these cases. However, participants also identified the need for more multi-disciplinary teams and training of professionals.

IV. Key Implications of Findings

Hoarding among older adults has far reaching implications for the older adult, service providers, and the community. Kansas has taken the first steps toward addressing the problem of hoarding in local communities. However, as indicated in this report, more needs to be done among researchers, service providers, and state and local officials in order to build on pre-existing service networks to address the problem. The following is summary of our key findings and implications.

1. Inconsistent definitions of hoarding limit previous research studies' usefulness.

One of the challenges in reviewing the existing literature is the lack of one commonly used definition of hoarding. For the purposes of our study, we used components of Frost and Hartl's definition of hoarding, as well as the Minnesota Veterinary Medical Association's definition of animal hoarding (see introduction for definition used). These concepts appeared useful in identifying older adults who hoard. This finding may have implications for researchers, funders and policy makers, in that they might consider standardizing the use of these definitions to promote common understanding among various groups.

2. Older adults are not a focus of most existing intervention research.

Despite indications that hoarding is a fairly common problem in older adult, with many negative consequences, and that considerable time and money are spent when professionals attempt to intervene in older adult hoarding situations, there has been very little research examining older adult hoarding. Specifically, there is almost no research to indicate whether the current treatments and/or non clinical interventions being developed to address hoarding are effective for older adults. Additional research is needed that focuses on the development, implementation and evaluation of these interventions and their outcomes for older adult hoarders. In particular, interventions involving a multidisciplinary team approach appear most promising in addressing the needs of older adult hoarders.

3. There is a lack of administrative and financial support for multidisciplinary team approach to interventions.

A multidisciplinary team (MDT) approach is critical for ensuring successful outcomes in older adult hoarding situations. However, many barriers were identified that kept communities from implementing MDTs, such as: lack of protocols, lack of agency

commitment, confidentiality concerns, limited time and funding availability to enable representatives to participate in interventions, and lack of legal authority to intervene. This has implications for local, state, and federal government, as their financial and administrative support for MDTs appears necessary for widespread use of MDTs. Finding ways to develop a comprehensive program that involves individuals at all government levels appears critical to the success of MDTs as an approach for addressing hoarding.

4. Community education about older adult hoarding is needed.

Increased community education is needed to understand hoarding, to identify the signs and symptoms of hoarding, and to know where and how to refer potential hoarding cases. Local and state governments, as well as social service and other agencies who frequently become involved in hoarding cases, are needed to provide financial and staffing resources to develop outreach materials, public service announcements, presentations and other public awareness tools.

5. Flexibility built into municipal codes can assist older adults in maintaining community tenure.

Municipal codes that allow code enforcement and other local government officials to extend the time by which older adults who hoard must be in compliance might increase the likelihood that they are able to maintain community tenure. Additional time may enable professionals involved in the situation sufficient opportunity to engage the older adult and assist them in the cleaning, organizing, and discarding necessary for their home to meet code requirements.

6. There is a lack of clearly established legal guidelines to address animal hoarding situations.

Virtually no laws or municipal ordinances specifically address animal hoarding situations. This lack of clearly established legal guidelines may hinder professionals who wish to intervene. An implication of this finding is the need for the development of "model codes" that municipalities may use to more clearly empower inspectors and other professionals in successfully intervening. Another implication is the need for state laws similar to that developed by Illinois.

7. Hoarding negatively affects not only those who hoard, but also those who live with them.

Many hoarders do not live alone. While there is some documentation in the literature about the negative consequences of living with a hoarder (including physical illness, injury, and social isolation), more research is needed to determine the full extent of the detrimental effects of living in a home where hoarding is occurring. This finding also has implications for service providers involved in hoarding situations, as not only may the hoarder need to be evaluated for health and safety risks, so do the other residents of the

home. Developing assessment instruments that evaluate not only the older adult, but any others who live with or have sustained contact with the elder seems imperative for determining the extent of the hoarding problems and for developing solutions.

8. Hoarders frequently experience co-existing mental and physical health conditions that may be impacted by hoarding.

Many hoarders have a mental and/or physical health problem that could potentially be exacerbated by hoarding conditions. This finding also has implications for service providers, who may need to make accommodations when planning services or treatment for older adults who hoard.

9. Hoarders' tendency to isolate may require unique identification and engagement strategies.

Hoarders tend to be socially isolative. Developing strategies to effectively identify older adults who hoard and to engage them needs to be a focus of future research.

10. Higher reported rates of African American older adults who hoard merit further investigation.

Since no other research has found proportionately higher numbers of African American older adults who hoard, until this finding is repeated, we can assume that this may be a finding that is unique to our study. Our finding might be explained by the fact that African American older Kansans are slightly more likely to use services such as those provided by the Area Agencies on Aging; therefore, African American older Kansans who hoard would be more likely to be identified by service providers who participated in our survey. African American older adults who hoarded were also more likely to move from their current living situation; this may be attributed in part to the fact that more African American older adult Kansans live in poverty than do the general older adult population. Lack of funding to provide older adults who hoard with the needed assistance to make their living environment safe and free from excessive clutter has been discussed as a factor that might impact their community tenure.

