Why do elderly hoarders present challenges for social workers, and what intervention strategies can be used to address these challenges?

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Introduction
Upon approaching the house for the first time visible signs of neglect were evident. Paint was peeling off the woodwork, gutters were broken, shutters were missing on some windows, bushes were overgrown and beginning to creep through gaps in the structure, and cats of various sizes, colors and ages were scurrying about. The front door could only be opened partially because of the pile of boxes behind it. The hallway and stairs contained piles of newspapers, mountains of clothes, and discarded food containers. Narrow pathways led from one room to the next, each containing further piles of household items, and the floor squelched with each footstep over decaying food and cat feces. A strong odor of urine and decay penetrated the nostrils.

This scenario is not untypical of what social workers or emergency responders might encounter on their first visit to the home of an elderly hoarder. The challenge, from a social work perspective, is what to do about, and whether anything should be done about it. Hoarding is not a new phenomenon, and over the past thirty years numerous detailed studies have been conducted and reports written on the subject. It has also attracted media attention and television has been used to portray real hoarders in TLC’s reality show Buried Alive (Schwartz, 2012). Although this type of publicity might serve some usefulness in raising public awareness about hoarding, the reality of the situation for hoarders can be emotionally and psychologically disturbing as they experience the ignominy of having their private life on public display.

One of the most famous cases of hoarding became public in 1947 with the discovery of the bodies of Homer and Langley Collyer in their brownstone house in New York. When the police and fire department were eventually able to get into the building they discovered a labyrinth of tunnels, some booby trapped, piles of cans, other assorted trash, fourteen grand pianos, and a Model T Ford. Workers removed over 170 tons of stuff from the house (Frost & Steketee, 2010). The case involving the Collyer brothers is one of extreme hoarding, and it is only a result of detailed research that we begin to understand the complex interrelationship between biopsychosocial principles, and how these can impact upon a person and result in the manifestation of hoarding behavior.

Compulsive hoarding is more than just a collection of items and, untreated, the behavior can have a profound effect on an individual’s physical and mental state, factors exacerbated by increasing age and declining health. Hoarding properties can also become a public health hazard resulting from the risk of fire, disease and infestation and, if the hoarding property is close to or adjoining other homes, the health and welfare of neighbors can also be affected.

A working definition of compulsive hoarding (Frost & Hartl, 1996) is:

- the acquisition of, and failure to discard, a large number of possessions,
- living spaces sufficiently cluttered so as to preclude activities for which those spaces were designed and,
- significant distress or impairment in functioning caused by the hoarding.
The aim of this paper is to discuss why elderly hoarders present challenges for social workers, and what intervention strategies can be used to address these challenges. Considerable research has been done on the causes of hoarding, different types of hoarding, and consequences of hoarding, but there is less empirical data and published resources to assist social workers in developing effective intervention plans. In part this may be attributable to a lack of financial resources, community attitudes and a fractured response by policy makers.

Throughout this paper I refer to the work of social workers, for it is these professionals who are often at the vanguard of organized response. This does not imply that the role of first responders (e.g., fire and rescue, police), medical and mental health professionals, and town or city officials is any less important.

Federal laws exist to protect the elderly and adults with disabilities (42 USC., Ch. 35, §3002), and each state is mandated to provide adult protective services to respond to allegations of abuse and neglect. Similar laws exist for children, but reference to protective services for children will only be used to explain differences in intervention strategies. Despite the existence of federal laws and adult protective service organizations in each state, there is a lack of uniformity regarding intervention strategies in cases of hoarding. This relates to not only each state, but to cities and counties within states, and urban and rural areas.

This paper is divided into a number of sections beginning with the causes of hoarding. For intervention to have any hope of being effective, it is essential that social workers have a basic understanding of what causes individuals to hoard. Three areas will be covered, obsessive compulsive disorder (OCD), dementia, and Diogenes syndrome. The next section will describe different types of hoarding, including household items and animals. The consequences of hoarding are discussed in section 3, taking account of the impact on the individual, family, community and policy makers, privacy, risk factors, and legal action. The final section will analyze and discuss intervention strategies that can be employed when working with elderly hoarders. This includes case management, public and private agencies, mental health, legal, and families.

Throughout this paper I refer to elderly hoarders, although it is recognized that younger hoarders also exist. Many of the causes, types of hoarding, consequences and intervention strategies are common to both groups.
Section 1 - Causes of hoarding

Obsessive Compulsive Disorder
In order to achieve any meaningful intervention with elderly hoarders, it is necessary to have some understanding of the etiology involved. This knowledge can help formulate intervention strategies, including the possible need for mental health services.

Social workers and other professionals who work with elderly hoarders in their homes need to be sensitive and alert to the consequences of their actions, either deliberate or unintentional. For example, moving an object or picking up a pile of papers from the floor could create severe distress to the hoarder. This may be associated with fears of contamination (e.g., another person touched their possessions), or interfering with their reliance on visual spatial organization (e.g., moving the papers off the floor). Equally, the hoarder might be resentful of the intrusion and embarrassed that the sanctity of their home is being exposed. These examples highlight some of the challenges for professionals during initial and subsequent contact with elderly hoarders.

A number of characteristics differentiate OCD-based hoarding from non-OCD related hoarding. Obsessive behavior, such as the previously mentioned fear of contamination can lead to extreme behavior. One hoarder collected magazines, but over time became concerned about printing flaws in the magazines and searched for perfect copies. She then became concerned that when she paid for it the clerk touched it and left fingerprints, thereby defiling its purity. To compensate she began buying two copies, but continued to be concerned about other people touching the magazines when they put them on the shelves. Her solution was to buy three copies, having also convinced the book store to allow her to open the packing boxes the magazines came in. Her rationale was the middle copy would be completely untouched (Frost & Steketee, 2010).

Superstitious thoughts about discarding items, feelings of incompleteness, and persistent avoidance can also prevail (International OCD Foundation, undated). An example of these three elements is a hoarder who was persuaded to give up a toy yellow swan. But not before she took numerous photographs of the swan, and videotaped and narrated its departure (Frost & Steketee, 2010). In this case the hoarder was trying to preserve ownership through photographs, and utilizing a lengthy avoidance procedure to compensate for the loss she was experiencing.

Hoarders will offer a variety of reasons for their actions, and no matter how unrealistic they might sound or appear they make complete sense to the hoarder and is their form of reference. Avoiding waste is a common motive that results in nothing been thrown away. Amongst the elderly hoarder cohort will be a number who grew up during World War II. They will have been accustomed to rationing and a ‘make-do’ attitude. As they progressed into adulthood these traits might have continued thereby justifying, in their mind, the reason to retain everything.

Another aspect related to the desire to retain objects is the notion that they might still be usable, or that someone else might want them. For example, a rusty watering can with a hole in the bottom. It can no longer be used for its original purpose, but a hoarder could come up with a list of reasons for keeping it (e.g., sentimental value, plans to repair the hole and re-use it, painting it and using it as flower pot). In reality it is unlikely that any of the reasons for keeping it will occur, and it will remain as it is.
Closely associated with these feelings are ones of guilt. If the hoarder had been persuaded to throw out the watering can, they might have agonized and felt guilty about discarding it, and considered the act wasteful.

The same applies to newspapers, magazines, brochures, etc. A hoarder will commonly say it is their intention to read all the materials, in the belief there will a piece of information they can use, or pass on to someone else. Invariably the materials remain unread and the piles grow larger.

Research into the cause of hoarding indicates that hoarders tend to demonstrate a lack of awareness of their behavior. They attempt to rationalize their acquiring and hoarding habits as normal, and will often resist intervention (Steketee & Frost, 2003). In studies involving friends and family members of hoarders, they report the hoarder as having poor insight or delusional (Tolin, Frost, Steketee, Fitch, 2008). This is not an uncommon response and, from personal experience, family members have expressed feelings of frustration and impotence about the situation. To them the solution is simple; go in and remove all the clutter. As will become apparent later in this paper, such action can have unforeseen and fatal consequences.