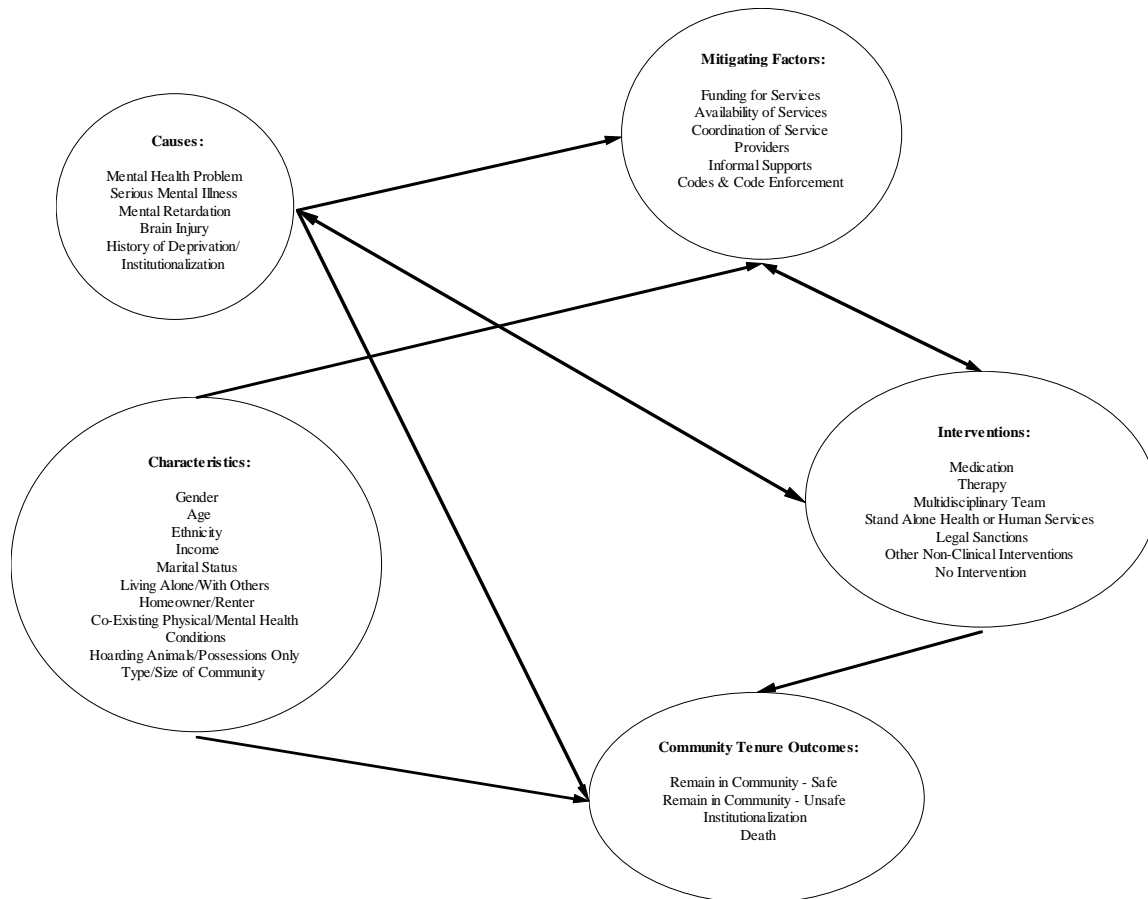
11. Lack of funding is a barrier to successful intervention in hoarding situations.

There is a lack of funding available to address the major cleanup and, sometimes, animal rescue efforts, that hoarding situations required. This finding has implications for local, state, and federal governments, who might need to establish financial resources for expenses that vary from dumpster rental to demolition of a home. It also has implications for funders of mental health, aging, and related service providers, as, older adult hoarders may not meet traditional criteria for the intensive services that they might need to effectively address their hoarding.

V. Community Tenure Outcome Model

Informed by our study, we have developed a beginning conceptual model to help consider the relationship between community tenure outcomes and causes of older adult hoarding, the characteristics of older adults who hoard, mitigating factors, and the types of interventions:

Community Tenure Outcome Model



As is illustrated by the model, many elements may directly or indirectly affect the outcome of a hoarding situation for an older adult in terms of their ability to maintain community tenure. Demographic and other characteristics may directly influence the outcome of whether an older adult is able to maintain community tenure; however, these characteristics may also indirectly impact the outcome of the situation through their relationship with mitigating factors such as a lack of resources. For example, an older adult living in a rural area might have inadequate access to the services needed to maintain community tenure.

Causes of hoarding may interact with mitigating factors and/or interventions, thereby indirectly influencing community tenure. For example, an individual diagnosed with a serious mental illness may have access to additional services that someone without a mental illness would not be able to access.

Mitigating factors such as funding, availability of services, service coordination, codes and code enforcement, and the availability of informal supports might impact the hoarding intervention, which, in turn, could impact the outcome. For example, the enforcement of codes might lead to legal sanctions that might thwart other types of interventions and result in the older adult no longer being able to remain in his/her own home thereby maintaining community tenure.

Finally, the type of intervention(s) that occurred would directly impact the outcome of the hoarding situation. For example, the use of a multidisciplinary team approach could cause sufficient resources to be mobilized to enable the older adult remain safely living in the community.