Recent studies of the causes of hoarding behavior have been extended to examine how specific areas of the brain function. The outcomes of these neuropsychological tests have identified specific activities that hoarders experience difficulty with, all of which suggest abnormal brain activity in the frontal lobe (Tolin, undated). The findings indicate that hoarders:

- experience difficulty sustaining attention,
- experience diminished non-verbal attention, variable reaction time, and greater impulsivity,
- experience poor memory and retain certain possessions out of fear they will forget important information and,
- organize and find items using visual spatial recall, instead of categorized recall.

These findings are useful in providing insight and explaining possible causal factors of hoarding behavior, but require further research. If abnormal frontal lobe activity is identified, this might be indicative of a pre-disposition toward hoarding behavior, but could also be related to other mental health disorders.

A number of recent studies indicate that co-morbidity among hoarders exist, and is associated with a variety of personality disorders (Samuels, 2008). The most common of these is Major Depressive Disorder (MDD) (Frost, Steketee, Tolin, 2011), but Generalized Anxiety Disorder (GAD) and social phobia has also been identified (Tolin, Meunier, Frost & Steketee, 2011). The result of these studies is leading researchers to believe that hoarding is not a subtype of OCD, but is a condition on its own. Nevertheless, the rate of OCD in hoarding is higher than in the general population suggesting there are elements of the disorder that remain related to OCD (Frost, Steketee, Tolin, 2011).
The American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders, 1994 (DSM-IV) (text amended in 2000), currently lists compulsive hoarding only as a symptom of OCD. As a result of the recent studies and research suggesting hoarding may be a distinct mental disorder; it has been recommended that hoarding be included in the DSM-5 using the following criteria, Figure 1:

| A. Persistent difficulty discarding or parting with possessions, regardless of their actual value. |
| B. This difficulty is due to a perceived need to save the items and distress associated with discarding them. |
| C. The symptoms result in the accumulation of possessions that congest and clutter active living areas and substantially compromise their intended use. If living areas are uncluttered, it is only because of the interventions of third parties (e.g., family members, cleaners, authorities). |
| D. The hoarding causes clinically significant distress or impairment in social, occupational, or other important areas of functioning (including maintaining a safe environment for self or others). |
| E. The hoarding is not attributable to another medical condition (e.g., brain injury, cerebrovascular disease, Prader-Willi Syndrome). |
| F. The hoarding is not better accounted for by the symptoms of another DSM-5 disorder (e.g., hoarding due obsessions in Obsessive-Compulsive Disorder, decreased energy in Major Depressive Disorder, delusions in Schizophrenia or another Psychotic Disorder, cognitive deficits in Dementia, restricted interests in Autism Spectrum Disorder). |

**Specify if:**

*With Excessive Acquisition:* If symptoms are accompanied by excessive collecting or buying or stealing of items that are not needed or for which there is no available space.

*Indicate whether hoarding beliefs and behaviors are currently characterized by:*

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

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

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

Figure 1 - Source: American Psychiatric Association DSM-5 Development
If the proposed revisions are approved and included in the DSM-5, it is unclear at this time how many of the criterions would be required to diagnose hoarding disorder. This also raises questions of intervention at a clinical level, and whether mental health professionals will require additional or specialized training for the diagnosis and treatment of Hoarding Disorder (HD). For social workers, family, or other professionals, a diagnosis of HD will help understand the hoarder’s complex feelings, emotions and behaviors. This can go some way toward developing appropriate intervention strategies.

Dementia
There is a paucity of research on dementia related hoarding, and existing studies have focused on elderly residents in long-term care settings (e.g., nursing home and assisted living facilities). Although the focus of this paper is on community-based hoarding, dementia and hoarding is included to stress the importance of obtaining accurate diagnoses and family history. In cases where hoarding behavior preceded the onset of dementia, this knowledge can greatly assist long-term care staff to understand and respond appropriately.

The most commonly reported hoarding behaviors among long-term care residents with dementia are rummaging through other resident’s possessions, and acquiring and hiding food, trash, newspapers or magazines (Hwang, et al, 1998). It is conceivable that the onset of dementia did not trigger hoarding tendencies, but merely accentuated previous and possibly undiagnosed or unreported, hoarding behavior (Pertusa, 2010). The evidence supporting this hypothesis is limited and would benefit from longitudinal studies.

Diogenes syndrome
Diogenes syndrome, also known as senile breakdown, social breakdown and senile squalor syndrome (Rosenthal, et al, 1999), is considered a behavioral disorder of the elderly. Existing research suggests it is difficult to diagnose, but it has been theorized that OCD may be the cause in cases involving hoarding behavior which cannot be explained by other psychiatric disorders or dementia.

Although there continues to be some debate about diagnostic criteria, schizophrenia paranoid type, bipolar disorder, compulsive disorders and chronic alcohol abuse have all been associated with Diogenes syndrome (Hanon, et al, 2004; Rosenthal, et al, 1999). Some of the symptoms associated with generalized hoarding are similar, but there are also extreme differences. Among the hoarding population it is not uncommon for hoarders to have jobs and to socialize. The same is not true for those elderly hoarders with Diogenes syndrome. Their common characteristics include living in extreme squalor, neglecting their physical state, unhygienic conditions, self-imposed isolation, tendency to accumulate unusual objects, and refusing the offer of intervention (Hanon, et al, 2004). Most live alone, the syndrome affects both men and women, and the average age range is 60 – 90 years (Rosenthal, et al, 1999).

Individuals with Diogenes syndrome also tend to be suspicious of outsiders, and have poor social integration skills. When their hoarding behavior is detected, it can accelerate a further breakdown of their personal and environmental hygiene. Implicit in the literature is the description of a recluse who has withdrawn into his ‘own world’ which will make it ethically challenging for social workers and other professionals to intervene, or whether they should.
Section 2 - Types of hoarding

In Section 1 the discussion focused on causes of hoarding, and provided an overview of how specific mental health disorders (e.g., MDD, GAD, social phobia, and OCD) can result in hoarding behavior. The interrelationship between these mental health disorders can assist to understand not only why people might develop hoarding behavior, but also how and what they hoard. Two specific types of hoarding will be discussed in this section; household items and animals. Taken individually, they present challenges, but when combined the risk factors to humans and animals increase significantly.

Household items

Any mention of the word ‘hoarding’ tends to conjure up images of piles of accumulated objects, with no apparent organization, and is characterized by the inability to utilize rooms and utilities for their original and intended purpose. It is estimated that severe hoarding can affect 92 – 96% of living rooms, dining rooms, kitchen and bathrooms; 87% of hallways; 75% of bathrooms, and 57% of stairways (Steketee et al., 2001). Studies of hoarding households have identified seven types of clutter that are the most common (Steketee et al., 2001). In more extreme cases hoarders have even been known to hoard urine and feces (Clairborn, 2006). Figure 2 is an example of an over-cluttered kitchen.

- Newspapers
- Paper products (e.g., magazines, brochures, junk mail, catalogues)
- Books
- Containers (e.g., cans, bottles, cardboard)
- Clothing
- Food
- Trash

Figure 2 - Example of a hoarder’s kitchen. Source: http://chicagotribune.com
The picture in Figure 2 illustrates the impact the behavior can have. The work surfaces are completely covered with jars and assorted food containers, the sink is unusable for the purpose it was intended, and paper on the floor in front of the stove increases the risk of fire. To a non-hoarder, this picture might suggest chaos and disorganization, but a hoarder’s perspective is likely to be very different. If they are using spatial recognition as a point of reference, they might argue that it is easier to locate a particular jar or food item because they are all on display and not hidden in cupboards where they might be forgotten. They might claim to wash dishes only once a week, thereby saving water and electricity, ergo being environmentally friendly. Although these are excuses, to a hoarder they are genuine issues.