VI. Community Involvement

Through participation in the Shawnee and Sedgwick County task forces and our meeting with service providers in Southeast Kansas, we have taken part in the development of a larger network of service providers concerned about the problems associated with hoarding and committed to helping individuals who hoard. We have participated in constructing a press release regarding our research and general information about hoarding for Shawnee County. The Sedgwick County Task Force has committed to educating all agencies that may participate in hoarding cases in addition to providing information about our research. Agencies in Southeast Kansas are now considering forming their own hoarding task force and we have helped them develop a contact list for their area of the state. We have helped to initiate greater awareness of our State's efforts to address hoarding by connecting the Shawnee and Sedgwick County task forces with the Children of Hoarders resource group and website. In addition, we have regularly reported our activities to other groups in which members of our Office participate, such as the Kansas Mental Health and Aging Coalition, the Governor's Mental Health Services Planning Council's Aging Subcommittee, and others.

In addition to networking we have presented at two separate conferences and have received media attention across the state. In April, the Sedgwick County Task Force hosted a conference on hoarding in which we presented our preliminary findings to an audience of 200 service providers and related stakeholders. Due to the large number of attendees, the local paper, the Wichita Eagle, reported the event on their front page the following day. In May the OALTC was asked to present preliminary findings from the study at the Kansas Governor's Conference on Aging.

Also, in April we held our stakeholder work session meeting in Topeka, Kansas, which is seated in Shawnee County. Two separate media outlets in Topeka were aware of the story printed in Wichita and interviewed OALTC staff during our work session for coverage of the story in their evening news. Hoarding was the lead story on both of these stations for the night's evening news. Transcripts from all three media spots can be found in the Appendix.

Through our community based research we have not only completed the project activities as outlined in our initial proposal, but we have become a key player in the dialogue in Kansas about hoarding. Important first steps in Kansas have been taken through our research. In addition, public interest has mounted as evidenced by the

television and news coverage on hoarding and the release of our findings. The findings of this report will guide future policy, research, and practice in Kansas and nationally.

VII. Next Steps

Next steps for dissemination of our research include the following: 1) a symposium abstract entitled, "Hoarding and Older Adults: A Multi-Disciplinary Perspective", has been submitted to the Gerontological Society of America for their November, 2007 conference; 2) we will submit an abstract to the Kansas Public Health Association conference for 2007; 3) we will submit an abstract to the National Association of Mental Illness-Kansas conference for 2007; and 4) an abstract will be submitted to the American Sociological Association Annual Conference for 2008. Finally, three articles are in the process of being drafted. The first will include overall findings from our research. One will focus specifically on ethical issues for practitioners involved in older adult hoarding cases. Another will address the legal aspects involved in hoarding cases; this article will be submitted to various law review journals.

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Appendix A

SHAWNEE COUNTY HOARDING TASK FORCE

AGENDA

July 18, 2006

WELCOME AND INTRODUCTIONS

VOLUNTEER TO TAKE MEETING NOTES

REVIEW OF PREVIOUS MEETING NOTES

AGENCY INFORMATION, CODES, ETC.

PRESENTATIONS AND CONFERENCES ATTENDED

HOARDING IN THE NEWS

OTHER

UPDATES:

BROCHARD RESEARCH GRANT

RWJ GRANT PROPOSAL

FALL WORKSHOP PLANNING

CASE DISCUSSIONS

OTHER:

Next meeting: 9:00 AM, August 15, 2006 at ?

SHAWNEE COUNTY HOARDING TASK FORCE

AGENDA

August 15, 2006

9:00-10:30 AM

JAAA

WELCOME AND INTRODUCTIONS

VOLUNTEER TO TAKE MEETING NOTES

REVIEW OF PREVIOUS MEETING NOTES

JULY 18, 2006

UNITED WAY COMMUNITY INITIATIVES ACTION TEAM SURVEY

HOARDING IN THE NEWS

REVIEW OF TASK FORCE PROGRESS TOWARD GOALS

PROTOCOLS FOR COMMUNITY RESPONSE

RESOURCES FOR INTERVENTIONS

PREVENTION, TRAINING, COMMUNITY EDUCATION

RESEARCH AND EVALUATION

UPDATES:

BROCHARD RESEARCH GRANT

RWJ GRANT PROPOSAL

FALL WORKSHOP PLANNING

CASE DISCUSSIONS

OTHER:

Next meeting: 9:00 AM, September 19,2006 at JAAA.

SHAWNEE COUNTY HOARDING TASK FORCE

AGENDA

September 19, 2006

9:00-10:30 AM

JAAA

WELCOME AND INTRODUCTIONS

VOLUNTEER TO TAKE MEETING NOTES

REVIEW OF PREVIOUS MEETING NOTES

August 15, 2006

HOARDING IN THE NEWS

UPDATES:

BORCHARD RESEARCH GRANT

FALL WORKSHOP PLANNING

PROTOCOLS FOR COMMUNITY RESPONSE

TOPEKA COALITION ON ADULT ABUSE

CASE DISCUSSIONS

OTHER:

Next meeting: 9:00 AM, October 17, 2006 at ?

SHAWNEE COUNTY HOARDING TASK FORCE

AGENDA

October 17, 2006

9:00-10:30 AM

United Way

WELCOME AND INTRODUCTIONS

VOLUNTEER TO TAKE MEETING NOTES

REVIEW OF PREVIOUS MEETING NOTES

September 19,2006

HOARDING IN THE NEWS

UPDATES:

BORCHARD RESEARCH GRANT

FALL WORKSHOP PLANNING

PROTOCOLS FOR COMMUNITY RESPONSE

CASE DISCUSSIONS

OTHER:

Next meeting: 9:00 AM, November 21, 2006 at ?

SHAWNEE COUNTY HOARDING TASK FORCE

AGENDA
November 21, 2006
9:00-10:30 AM
United Way

WELCOME AND INTRODUCTIONS
VOLUNTEER TO TAKE MEETING NOTES

REVIEW OF PREVIOUS MEETING NOTES
October 17, 2006

HOARDING IN THE NEWS

UPDATES:
BORCHARD RESEARCH GRANT
FALL WORKSHOP PLANNING
PROTOCOLS FOR COMMUNITY RESPONSE

CASE DISCUSSIONS

OTHER:

Next meeting: January 16, 2007 at JAAA?

SHAWNEE COUNTY HOARDING TASK FORCE

AGENDA

January 16, 2007

9:00-10:30 AM

Jayhawk Area Agency on Aging

WELCOME AND INTRODUCTIONS

VOLUNTEER TO TAKE MEETING NOTES

REVIEW OF PREVIOUS MEETING NOTES

November 21, 2006

HOARDING IN THE NEWS

UPDATES:

BORCHARD RESEARCH GRANT

WORKSHOP PLANNING

PROTOCOLS FOR COMMUNITY RESPONSE

CASE DISCUSSIONS

OTHER:

Next meeting: February 20, 2007 at JAAA

SHAWNEE COUNTY HOARDING TASK FORCE

AGENDA

March 20, 2007

9:00-10:30 AM

Jayhawk Area Agency on Aging

WELCOME AND INTRODUCTIONS

VOLUNTEER TO TAKE MEETING NOTES

REVIEW OF PREVIOUS MEETING NOTES

February 20, 2007

HOARDING IN THE NEWS

UPDATES:

BORCHARD RESEARCH GRANT

CHILDREN OF HOARDERS BROCHURES

WORKSHOP PLANNING

PROTOCOLS FOR COMMUNITY RESPONSE

CASE DISCUSSIONS

OTHER:

Next meeting: April 17, 2007 at JAAA

Appendix B

KU- School of Social Welfare Office of Aging and Long Term Care

The Community Tenure of Older Adult Hoarders: Identifying Risks and
Enhancing Opportunities
April 23, 2007
Topeka Public Library

Agenda

- 10:00 Welcome and Introductions
- 10:20 Literature Review/ Questions
- 11:00 Survey/Questions
- 11:30 Breakout- Small Groups
- 12:00 Lunch
- 12:45 Task Force Interviews/ Questions
- 1:10 Task Force Member Presentation
- 1:50 Break
- 2:00 Codes/ Questions
- 2:30 Breakout- Small Groups
- 3:15 Presentation by Small Groups
- 3:45 Wrap-up
- 4:00 Adjourn

April 23, 2007
Stakeholder Worksession Participants

Name	Agency
Jan Dietrich	Shawnee County Health Department
Annette Graham	Central Plains Area Agency on Aging
Valerie Merrow	Kansas Department on Aging
Randy Bottorff	Adult Protective Services
Deb Back-wenzel	Adult Protective Services
Vern Norwood	Kansas Department on Aging
Linda Stanislaus	Chanute Housing Authority
Karen Peterson	Kansas Department of Social & Rehabilitation Services
Eldonna Chestnut	Johnson County Public Health Department
Patti Rule	Johnson County Public Health Department
Linda Halford	Topeka Police Animal Control
April Maddox	Jayhawk Area Agency on Aging
Nancy Trout	Kansas Mental Health and Aging Coalition
Jeanne Reeder	Heart of America Alzheimer's Association
Debra Duncan	Kansas Animal Health Department
Nancy Luber	Johnson County Mental Health Center
Susan Erlenwein	Sedgwick County Environmental Services
Terrill Florence	City of Wichita
Lori Marceau	Wichita Police Department
Dennis Graves	Wichita Animal Services
Krista Lovette	Central Plains Area Agency on Aging
Nancy Rapp	Kansas Department of Mental Health-SRS
Marilyn Rivera	Meals on Wheels
Bessie Walker	Adult Protective Services

The Community Tenure of Older Adult Hoarders: Identifying Risks and Enhancing Opportunities

April 23rd Work Session

Approved by the Human Subjects Committee Lawrence Campus, University of Kansas.
Approval expires one year from 7/11/2006.

Your participation in this study is completely voluntary. While we would like to hear your views, you may choose to decline answering any questions you would rather not discuss. You may elect to withdraw from this study at any time and the information we have collected from you will be destroyed. Today's work session will be audio taped and the data from this study will be coded from these tapes. Your individual privacy will be maintained in all published and written data resulting from the study. By signing below, you are agreeing to participate in a research study. Your signature indicates that you have received a copy of this agreement to participate. If you have questions, please feel free to ask a member of the research team.

Signature _____

Appendix C

Hoarding and Older Adults: A Multidisciplinary Perspective

Chapin, R. and Koenig, T., University of Kansas School of Social Welfare, Office of Aging and Long Term Care, 1545 Lilac Lane, Lawrence, Kansas 66045

PARTICIPANTS:

Chapin, R., Koenig, T., McKenzie, S., Landry, S., Reynolds, K. University of Kansas, Lawrence, Kansas. **Older Adult Hoarders: Characteristics and Intervention Attempts by Service Providers.**

Ayers, C. Veteran's Administration San Diego Healthcare System, San Diego, California. **Characterization of Compulsive Hoarding in Older Adults.**

Lyons, B., Mental Health Association of San Francisco, San Francisco, California, Eckfield, M., University of California School of Nursing, San Francisco, California.