It is not uncommon for hoarders to believe their collection is valuable, or that others might consider it valuable, and is therefore worth keeping. This is associated with delusional thoughts, but they are very real to hoarders, and can cause extreme distress when their possessions are interfered with in any way. This persistent difficulty discarding and perceived need are both addressed in the proposed inclusion of hoarding disorder as a separate mental health diagnosis in the DSM-5 (American Psychiatric Association, 2012).

Researches about the type of things hoarders collect indicate a wide variety, even within the seven most common types. Current research is now examining the methodology of hoarding, specifically active and passive acquisition. Findings indicate that between 80 and 95% of hoarders actively acquire possessions, including compulsive buying and free items (Frost et al., 2009). In contrast, passive acquisition suggests hoarders simply allow trash, mail, papers, etc., to accumulate (Frost et al., 2011).

Both forms of acquisition are indicative of deficits in processing information, decision making, and organizational abilities (Frost, et al., 2011). Recognizing the difference is important and can better inform and direct a social worker or other professional in developing appropriate intervention strategies.

Hoarders who actively acquire possessions are likely to be more difficult to work with because of underlying obsessive compulsive behavior. Personal experience of hoarders who acquire actively has found them to express intense connectivity with their possessions. Some have described a sense of security from being surrounded by their possessions, and one elderly hoarder used the analogy of them being like the walls of a castle.
Animals
Hoarding is not confined to objects though, and among this cohort are those who hoard both objects and animals. Both types of hoarding contain similarities and differences in relation to the amount of clutter, disorganization, and difficulty discarding (Frost et al., 2011). One major difference is that hoarders of both objects and animals can incur significant increases in neglect, and deterioration of the health, and well-being of both themselves and the animals. The pathology regarding animal hoarding is unclear, but some researchers have suggested it may be a form of OCD associated with attachment and personality disorders or likened to gambling, compulsive shopping or substance abuse habits (ASPCA, 2010a; Hayes, 2010).

The prevalence of animal hoarding is high and it is estimated that 700 – 2,000 new cases are detected each year in the U.S. (Frost et al., 2011; ASPCA, 2010a). There is some controversy regarding gender distribution of animal hoarders, although research indicates it is more common among women. A 2001 – 2002 study conducted by the Hoarding of Animals Research Consortium (HARC), found instances of animal hoarding among 73.3% of females between the ages of 50 – 59. This compared with 33.3% for men in the same age range (HARC, 2002). One possible explanation for this variation might be female nurturing tendencies.

The ASPCA uses the following criteria to define animal hoarding (ASPCA, 2010a):

- More than the typical number of companion animals
- Inability to provide even minimal standards of nutrition, sanitation, shelter and veterinary care, with this neglect often resulting in starvation, illness and death
- Denial of the inability to provide this minimum care and the impact of that failure on the animals, the household, and human occupants of the dwelling

A significant difference between object and animal hoarding is the level of sanitation. Research indicates that squalor among object hoarders is minimal (Rasmussen, et al., 2010), whereas it is nearly 100% evident in homes of animal hoarders (Patronek, et al., 2009). This increase is usually associated with high concentrations of animal feces throughout the home, and urine soaked surfaces. Furthermore, the existence of unhealthy, dead, and decomposing animals adds to the squalor and risk of disease and infection. Despite these clear signs of neglect, animal hoarders continually exhibit a lack of insight and will frequently resist attempts by the authorities to remove their animals. Although the action of animal hoarders is detrimental to the health and well-being of animals, it has been suggested that their motivation is not to cause harm. Some perceive their action as performing a public service by providing a shelter for them (Hayes, 2010). Control and delusional ideations are major factors here, and animal hoarders perceive they are the only ones capable of caring for their animals (Frost, et al., 2011) even when presented with evidence of their neglect.

Studies relating to the acquisition of animals indicate similarities to the active and passive approach to acquiring objects (Patronek, et al., 2006). Active acquisition implies a ‘mission-driven’ approach (Patronek, et al., 2006), that can involve advertising for unwanted pets, collecting animals from legitimate shelters, and removing animals from off the streets.
Passive acquisition results from a failure to have animals spayed and neutered, thereby allowing excessive breeding to occur (Frost, et al., 2011). This may be partly due to health, physical and financial limitations, or a belief that such intervention is interfering with the laws of nature. Whether the acquisition is active or passive, the resultant neglect will still occur.

It has been well documented that hoarders of objects form an attachment to their possessions, but in cases of animal hoarding the attachment is more extreme and excessive (Nathanson, 2009). Examples include attaching human-like qualities to the animals and referring to them as family members; the belief that animals possess the same characteristics and intelligence as humans and; the belief they are able to communicate with their animals (Nathanson, 2009; Frost et al., 2011). These excessive and emotional beliefs make it more difficult and challenging for social workers and other professionals to intervene. This is primarily due to the emotional attachment, lack of insight, and belief that only the hoarding person can provide the appropriate level of care for the animals. These feelings can remain extant even when presented with evidence of their gross neglect.

The detection of active or passive animal hoarders is usually easier to identify than cases involving solely object hoarding. The most obvious sign will be the presence of a large number of animals, and their appearance can also provide useful clues. Other indicators include the condition of the home (e.g., broken windows, strong smell of ammonia, feces, rodent and/or insect infestation) (ASPCA, 2010a).

Studies have found that among active hoarders are those who often pose as rescue groups or sanctuaries (ASPCA, 2010). This suggests a strong obsessional compulsion to acquire, rather than a genuine interest in providing a safe shelter for animals. In an attempt to deceive the public regarding their legitimacy, many hoarders are using a 501(c)(3) not-for-profit label as a cover. They will also go to great lengths to avoid allowing potential animal adoptees to visit their home. Indicators of a bogus shelter include (ASPCA, 2010a):

- Unwillingness to disclose the number of animals in its care
- Minimal effort made to find homes for the animals
- More animals are taken in, despite the poor condition of existing ones
- Legitimate shelters and rescue organizations are viewed as the enemy
- Animals are usually received at a remote location

An example of this was a ranch advertising itself as a cat sanctuary which was discovered to have nearly 700 cats living in severe neglect. Many of the animals had upper respiratory conditions, eye infections, and other medical issues. Filth was prevalent, and sick and healthy cats were not segregated to prevent cross-infection. Twenty-nine dead and decomposing cats were found on the property (ASPCA, 2012b). Figure 3 illustrates the impact such neglect can have.
Although laws exist within each state addressing animal cruelty, Illinois and Hawaii are the only two states having laws specifically relating to animal hoarding. Legal issues will be covered in more detail later in this paper.
Section 3 - Consequences of hoarding

In section 1 causes of hoarding were discussed to obtain a better understanding about the obsessive characteristics and belief systems that are inherent among hoarders. They help us to make sense of the complex, and often interrelated, cognitive processes, and the need for sensitivity and understanding. It is an attempt to see the world from the hoarder’s perspective; to understand their fears, concerns and values as social workers and other professionals seek to engage with them.

The causal effects of mental health disorders (e.g., OCD, MDD, GAD, and social phobia) were covered in section 2 in relation to object and animal hoarding. This provided insight to the active and passive methodology of acquiring objects and animals, including the covert action employed by many hoarders of animals.

This section examines the consequences of hoarding behavior by the elderly, and the effect it also has on family, community and animals. It begins with a discussion about ‘invasion of privacy.’

For the elderly

Hoarding is not a new phenomenon, but is a subject that has attracted considerable research over recent years and generated copious studies. These studies have enabled us to gain a deeper understanding of the underlying psychosocial aspects of hoarding and, armed with this knowledge; social workers and other professionals are better informed and prepared for their engagement with elderly hoarders.

As individuals we tend to have a strong propensity for maintaining our privacy and right to self-determination. These are intrinsic values and uninvited intrusions can upset them, causing considerable stress. In social work parlance, many hoarders have been “flying under the radar” for years. Their behavior has gone undetected, been ignored, condoned or enabled in some manner. It requires only one incident or report to destroy this anonymity and for the hoarding behavior to be in the public domain.

A study conducted by Steketee, Frost & Kim (2001) found that 73% of referrals to service providers were generated by another agency, and referrals from family, neighbors or anonymous complainants, accounted for 21%. They suggest that the high percentage of referrals from other agencies is indicative of the long-standing hoarding behavior. Anecdotal knowledge supports this theory and, in some cases, the hoarding behavior has been going on for more than 20 years.

Invasion of privacy is ultimately a consequence of hoarding behavior, and individual reaction to any intrusion will vary considerably depending on the type and form it takes. Some hoarders might express embarrassment, but it is speculated that hoarders’ main concerns will be the fear of other people touching and disturbing their valued possessions (i.e., contamination). The absence of embarrassment could be attributable to the lack of insight that manifests itself with hoarding behavior. Hoarders are known to derive pleasure and feelings of safety from their possessions, and form strong attachments to objects. Consequently, this is ‘normal’ and is not something to be embarrassed about.
The effect on hoarders’ physical and mental health and personal safety resulting from their behavior has been extensively researched. Findings consistently draw similar conclusions about the damaging impact of excessive hoarding, a fact that is frequently ignored or overlooked by hoarders. Hoarding behavior by the elderly is, by definition, a form of adult abuse, specifically neglect or self-neglect. According to the Virginia Department of Social Services (2011), indicators of neglect include “malnourishment, dehydration, the presence of pressure sores, inadequate personal hygiene, inadequate or inappropriate clothing, inadequate or inappropriate supervision, extreme filth of person or home, severe pest/rodent infestation, offensive odors, inadequate heat, lack of electricity or refrigeration, and untreated physical or mental health problems.”

Despite these indicators personal experience finds that most hoarders ignore the risk factors and develop compensatory and survival techniques. There is an absence of evidence to indicate that the risk of fire is adequately considered, or plans for evacuation in the event of a fire. A study by Steketee, Frost & Kim (2001) found that in 45% of cases combustible materials constituted a fire risk. Blocked air vents and doors, unsafe heaters, faulty electrical wiring, close proximity of heating appliances to combustible materials, and smoking, all significantly increase the risk of fire. Anecdotal knowledge has found hoarders turning their oven on and leaving the oven door open to generate heat, while at the same time the floor was covered with newspapers.

The restricted ingress and egress caused by excessive clutter impacts not only on hoarders, but also risks the safety and lives of emergency services personnel (e.g., fire and rescue). Narrow pathways restrict access in the event of an emergency, and piles of clutter can become unstable and fall upon and trap hoarders and first responders.

As the following chart illustrates (Figure 4) the excessive accumulation of clutter also impinges on the ability to access and utilize areas of the home, thereby increasing the health risks.

![Consequences of Hoarding Chart](chart.png)

Figure 4 - Adapted from: Steketee, Frost & Kim. Hoarding by Elderly People (2001)
The risk of falls and injury is a constant and inherent danger. If an individual’s gait is already unsteady and requires the use of a mechanical device to assist with mobilizing, the likelihood is that the narrow pathways preclude the use of such devices. Resorting to furniture walking, which is often the only option, further increases the risk of piles of clutter shifting and falling to create obstacles. Approximately 80% of hoarders in a study expressed severe to substantial difficulty mobilizing about their home (Steketee, Frost & Kim, 2001).

Physical appearance, sanitation, and the ability to store and prepare food can also be affected by the hoarding behavior (Figure 5). Bathrooms and sinks become unusable or inaccessible, toilets no longer function, and the supply of water might have been turned off (Figure 6).

![Figure 5 – Hoarder’s fridge. Source: http://www.wjla.com](http://www.wjla.com)

![Figure 6 – Hoarder’s bathroom. Source: http://izismile.com](http://izismile.com)
These pictures illustrate the severity of hoarding behavior and the level of self-neglect that becomes a co-component of it. Without adequate storage facilities food can quickly perish and, if not discarded, increase the risk of becoming rotten and attracting rodents and insect infestation. The inability to store and prepare food can also result in increased dependency on canned or ready-prepared meals, or eating out on a regular basis. This in turn can result in increased financial burden and obesity (Neziroglu & Bubrick, 2006 – 07).

The inability to access and use bathroom and washing facilities is frequently due to their use as storage receptacles. In a study of 62 cases in the Boston area the findings indicated that nearly two-thirds had difficulty with personal care, to the extent of being extremely dirty with filthy hair, blackening to the skin and soiled clothing (Skeet, Frost & Kim, 2001). However, within this same study 44% of service providers reported that the hoarding behavior did not interfere with personal hygiene. There are a number of possible explanations to account for this. The first is compensatory and survival skills mentioned earlier. Although bathrooms are frequently overrun with clutter, anecdotal knowledge has also found instances in which these rooms are clutter free and functional. Second the acquisition of potable water in containers that is used for washing. And third, a combination of potable water and weekly visit to a motel for the purpose of showering.

The effect of hoarding behavior on physical health and personal safety cannot be overstated. Although mental health disorders can help to understand and offer explanations for the behavior, it is unclear why so many elderly hoarders neglect their personal health. Further studies are needed to examine this facet in more detail. It is possible that the reluctance to seek medical attention includes lack of insight, lack of health insurance, lack of financial resources, and the stigma attached to mental health by the elderly in general. It is also theorized that visiting a health professional could draw unwanted attention to their self-neglect and result in a referral to the authorities; something hoarders would wish to avoid.

Over a period of time the accumulation of rotting food, spilt liquids, dust and debris, urine soaked floors and decaying feces, can result in respiratory problems, headaches and allergies (Neziroglu & Bubrick, 2006 – 07). In addition the cumulative effect of the weight from excessive hoarding materials can compromise the structural integrity of floors, causing them to collapse.

The risk of rodent and insect infestation is extremely high in hoarding homes. Food can become contaminated and act as a breeding ground for insects and if feces is present, human and/or animal, the risk increases exponentially. Rodent and insect bites can cause disease and infection, which if left untreated could have severe and possibly deadly consequences.

The effect hoarding has on the mental health of elderly hoarders is difficult to determine because of pre-existing conditions. In other words, the most common disorders associated with hoarding; MDD, GAD, OCD and social phobia (Frost et al., 2011; Tolin, 2011) are likely to be causal factors of the behavior. What we do know from studies is the intense attachment hoarders develop toward their possessions, and any disruption or interference could lead to a destabilization in their ability to function and possibly exacerbate depressive tendencies.
Studies of elderly hoarders indicate that social isolation is often preferred and may be related to social phobia. However, there are also cases involving hoarders who are married, with the non-hoarding spouse seemingly having no control over the behavior and reluctantly accepting it. Although in some instances it can lead to separation and divorce (Neziroglu & Bubrick, 2006–07).

It is theorized that in many instances elderly hoarders prefer social isolation because it provides them with privacy and enables them to acquire, actively and/or passively, without necessarily drawing attention to their behavior. The term social isolation is used in two overlapping contexts. One is the deliberate withdrawal into the sanctity of the home; the other is a geographical context in which hoarders live in remote areas, often some distance from their nearest neighbor, or shielded from view. Hoarders who live in remote areas are generally harder to detect, and the collection of objects frequently extends beyond the confines of the home and can include larger and more assorted objects (e.g., fridges, stoves, tools, cars). Anecdotal knowledge of a geographically isolated hoarder found over 20 cars, many of them vintage, scattered about the property. In another case involving anecdotal knowledge, an elderly hoarder used social isolation as a defense mechanism, although it is unclear whether this was an excuse for avoiding taking action to de-clutter, or perceived feelings of security derived from being surrounded by familiar possessions. Following a number of unsuccessful marriages, the elderly hoarder intimated that the hoarding averted having to invite anyone into her home; therefore avoiding the risk of engaging in a relationship and being rejected.