Compulsive Hoarding and Cluttering and Older Adults.

Bratiotis, C., Boston University, Boston, Massachusetts. **Task Forces as a Community Response to Compulsive Hoarding.**

DISCUSSANT:

Ekerdt, D., University of Kansas School of Sociology, Lawrence, Kansas.

Older adults who engage in hoarding behavior, defined as acquiring and failing to discard useless possessions, face personal and environmental issues due to their hoarding. Hoarding in older adults frequently results in chronic physical health problems, injuries, increased social isolation, eviction, premature institutionalization, and even suicide. These multifaceted consequences point to the importance of multidisciplinary interventions. The purpose of this symposium is to examine hoarding in older adults from a multidisciplinary perspective. The first paper reports survey findings of aging and other community service providers on characteristics of older adult hoarders and referral and intervention outcomes. The second paper reports on findings of older adults in an obsessive compulsive disorder day treatment program including symptom severity and response to multimodal treatment by older adults identified as obsessive-compulsive hoarders. Further, the age of onset, psychiatric co-morbidities, and neuropsychological functioning of late life compulsive hoarders will be discussed. The third paper reports on the use and effectiveness of community-based treatment programs, including peer support groups as interventions for hoarders who are older adults. The final paper reports on findings from a qualitative comparative case study of hoarding task forces throughout the United States.

Older Adult Hoarders: Characteristics and Intervention Attempts by Service Providers

Chapin, R., Koenig, T., McKenzie, S., Landry, S., Reynolds, K.

Despite the significant personal and financial costs incurred by older adult hoarders and the communities in which they live, little is known about the characteristics of older adult hoarders or intervention outcomes. This presentation will report on a study conducted by the University of Kansas, School of Social Welfare's Office of Aging & Long Term Care. Findings included: older adult hoarders were more likely to be women, white, and live alone; a third of all cases reported involved animal hoarding; and, even after the hoarding had been identified by an agency, and referrals for various services had been made, over 40% of hoarders remained residing in their homes with little or no change to their environment. Implications for research and practice include developing and pilot testing a multidisciplinary intervention designed to address the personal and environmental needs of the older adult hoarder and the community.

Appendix D

<p>Approved by the Human Subjects Committee University of Kansas, Lawrence Campus (HSCL). Approval expires one year from 7/17/2006</p>

Dear -----,

The purpose of this letter is to invite you to participate in a study conducted by the Office of Aging and Long Term Care at the University of Kansas, School of Social Welfare on the issue of hoarding by older adults age 60 and older. The Office of Aging and Long Term Care (OALTC) has been awarded a grant to investigate hoarding by older adults in Kansas and your input is essential to the needed results of this project.

The purpose of the project is to provide baseline information for service providers and state and local policymakers on hoarding problems among older adults in Kansas, and to identify code enforcement regulations and related policies that may affect their community tenure. Since no aggregate data on the issue of hoarding has been compiled statewide, we are conducting a survey of professionals who may come into contact with older adults who have a hoarding problem. One of the foremost researchers in the area of hoarding, Dr. Gail Steketee, has provided a definition of hoarding that will be used for this project. A significant subset of hoarders – animal hoarders- has also been defined by the Minnesota Veterinary Medical Association, and will be used for this project.

- Hoarding: “A debilitating disorder characterized by the acquisition of a large volume of possessions that clutter living areas to such a degree that living spaces cannot be used for their intended purpose”.
- Animal hoarding: “A complex disorder characterized by the keeping of an unmanageably large number of companion animals and/or other species”.

This study offers you an opportunity to share your experiences in working with older adults who have a hoarding problem. It also provides an opportunity to better understand the needs of older adults who hoard in Kansas. Your participation is completely voluntary. *No identifying information about you or your agency will be released, and study reports will not include your name or other identifying information. Results from the survey will be reported in an aggregate manner. **The content of the survey should cause you no discomfort.***

A written survey is attached to this letter. ***Please complete this survey on any hoarding case that was open on July 1st, 2006 and any new cases you have experienced after July 1st, 2006 and return it in the enclosed self-addressed, stamped envelope.*** The survey should take less than twenty minutes of your time to complete. Some survey participants may be contacted regarding participation in a work session during the spring to identify next steps toward addressing hoarding among older adults in Kansas and to develop

recommendations that can help communities build on pre-existing service networks to address hoarding problems.

Again, your participation is completely voluntary. Completion of the survey indicates your willingness to participate in this project and that you are at least eighteen years old. If you have any additional questions about your rights as a participant you may call (785) 864-7429, or write Human Subjects Committee Lawrence Campus (HSCL), University of Kansas, 2385 Irving Hill Road, Lawrence, Kansas 66045-7563, email dhann@ku.edu.

If you have questions regarding the survey or would like additional information, please feel free to contact the project coordinator, Sarah Landry, at the University of Kansas at (785) 864-3823 or Kimberly Reynolds, project co-coordinator, at (785) 864-3797. Thank you for your time and consideration of participation in this study. We look forward to hearing from you soon.