Suicide and death resulting from hoarding behavior is both tragic and often avoidable. There is limited research on the subject of hoarding related suicides, and is an area that would benefit from further study. Existing literature tends to be produced by the media, and is commonly associated with suicide following compulsory clean-up of hoarders’ homes. Similar findings of hoarding related suicide were reported by Frost & Steketee (2010). This raises concerns about sensitivity and respect as staff from clean-up companies or local authorities scoop up belongings and deposit them on the sidewalk or remove them to local dumps (Figure 7).

In 2010 a woman living in Washington DC was evicted from the apartment she had rented for 15 years for failure to pay her rent. She had been unemployed for two and a half years, owed the landlord $10,096, but was unable to pay the $1,318 monthly rent in addition to a payment schedule of $300 a month. The woman’s 30,000 pounds worth of possessions were removed from the apartment and dumped on the sidewalk (Vargas, 2010).

These situations leave hoarders feeling violated and without a form of reference that is an integral part of their life. It is conceivable this caused considerable embarrassment and unwanted publicity, in addition to affecting the woman’s cognitive state. Her possessions were effectively discarded and, if reliant on visual spatial recognition, this would have been disrupted. Similarly, feelings of attachment would have been affected if other people touched her belongings; thereby increasing levels of stress, anxiety and risk factors for suicide.

An equally important factor is that compulsory clean-ups’ remove the clutter, but without appropriate follow-up intervention, they fail to address the underlying cause of the hoarding behavior.
Death resulting from excessive hoarding is frequently the result of unstable ‘mountains’ of clutter falling and trapping hoarders’ beneath the piles. The cause of death in these situations is often asphyxiation and/or dehydration. In some cases even the presence of another person living in the home is insufficient to locate a hoarder amidst excessive clutter. The body of a 67 year old female hoarder lying beneath a ‘labyrinth of squalor’ was eventually found by her husband four months after she was reported missing. Search dogs used in the aftermath of 9/11 had been unable to detect her presence among the piles of debris (Garcia, 2010). In another case that exemplifies the risk factors, it took police in the U.K. two days to locate the body of a 77 year old spinster trapped beneath a pile of suitcases that had fallen on top of her (Tozer, 2009).

Studies indicate that legal action in relation to cases of hoarding varies considerably according to state laws, local ordinances and, to some extent, community standards and values. There is an interesting paradox here. Hoarders generally do not seek or welcome intrusions into their life and home. Yet the action of their hoarding behavior can result in utility bills and rent not being paid, thereby drawing unwanted attention. Ultimately, the supply of utilities might be cut off, and the non-payment of rent could result in eviction, as described in the example of the Washington DC woman.

Another example is employed hoarders who continually stop on their way to work to acquire new things. They become so obsessed and distracted that they never make it to work. Ultimately they lose their job and source of income, and are no longer able to pay bills, rent, or mortgage and risk eviction and foreclosure (www.hoarding.advisor.com, 2010).
Empirical data relating to fines is minimal, but appears to reflect community standards and geographical location of hoarding properties. Hoarders in densely populated urban areas, which tend to have a higher number of enforceable ordinances, are more likely to incur fines, than those living in remote rural locations. However, fines are not necessarily limited to the physical condition of hoarders’ homes, but are also causal factors of the hoarding behavior. The excessive accumulation of papers, mail, bills, etc., can result in important documents being lost among the clutter. A study by Tolin et al., (2007) found instances of hoarders who had failed to file income tax returns in at least 1 of the previous 5 years. Apart from increasing the financial burden on hoarders it also demonstrates the intense emotional attachment to possessions, impaired executive functioning, and lack of insight regarding the causal effects of hoarding behavior.

Anecdotal knowledge indicates that fines, particularly in rural communities, have limited impact in preventing hoarding from continuing. In cases where legal action has occurred and local authorities have instigated compulsory clean-up, a lien on the property is often the result. Access to financial resources might be limited, although not in all cases. By attaching a lien to a property the local authority is effectively seeking to recover unpaid taxes, fines or monies used for clean-up operations. Invariably, recovery of the lien takes effect when the property is sold, foreclosed upon, or the hoarder dies.

The loss of property, possessions and compulsory clean-up are consequences that can ultimately befall elderly hoarders. Failure to pay rent or mortgage breaches of tenancy contracts, complaints by neighbors, homes that become uninhabitable and are condemned; are some of the factors that hoarders wish to avoid, yet seem powerless to prevent in many instances.

Such action can have far reaching consequences for elderly hoarders that increase the social burden on communities, let alone the psychological impact on displaced hoarders. The strong feelings of attachment hoarders experience will have been violated. Their points of reference lost as they watch piles of their possessions unceremoniously removed and deposited on the sidewalk or placed in dumpsters. If eviction occurs as a result of compulsory clean-up the opportunity to obtain future rental properties will be more difficult because of prior rental history. For those elderly hoarders on low, fixed incomes; homeless shelters might be the only option.

However, laws are in place to safeguard tenants and prevent illegal evictions. The Fair Housing Act of 1968, as amended, prohibits housing discrimination (www.FEMA.gov) and landlords cannot begin termination and eviction procedures without first providing tenants with written notice. The laws describing the process to end a tenancy agreement varies from state to state (www.nolo.com), details of which are beyond the scope of this paper.

Family
The impact of hoarding on family members creates tension, frustration, embarrassment, resentfulness and hopelessness (Neziroglu & Bubrick, 2006 – 07) as functional areas of the home reduce in size from the excessive accumulation of clutter. A number of studies have examined the impact of hoarding on children, but a detailed discussion of them is also beyond the scope of this paper.
Situations do exist though in which elderly hoarders also occupy the same home as younger adults and children. This can further add to the stress, financial burden, resentment and health and welfare of the occupants. In addition to the potential of attracting adult protective services social workers, the presence of young children can also result in child protective services being involved. As previously mentioned, state laws regarding protective services vary, but hoarding situations in which young children are present could, and do sometimes lead to the removal of the children from the home. Such action can increase existing levels of stress, anger and frustration, but also act as a strong incentive to de-clutter to enable children to be reunited with their family. However, without adequate follow-up intervention the risk of recidivism is high; which is similar to findings involving only elderly hoarders.

There is evidence that hoarding behavior is tolerated in return for companionship and assistance with personal care (HARC, 2002). Anecdotal knowledge supports this theory and similarities have also been found in cases involving neglect or financial exploitation by family members. The ability to maintain freedom and contact with abusers outweighs the consequences of their actions.

Estrangement from family is not uncommon among elderly hoarders, and is usually a result of conditions within the home. The excessive accumulation limits the opportunity to socialize and family members are often too embarrassed to visit, or acknowledge the existence of a hoarding relative. It is also theorized that as the hoarding behavior intensifies over time, so too do the feelings of attachment. Consequently, hoarders may not welcome visits from family or friends out of fear they will touch and contaminate their possessions or, in more extreme cases, a fear that objects will be stolen. An example of this intense emotional attachment hoarders assign to their possessions is a woman who equated someone underlining passages in her book with being sexually assaulted (Grisham et al., 2009).

Community
The consequences of hoarding on the community varies considerably, according to the severity, the impact or potential impact on neighbors, environmental damage and location of hoarding properties. The impact from hoarders living in remote rural areas is considerably less than hoarders residing in heavily populated urban locations. The largest and most threatening impact is likely to result from hoarders living in townhouses and apartments. The close proximity to neighbors increases the risk of contamination from rotting food, rodent and insect infestations, mold and fungus, structural damage and fire.

However, it is conceivable that hoarders in rural communities might present a different environmental threat. Rural properties mostly receive their water from wells, and some older homes may lack indoor plumbing or toilet facilities. Consequently, buckets are often used to contain urine and feces, the contents of which are emptied about the property. Over time the waste seeps into the ground thereby risking contamination of the well water. Anecdotal knowledge has found this practice to be common in rural settings. Conversely, it is theorized that this practice is less likely to occur in heavily populated urban areas where it would draw unwanted attention.
Earlier in this section I alluded to hoarders “flying under the radar.” They do not seek attention, but ultimately risk attracting attention from the community as a result of their hoarding behavior. When this does occur multiple agencies may become involved, the extent of which will vary. A study by Steketee et al., (2001) identified a number of community agencies that could potentially respond when hoarding behavior is detected (Figure 8).