Sincerely,

Rosemary Chapin, Ph.D.
Director, Office of Aging and Long Term Care

Thank you for taking the time to complete this survey! Your input will provide state and local policymakers and other stakeholders with important information to assist older adults experiencing problems with hoarding.

Surveys should only be completed for those individuals who were age 60 or older as of July 1, 2006. When more than one older adult hoarder lives in the same household, please complete separate surveys for each older adult hoarder.

Hoarding is defined by Dr. Gail Steketee as, “A debilitating disorder characterized by the acquisition of a large volume of possessions that clutter living areas to such a degree that living spaces cannot be used for their intended purpose”. Animal hoarding is defined by the Minnesota Veterinary Medical Association as, “A complex disorder characterized by the keeping of an unmanageably large number of companion animals and/or other species”.

The following is a detailed explanation clarifying each question on the survey.

For further information, or to submit a completed survey, please contact: **Sarah Landry: stbone@ku.edu, Telephone: (785) 864-3823, Fax: (785) 864-5277.**

Person Completing Form: Please indicate the name of the individual staff person who is completing the form.

Email/Telephone #: Please indicate the email address and/or telephone number of the individual completing the form.

Agency Name: Please indicate the agency where the individual who is completing the form works.

Today’s Date: Please indicate the date on which the form is being completed.

Date Reported to Agency: Please indicate the date on which the older adult about whom the survey is being completed was first reported, referred to, or approached your agency.

Unique ID: KU encourages all agencies involved in a particular hoarding case to complete a survey; in order to identify those individuals, so, as to avoid duplicate counting of cases at the end of the study period, a method was devised so that individuals could be distinguished from each other in such a manner as to maintain their confidentiality. The first letter of the Unique ID relates to the gender of the older adult about whom the survey is being completed – F for female, M for male, and U for unknown. The next set of numbers relates to the street address or post office box number of the older adult about whom the survey is being completed; for example, for “PO Box 6412”, the number “6412” would be placed after the letter indicating gender. If the individual lives in a nursing facility, homeless shelter, etc., the street number of the housing situation would be used. The next set of numbers/letters are only entered when the individual has an apartment number, room number, etc.; for example, for “Room 2F”, “2F” would be entered. The final set of letters would indicate the two letter county abbreviation of the county in which the older adult lives; for example, “Sedgwick County” would be “SG”.

Hoarding Characteristics: For **each** characteristic listed, please check/select whether you believe that it is “present” or “not present” or “unknown” regarding the individual for whom the survey is being completed.

Approximate Age: Please provide the age of the individual, or, a close estimate; if unknown, please indicate “unknown”.

Level of Education: Please indicate the highest level of education attained by the individual; if unknown, please indicate “unknown”.

Approximate Monthly Family income: Please provide the household/family monthly income, or, a close estimate; if unknown, please indicate “unknown”.

Ethnicity: Please check all ethnicities that are believed to apply to the individual; if unknown, please indicate “unknown” in the “other” section.

Previous/Current Occupation: Please indicate the primary previous or current occupation of the individual; if unknown, please indicate “unknown”.

Approximate # of Contacts with Your Agency: Please indicate the approximate number of visits, communications, etc., between your agency and the individual, that have occurred between the date indicated at the top of the survey in the space for “Date Reported to Agency”, and today’s date.

Marital Status: Please indicate the current marital status of the individual.

Residence: Please indicate the current residential situation of the individual; if unknown, please indicate “unknown” in the “other” section. Note: if the current situation is a hospital, shelter, relative’s home, etc., but the individual maintains permanent housing at which the hoarding occurred, please check the residential situation that best describes their permanent residence.

Living: Please indicate the current living situation of the individual; if unknown, please indicate “unknown” in the “other” section. Note: if the current situation is a hospital, shelter, relative’s home, etc., but the individual maintains permanent housing at which the hoarding occurred, please check the box that best describes the individual’s permanent living situation.

Reported to your agency by: Please check all that apply.

Do you suspect mental illness?: Please check “yes” if a mental illness is suspected or is known to be present.

:

If mental illness known, what type(s)?: If you are reasonably certain that the individual has a mental illness, please indicate all that are known (example, “depression”, “bipolar disorder, etc.).

Do you suspect physical disability?: Please check “yes” if a physical disability is suspected or is known to be present.

If physical disability known, what type(s)?: If you are reasonably certain that the individual has a physical disability, please indicate all that are known (example, “paralysis”, “legally blind”, etc.).

Do you suspect illness/injury due to hoarding (asthma, flea bites, etc.)?: Please check “yes” if you are reasonably certain that the individual has experienced an illness or injury (or an exacerbation of an illness or injury) due to hoarding. For example, breathing problems can be

exacerbated by large amounts of newspapers or dusty areas; individuals may be injured by falling clutter; individuals may experience flea bites when hoarding animals.

If illness/injury due to hoarding, what types?: If you are reasonably certain that the individual has an illness/injury due to hoarding, please indicate all that are known (see examples above).

How did your agency respond to the report?: Please check all that apply.

What was the outcome of the situation?: Please check all that apply.

If moving/being removed from the home, what hoarding/non-hoarding related circumstances caused their move?: Please describe any hoarding-related circumstances that impacted their move, such as: “house was condemned”, “individual was evicted”, etc. Also, please describe any non-hoarding-related circumstances, such as: “individual had a stroke and could no longer live at home”, “individual moved to live with relatives out of state”, etc.