<table>
<thead>
<tr>
<th>AGENCIES</th>
<th>PERCENTAGE</th>
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<tbody>
<tr>
<td>Health Services</td>
<td>52</td>
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<tr>
<td>Health Departments</td>
<td>49</td>
</tr>
<tr>
<td>Mental Health Services</td>
<td>45</td>
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<tr>
<td>Fire Departments</td>
<td>30</td>
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<tr>
<td>Police</td>
<td>23</td>
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<tr>
<td>Elder at risk services</td>
<td>21</td>
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<tr>
<td>Council on Aging</td>
<td>13</td>
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<tr>
<td>Housing Authority</td>
<td>11</td>
</tr>
<tr>
<td>Legal Services</td>
<td>8</td>
</tr>
<tr>
<td>Animal Welfare</td>
<td>3</td>
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Figure 8 - Adapted from Hoarding by the elderly: Steketee et al., (2001)

At the point where multiple community agencies become involved the relative anonymity that hoarders seek comes to an abrupt end. They risk losing control of their lives as well as their possessions and homes.

Depending on state and local ordinances, health and fire departments have the potential for condemning properties; actions that could lead to eviction. Conversely, these same departments may resort to legal action that requires hoarders to bring their homes into compliance with health and safety codes (Schmalisch, undated). This effectively places the onus on hoarders to comply, but it is theorized that without additional professional support the likelihood of success is limited. Hoarders may be resistant to change, fail to acknowledge the consequences of their actions, procrastinate; or lack the financial and cognitive abilities to take necessary remedial action.

According to Schmalisch (undated) there is evidence that judges and lawyers across the U.S. are beginning to recognize that the legal system can be instrumental in supporting change through better understanding of hoarding as a social and personal problem. This is a positive and humane response that seeks to respect and protect the rights of hoarders.

The economic impact of hoarding on the community is harder to quantify due to a lack of any large scale research on the subject (Tolin et al., 2007). However, in one case a small health department spent most of its $16,000 budget clearing out a hoarding house, only to have the same problem re-emerge 18 months later (Frost et al., 2000). This serves to illustrate the quandary facing many local government agencies, particularly those in rural and less populated areas.
A further economic impact, and one that appears to lack any detailed research on, is real estate. It is theorized that knowledge of an existing or former hoarding house in a neighborhood could adversely affect property values. This in turn could result in reduced tax revenue for a community.

It is further suggested that hoarders who live in apartments can have a greater impact on economic values. The potential for structural damage, mold, fungus and infestation affecting neighboring apartments could result in tenants moving out and costly renovations occurring. Landlords might seek to increase rents to recoup this additional expenditure.

There is an increasing number of hoarding task forces being created across the country, particularly in urban areas. This topic will be discussed in more detail in Section 4, but the economic impact of sustaining these forces, with their multi-agency composition is likely to be considerable.

Animals
In section 2 animal hoarding was discussed as one type, with examples of the extreme conditions that can often result from this behavior. Squalor in cases of animal hoarding is nearly 100% (Patronek; Nathanson; 2009) and represents a major health problem for both humans and animals (Figure 9). However, studies indicate that the response to animal hoarding and the consequences lacks a consistent approach across the country.

Figure 9 – Cat hoarding (a). Source: http://www.cbsnews.com
Animal hoarding is a severe form of self-neglect, and at its worst it can cause extreme suffering and death to the animals. Yet cases exist where health agencies effectively ‘looked away’ or discontinued their involvement after determining hoarders’ failed to meet the criteria to establish mental incompetence (Patronek, 1999; HARC, 2002). One such case involved a woman named Vicki Kittles who traveled across the country in a school bus containing 115 dogs. When officials recognized the extent of the hoarding, their response was to give her money for a tank of gas and told to leave town (Marquis, 1996). In another case an environmental officer reportedly stated “The only exterior problem was odor, which is not a health hazard to the community. Her home is her domain and she can live as she wishes” (HARC, 2002).

These attitudes suggest indifference by communities to animal hoarding, and it is theorized this might be due to two main factors; legal and economic. Studies indicate that agencies are unclear about the legal route to adopt and rely on broad anti-cruelty laws. These laws mandate that owners must provide animals with adequate food, water and shelter, but leave room for interpretation (Berry et al., 2005). Officials are often unclear about using the legal system to address the hoarding behavior and in taking action that would be in the best interests of the animals (Berry, et al., 2005). Ultimately, this could result in no action being taken, thereby enabling the hoarding to continue.

The economic impact relates to both the costs of legal action and the removal and boarding of impounded animals. The example of the small health department that spent nearly its entire $16,000 budget highlights the dilemma many smaller communities face in deciding whether to respond to cases involving animal hoarding. In another case 16 dogs, 5 cats and 3 squirrels were being hoarded inside a home, in a vehicle and tied up outside. There was no food or water and the animals were living among urine and feces. The hoarder escaped prosecution in exchange for the animals. Three years later 37 dogs, cats and chickens were removed from the same property, again without prosecution in exchange for the animals. Four years after the second incident 20 emaciated dogs were removed from inside the home and legal action was taken (Berry et al., 2005). These two examples illustrate the challenge facing communities in relation to cases of animal hoarding; but they also exemplify the lack of any consistent response that seeks to hold animal hoarders responsible for the consequences of their action.

The homes in which animal hoarding occurs typically result in excessive accumulation of animal feces and urine. Together they increase the risk of structural damage, mold, fungus, rodent and insect infestation; as well as risking the health of occupants, social workers and other professionals. The environment can create a toxic atmosphere, sometimes necessitating the wearing of protective clothing and breathing apparatus (HARC, 2002).

High levels of ammonia from animal waste constitute a major health risk, but there is limited information on the subject in cases of animal hoarding. This is an area that would benefit from further research. The Occupational Safety and Health Administration (OSHA) recommend that continuous exposure to ammonic environments should not exceed 35 particles per minute (ppm) over an 8 hour period (CDC, 2011). And the National Institute for Occupational Safety and Health (NIOSH) consider that concentrations of 300 ppm or greater as being immediately dangerous to life and health (HARC, 2002). In one case ammonia levels were recorded at 152 ppm after the home was ventilated (HARC, 2002).
The main impact on health from prolonged exposure to ammonia is the effect it can have on the respiratory system, resulting in acute lung damage, edema, asthma, pulmonary fibrosis; and irritation to the nose, eyes and skin (OSHA, 2003). It is currently unknown whether animal hoarders become anosmatic as a result of prolonged exposure to the toxic environment, or simply become acclimatized to it. It has been theorized that if they do become anosmatic and are able to tolerate the toxic environment, this could be an indication of neurological damage (HARC, 2002).

There is also a lack of research in relation to the effect high concentrations of ammonia have on the animals which, in many instances, are kept inside and in confined areas (Figure 10).

Figure 10 – Cat hoarding (b). Source: http://www.cbsnews.com
Section 4 – Intervention strategies

In this final section the question “Why do elderly hoarders present challenges for social workers, and what intervention strategies can be used to address these challenges?” will be discussed. Studies have provided us with a better understanding of probable causes of hoarding behavior, and how this can explain the acquisition of objects and/or animals, and the consequences of these actions. Deciding on the most appropriate form of intervention to address the effects of hoarding behavior is more problematic; and also raises many ethical issues, among which is the right to self-determination and whether social workers and other professionals should be legally obligated to intervene, and if so, to what extent.

Codes of ethics are set by leading institutions and professionals within specialized fields are subject to these codes. They are designed to protect the public and establish standards of behavior and conduct aimed at ensuring all clients are treated equitably and ethically. This includes boundary setting; privacy, confidentiality and mandated reporting; and record keeping. Because ethical standards can conflict with state and local regulations, social workers and other professionals need to be aware of the laws as they pertain to the state in which they are working (Gibson, Rasmussen, Steketee, Frost, Tolin, 2010).

Social work is a dynamic profession, and although each case broadens one’s knowledge and skills, intervention that worked successfully in one case does not mean a similar outcome will be achieved in the next or subsequent cases. Flexibility, adaptability and the ability to “think outside the box” are necessary and essential traits required of social workers when engaging with elderly hoarders, family and other professionals. Equally important is a person-centered approach that focuses on individuals, and not the perceived needs of the community, family, landlords, or other agencies. These often conflicting interests will be discussed in more detail in this section.

Studies of hoarding behavior suggest that in the majority of cases, elderly hoarders do not actively seek or welcome outside intervention; and are likely to be resistant to any form of intrusion that potentially threatens their lifestyle and possessions. With this in mind it is essential that initial and subsequent contacts with elderly hoarders’ respects their dignity and acknowledges the strong feelings of attachment toward possessions. It is an exercise in building dialogue and establishing trust that reflects honesty and professionalism. To achieve any level of success social workers and other professionals, need to adopt and maintain certain attitudes and behaviors, including respecting individuals’ right make their own decisions at their own pace; and empathizing and attempting to understand hoarders’ perspective and attachment to their possessions (Sorrentino, undated).

Because of strong and often intense feelings of attachment, hoarders are likely to be fearful that the presence of a social worker could result in other agencies also becoming involved. In reality this does occur, but the level of involvement by other agencies is dependent on the laws of the state in which they live, and whether their community has developed multiagency task forces.
Reports of hoarding involving the elderly are commonly made to departments’ of social services where they fall under the auspices of Adult Protective Services (APS) because of the neglect or self-neglect that is generally associated with hoarding behavior. Older adults are a protected class under federal and state laws (Bratiotis; Schmalisch; Steketee, 2011), thereby requiring elder protective service agencies to investigate complaints of adult abuse and neglect. The criteria for a valid report are likely to vary from state to state, and social workers and other professionals need to ensure they are aware of the laws as they pertain to their state. The criteria used by Virginia to determine the validity of reports are (VDSS Adult and Family Services Manual Adult Protective Services, 2012):

- Adult must be at least 60 years or older, or age 18 to 59 and incapacitated
- Adult must be living and identifiable
- Circumstances must allege abuse, neglect or exploitation; and
- Local department must be the agency of jurisdiction

In 2011 Virginia reported 5,525 substantiated cases of self-neglect (54%) and an additional 2,035 substantiated cases of neglect (20%) (Virginia Department of Social Services, 2011). Although self-neglect is the most common type of abuse/neglect it cannot be determined how many of these reports related to cases of elderly hoarders because of current data collection methods. This is an area that would benefit from further research to determine national, state and local trends.

The most challenging aspect for APS social workers will often be the ability to gain access to hoarders’ homes. Reluctance to allow admission should be anticipated, and will require considerable skill, tact and diplomacy to encourage hoarders to allow someone into their ‘world.’ Suggestions of legal action or possible consequences for refusing to allow access could seriously jeopardize future attempts to establish a professional working relationship, and should be avoided whenever possible. This approach is likely to cause resentment, an unwillingness to cooperate and increased levels of stress and anxiety.

When a social worker, official or other professional first enters the home of an elderly hoarder, the senses become heightened and effectively go into overdrive as a myriad of information is absorbed and processed. Determining risk and capacity will be paramount as the environment is assessed for factors that can seriously affect the health and well-being of the elderly hoarder and/or animals, including their personal safety and the safety of others. The hoarder’s appearance can provide useful clues about their level of self-neglect; smells also provide strong indicators of the level of neglect and other potential health hazards (e.g., mold, rotten food, urine, feces). Indicators of a person’s cognitive state, specifically their capacity, can be obtained from questioning. However, it should be stressed that this is not a formal clinical assessment, but one based on experience and training that seeks to determine a hoarder’s ability to make, communicate and carry out any given action. Examples include asking questions to determine if a safety plan exists in the event of fire or other similar emergency, the storage and preparation of food.
The condition of a hoarder’s home can be overwhelming at first sight, irrespective of the number of similar situations a social worker or other professional has witnessed. Even with heightened senses it is almost impossible to retain every piece of critical information, as the picture below illustrates, Figure 11.

![Figure 11 - Example of a hoarder's kitchen (a). Source: http://izismile.com](image)

To assist with this problem a number of assessment tools have been developed, and personal experience has found the HOMES Multi-disciplinary Hoarding Risk Assessment (Figure 12) (Bratiotis, 2009) to be particularly effective. This simple-to-use assessment tool is designed as an initial and brief assessment (Bratiotis, 2009), and assists in capturing the issues discussed above in Figure 11. It also enables an initial assessment of risk and capacity to be determined; knowledge that will be essential in developing case management intervention strategies.

Apart from the general clutter covering the floor and surfaces in Figure 11, the picture highlights a number of specific risk factors a social worker should detect and incorporate into their assessment. The floor in front of the refrigerator is cluttered suggesting that use of the appliance for its intended purpose may no longer be possible. If this is the case, it should prompt questions about food storage, particularly perishable items. The area in front of the oven is blocked, also suggesting this appliance cannot be used, and the stove beside it is covered with various objects. The use of the oven and stove would constitute a serious fire risk as a result of the excessive accumulation of clutter. It should also direct the social worker to ascertain how food is prepared. It is not uncommon for hoarders to use microwaves when access to other cooking appliances is no longer accessible.
HOMES® Multi-disciplinary Hoarding Risk Assessment

Health

- Cannot use bathtub/shower
- Cannot prepare food
- Presence of spoiled food
- Presence of insects/rodents
- Cannot access toilet
- Cannot sleep in bed
- Presence of feces/Urine (human or animal)
- Presence of mold or dampness

Obstacles

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

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

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

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

- Threat to health or safety of child/minor
- Threat to health or safety of person with disability
- Threat to neighbor with common wall
- Threat to health or safety of older adult
- Threat to health or safety of animal

Structure & Safety

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

Notes:

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

Household Composition
# of Adults ___________________ # of Children _____________________________ # and kinds of Pets __________________________
Ages of adults: ___________________ Ages of children: ___________________________ Person who smokes in home □ Yes □ No
Person(s) with physical disability________________________________________________________
Language(s) spoken in home____________________
Assessment Notes:________________________________________________________________________
_______________________________________________________________________________________
_______________________________________________________________________________________
Risk Measurements
□ Imminent Harm to self, family, animals, public:_________________________________________________
□ Threat of Eviction: ___________________________________________ □ Threat of Condemnation:______________________________

Capacity Measurements
Instructions: Place a check mark by the items that represent the strengths and capacity to address the hoarding problem
□ Awareness of clutter
□ Willingness to acknowledge clutter and risks to health, safety and ability to remain in home/impact on daily life
□ Physical ability to clear clutter
□ Psychological ability to tolerate intervention
□ Willingness to accept intervention assistance
Capacity Notes:____________________________________________________________________________
_______________________________________________________________________________________
_______________________________________________________________________________________
Post-Assessment
Plan/Referral____________________________________________________________________________
_______________________________________________________________________________________
_______________________________________________________________________________________
Date: ____________ Client Name: ____________________________________________ Assessor: ____________________________

Figure 12 - © Bratiotis, 2009, reproduced with permission.
The HOMEs Multi-disciplinary Hoarding Risk Assessment (Figure 12) contains sections that address risk and capacity. These assist in determining an individual’s cognitive state and whether they display a lack of insight to their situation, behave in a defensive manner, and/or express a willingness to change their behavior and allow outside intervention.