Please return the completed survey to KU by the last day of each month for individuals referred, reported or approached your agency within the previous month. Thank you!

University of Kansas School of Social Welfare Survey of Older Adult Hoarding Situations

Person Completing Form _____ Email/Telephone # _____

Agency Name _____ Today's Date _____ Date Reported to Agency _____

Unique ID _____ use Gender + House # + Apartment # + County (ex: F14123BSN is a female living @ house # 1412, apartment # 3B, in Shawnee County – see instruction sheet for detailed instructions)

Please complete and return the following survey for each report of a potential hoarding situation in which hoarder is an adult aged 60 and older.

Was this case open on July 1st, 2006? Yes No

Hoarding characteristics (please complete "present"/"not present"/"unknown" for each characteristic):

Characteristic	Present	Not Present	Unk
Acquisition of large volume of possessions cluttering living areas to extent that use of space is inhibited			
Acquisition of possessions that appear to be of useless/limited value			
Difficulty discarding possessions that appear to be of useless/limited value			
Accumulation of combustible materials (newspapers, magazines, etc.)			
Structural problems (broken windows, rotting floors, etc.)			
Blocked exits (due to clutter)			
Narrow pathways in the home (due to clutter)			
Useful living space has been confined to one room/area			
Non-working utilities (electrical, plumbing, refrigeration, etc.)			
Upset/defensive when cleaning is suggested			
Others perceive belongings as bothersome/dangerous			
Rat/Insect infestation			
Rotting food &/or used food containers			
Human &/or animal waste			
Unmanageably large number of companion animals			
Presence of dead/dying companion animals (Approximate # _____)			
Socially isolated/reclusive			
Other: _____			

Approximate Age: ____ **Level of Education:** _____ **Approximate Monthly Family Income:** _____

Ethnicity: Hispanic African American Native American Asian White
Other: _____

Previous/Current Occupation: _____ **Approximate # of Contacts with Your Agency:** _____

Marital Status: Single, Never Married Single, Widowed Single, Divorced Married Partnered

Residence: Apartment Single Family Dwelling Public Housing
Other: _____

Living: Alone Living with Spouse/Partner Living with Relative(s)
Other: _____

Reported to your agency by: Police/Fire Health Department Meals on Wheels
 Code Enforcement Neighbor Landlord Area Agency on Aging
Other: _____

Do you suspect mental illness?: Yes No **If mental illness known, what type(s)?:** _____

Do you suspect physical disability: Yes No **If physical disability known, what type(s):** _____

Do you suspect illness/injury due to hoarding (asthma, flea bites, etc.)?: Yes No
If illness/injury due to hoarding, what type(s)?: _____

How did your agency respond to the report? (please check all that apply):

- No referral made
- Referred to code compliance Services
- Referral to mental health services
- Referral to professional cleaning agency
- Home visit to investigate further home/contact refused
- Removed/arrange removal of older adult from the home
- Other (specify agency if referral made): _____
- Referral to Adult Protective Services
- Referral to aging services
- Referred to environmental health agency
- Not allowed entry into home

What was the outcome of the situation? (please check all that apply):

- | | |
|---|--|
| <input type="checkbox"/> Refused services from your agency
community | <input type="checkbox"/> Moved to a different home in the |
| <input type="checkbox"/> Hospitalized | <input type="checkbox"/> Moved to assisted living facility |
| <input type="checkbox"/> Moved to nursing facility | <input type="checkbox"/> Died |
| <input type="checkbox"/> Suicide attempt
referrals | <input type="checkbox"/> Utilized some/all of above |
| <input type="checkbox"/> Home was demolished | <input type="checkbox"/> Fined |
| <input type="checkbox"/> Charged with animal cruelty/neglect | <input type="checkbox"/> Codes enforced |
| <input type="checkbox"/> Evicted/ in process of eviction
possession of home | <input type="checkbox"/> Local government seized |
| <input type="checkbox"/> Remained in home with little/no change to the environment | |
| <input type="checkbox"/> Remained in home that had been cleaned/repaired/organized | |
| <input type="checkbox"/> Agency worker experienced injury/illness due to visiting the home (throat/lung
problems, allergic reaction, flea bites, hepatitis shot required, etc.) Please
explain: _____ | |

Other: _____

**If moving/being removed from home, what hoarding/non-hoarding related
circumstances caused their
move?** _____

Thank you for completing this survey! Please return to:
Sarah Landry: stbone@ku.edu , Telephone: (785) 864-3823 Fax: (785) 864-5277
University of Kansas School of Social Welfare Office of Aging and Long Term Care
Twente Hall, 1545 Lilac Lane, Lawrence, KS 66044-3184
Or, complete the survey online at: www.oaltc.ku.edu

Appendix E



Paper: Wichita Eagle, The (KS)
Title: HOARDING PROBLEM GETS STATE ATTENTION - MEETING IN TOPEKA
Date: April 23, 2007

The idea of **hoarding** - collecting food, trash, odd bits of hardware, even animals - often brings raised eyebrows and sometimes brings chuckles.

But it's a serious **problem** that can affect people's health and public safety, the director of the Central Plains Area Agency on Aging said Friday.

A statewide meeting about **hoarding** begins today in Topeka as leaders of several agencies get together to talk about the issue.

Annette Graham, director of the agency's Central Plains region, said it's difficult to know how often **hoarding** occurs because usually it goes unreported.

It often starts behind closed doors.

Unused spare rooms get filled to the point where doors won't open. Basements or garages are stuffed to overflowing.

The Office of Aging and Long Term Care at the University of Kansas' School of Social Welfare will release results of a study on **hoarding** today in Topeka.

A statewide **hoarding** task force has been meeting for about a year.

The clinical diagnosis of **hoarding**, Graham said, is the acquisition of and failure to discard a large number of possessions of limited or useless value. When it begins to limit a person's activities, it becomes a **problem**.

"It can result in code and fire violations," Graham said. "It can lead to extreme rodent or insect infestation. It can be the **hoarding** of animals, which leads to neglected animals. It can be a collection of debris in and outside the home, which leads to blight."

Blight has become an issue in Wichita, where officials and neighbors have made headlines for trying to get homeowners to clear junk from yards and lots.

Law enforcement and social service agencies usually learn about **hoarding** after health or other **problems** come to their attention.

Some cases seem more bizarre than others: In 2000, Wichita firefighters discovered 40 to 60 cats stuffed in plastic bags inside two freezers when they responded to a fire at a home near North Bluff. Several live cats were in the home, too.

The homeowner admitted she hoarded cats, often scraping dead ones off the road and storing them in freezers in her home.

Mental health professionals often consider **hoarding** a compulsion. Collecting items can provide a sense of security, but the clutter can provoke anxiety - leading to still more collecting.

Hoarding is not just a **problem** for the elderly, Graham stressed.

"It typically starts at a much younger age," she said. "The person may be able to manage the situation when they are younger, but when they become older, they have health **problems** or cognitive **problems** and then it becomes apparent to others outside those individuals and their families."

Reach Deb Gruver at 316-268-6400 or dgruver@wichitaeagle.com.

Now you know

Signs of **hoarding**

- An accumulation of items that seems out of hand and beyond normal clutter
- Obsession with keeping items of little or no value
- Piles of belongings that interfere with the ability to use a home the way it's supposed to be used. For example, there may be no room to sleep on a bed. Stacks of books or papers may block a bathroom or bedroom. Or there may be a path snaking through the home.

For more information about **hoarding**, call Krista Lovette at the Central Plains Area Agency on Aging, 316-660-5222.

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Author: DEB GRUVER, THE WICHITA EAGLE

Section: MAIN NEWS

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Hoarding Discussed In Topeka- NBC

Meagan Farley

 [Video High](#)

A statewide task force has been meeting for about a year focusing on a serious disorder called Hoarding. It affects millions of households in the United States.

"Insects, infestation, lots of mice and sometimes dead animals are what you can find in a house," said Karen Peterson, who heads up the Shawnee County Hoarding Task Force. She remembers one case in particular. "We had adult protective services go in and the people allowed that, but that individual committed suicide because they had a problem letting go of their possessions."

Experiences similar to that prompted the Shawnee County Hoarding Task Force to ask for outside help. They got that help from the KU school of Social Welfare Office of Aging and Longterm care. Then they found someone to fund their partnership.

"We went to the Borchard Foundation on Law and Aging, applied and were one of only four grants given."

Monday, everyone met up at the Topeka Shawnee County Public Library to compare notes

"We will now put together our final report and send it throughout the state and the country."

Story Created: Apr 23, 2007 at 11:57 PM EDT

Story Updated: Apr 24, 2007 at 12:33 AM EDT

Kansas agencies tackle problem of hoarding in state

Topeka man calls collectables decorations, neighbors disagree

Story by [Marshanna Hester](#) ([Contact](#))

10:42 p.m. Monday, April 23, 2007

From cans of food, to a suitcase, to spring flowers and season's greetings, you can find all that and more on Jim Peters porch.

And though Peters says it looks junky, he has a plan and purpose for everything, even if he doesn't know what it is.

Take for example, this gadget.

"I'm hoping that somebody will tell me what it is so that if they can use it or I can ask people, hey do you need one," he said.

What is hoarding?

Hoarding is when someone collects food, trash, odd bits of hardware, or even animals that can accumulate inside or outside of the home.

The study conducted by the office of aging and long-term care at KU's School of Social Welfare found that hoarding stems from some type of mental illness. The practice can begin at any age and affect people of all types of soci-economic backgrounds.

Many people looking at Peters' wide array of collectables would say he's a hoarder, but to him it's just a hobby.

"I don't keep anything that's going to be a hazard to other people's health like dead animals or fish, fish guts," he said.

Neighbor Mary Corbett says it's painful to look at the mess next door that is ruining the neighborhood.

But the problem she says continues on the inside.

"It's full to the ceiling, in every room and there's a pathway through the house, one pathway," she said.

Corbett says Peters is a good neighbor by picking up trash and keeping his lawn mowed.

But because her neighbor's home is a potential fire hazard, she says she's called the city's code compliance to get the mess cleaned up.

But until they come and make a clean sweep, Peters says his home will stay like it is.

“No I’ll never get rid of all of it,” he said. “I’ll always have something.”

Researchers found that medications used to treat mental illnesses like obsessive compulsive disorder are not successful treatment options for those dealing with compulsive hoarding.