An initial assessment should not include discussions about a clean-up plan, particularly if the elderly hoarder is defensive. Social workers and other professionals need to attempt to view the situation from the hoarder’s perspective and adapt their intervention strategies accordingly. The initial focus should be on safety and discussions that seek to address immediate concerns. Although it is theorized that capacity cannot be altered, and therefore the focus should be on risk reduction; I suggest this is not an entirely accurate theory. Capacity can be fluid and is a term that is often misused and has many connotations. In a court of law capacity is used to determine whether an individual requires the appointment of a guardian and/or conservator. Social workers and other professionals use the term to assess and individual’s ability to make, communicate and carry out decisions or actions. An elderly hoarder may become physically incapacitated as a result of a broken leg, and is therefore restricted in their ability to perform activities of daily living or independent activities of daily living (e.g., shopping, laundry, driving). This implies a temporary incapacity, although it is recognized that the hoarding behavior is still indicative of some form of mental disorder that can impact decision making abilities.

Conversely, an individual may believe they have capacity and ignore or choose to acknowledge risk and the consequences of their actions. One such example was the case of Mary Northern who was admitted to a Nashville hospital in January 1978 with severe frostbite to both feet. Gangrene developed and doctors believed that amputation was necessary to save her life. She refused to consider amputation, believing the blackness of her feet was the result of soot or dirt. A psychiatrist determined she was lucid but functioning on a psychotic level, thereby affecting her ability to accept the need for amputation (Callender, 1982). The local APS unit petitioned the court for authorization to allow the feet to be amputated. Following a succession of appeals the case was before the United States Supreme Court when Mary Northern died in May 1978; never having undergone the amputation of her feet which, in the interim, had undergone auto-amputation (Callender, 1982). This case exemplifies the challenges facing social workers and other professionals in determining level of capacity.

Because of the difficulty in assessing risk, another useful tool is a risk and capacity model that through observation and questioning can help determine elderly hoarders’ willingness to cooperate, ability to respond to intervention, an understanding of the risk factors resulting from their hoarding behavior, whether other agencies should become involved, or whether any action should be taken (Figure 13).
If an individual expresses an understanding of their behavior, acknowledges the risk factors, but chooses not to take any corrective action or accept outside intervention; their capacity could be determined as being high, despite apparent risks. In this situation of high capacity and high risk, the model suggests no intervention should take place. Conversely, someone with low capacity with the same risk factors would indicate the need to involve other agencies and make attempts to reduce the underlying risks.

Although an effective tool, it also raises ethical issues and individuals’ right to self-determination. An elderly hoarder who demonstrates high capacity and high risk is unlikely to cooperate and could strongly object to any intervention. However, if the hoarding situation was reported to a local APS unit there is a legal obligation to respond, and make attempts to ameliorate the situation. This presents enormous challenges and has to be balanced with respecting individuals’ right to autonomy, with attempts to ‘encourage or persuade’ the acceptance of intervention. As stated earlier in this paper, every case is different and when faced with decisions regarding autonomy, elderly people in general will elect for freedom over safety. There will also be considerable variations among communities in response to hoarding situations, irrespective of an individual’s capacity.

This variation also extends to the role of child protective services (CPS), and can present a different challenge. Unlike adults who have the right to self-determination and can refuse services (unless subject to legal intervention), children under the age of 18 do not have similar rights. Adults cannot be forcibly removed from their home, unless specific legal criteria are met, whereas a child can be legally removed from a hoarding household if the child’s safety is deemed at risk. If the situation involves younger adults CPS is likely to continue working with the family to de-clutter with the ultimate goal of reunification with the child. This form of intervention can be a strong motivator to de-clutter, but without adequate ongoing case management there is the potential risk of recidivism.
Situations do occur in which elderly hoarders have custody of young children and, if the children are removed from the home, both CPS and APS is likely to be involved. Although reunification would still be the primary goal, an elderly hoarder might be more resistant to change, and physically less able to achieve the desired outcome within specified timeframes.

Case management is not a linear process that begins and ends with the first visit. It is ongoing and subject to continual monitoring to ensure measurable goals are being achieved. Because of the complex emotional factors involved, social workers and other professionals may need to modify intervention strategies in response to situational changes. These changes could include the threat of eviction, sudden change in physical and/or mental status, legal action, non-compliance by the elderly hoarder, or some other unforeseen event. For this reason a cyclic model is more appropriate (Figure 14); and if an event occurs after an action plan has been implemented, it can be reassessed and, if necessary, modified to reflect changes.

Prioritizing and establishing measurable goals is a fundamental and integral part of case management. It should also be a collaborative effort with the elderly hoarder, taking account of their needs and emotional status. They are being asked to re-evaluate their life style, discard items to which they have developed strong emotional attachments, and accept the intervention of strangers into their home who will touch and handle their possessions. In defining goals I propose three-tier model; initial, mid-term, and long-term goals.

Initial as opposed to immediate implies a softer and more sensitive approach, and is also less threatening. The outcome will be the same though and that is to attempt to reduce the immediate risk factors.

Mid-term goals attempt to focus on action to be taken over the next month of two. There is little to be gained in suggesting to an elderly hoarder that all the cluttered rooms need to be emptied in the next two months. But if the goal is to de-clutter one room at a time, it is less overwhelming and increases the chance of success.
Long-term goals should be looking at the next six months and beyond. Setbacks are likely and have to be allowed for, but as progress is made motivation may increase. For example, an elderly hoarder estranged from her family because of the hoarding behavior might want to invite them to her home to celebrate a special event, and is therefore more self-motivated to de-clutter.

But as previously stated, case management is not a linear process and the cycle of events may necessitate constant re-evaluation to compensate for unplanned and unexpected events. The importance is to maintain the focus and momentum toward attainment of the desired goals. The taking of photographs (with the client’s permission) is also a useful tool and can be used to illustrate before and after scenes. This provides tangible evidence of achievement toward goals.

Implementing one of more goals is described using the photograph in Figure 15. Only one side of the staircase is accessible because of the piles of newspapers. The risk factors include fire, structural damage due to the weight of the piles, and injury from falls if the piles were to move. An initial goal would be to encourage the removal of the newspapers. Such a suggestion could be met with resistance and numerous excuses of why the newspapers are important to the hoarder, or the information contained within them might be useful to someone else. There is no ‘off-the-shelf’ response to this, and simply suggesting they be thrown out could, in the view of the hoarder, suggest a non-caring attitude toward their possessions.

It is at this juncture that social workers need to resort to their ‘virtual tool-bag’ and extract a response that best fits the situation. An initial goal might become a mid-term goal in which it is suggested that to reduce the risk factors, the piles of newspapers be stored in another location. If it is too emotionally painful for the hoarder to simply discard them, then a suggestion of taking them to be recycled might be a more acceptable alternative.

Figure 15 - Example of a hoarder’s staircase. Source: Fairfax County Department of Board Compliance
Accessing and coordinating resources represents another major challenge for social workers, particularly in communities where departments’ of social services are the lead agency. In smaller agencies it is not uncommon for social workers to be responsible for both APS and Adult Services (AS) cases. Consequently, high caseloads can negatively impact on the time, resources and quality of intervention. This in turn can have a detrimental impact on hoarders’ motivation and risk non-compliance with action plans and a continuation of the hoarding behavior. It is therefore essential that to achieve any level of success, social workers and other professionals must maintain regular and ongoing contact to:

- Provide reassurance, encouragement and motivational support.
- Monitor progress or lack thereof.
- Advocate on behalf of elderly hoarders.
- Continually monitor health and safety issues.

The type of hoarding (object, and/or animal) and the location of the hoarding home (urban or rural), will be a contributing factor in the coordination of resources. The social worker’s role is likely to be pivotal as they interact with other agencies. It can also be contentious as they advocate for the rights of the individual which can be in conflict with other agencies and community expectations.

To avoid the potential for conflict social workers’ need to develop working relationships with other community agencies, and maintain open lines of communication with them. This can be achieved by an understanding of each agency’s role, the services they can provide, as well as their limitations. However, it is not sufficient for social worker’s to have this knowledge; each agency within a community that could potentially be involved in cases of hoarding should understand the capabilities and limitations of other agencies. This model of interaction and coordination (Figure 16) is person centered and less oppressive than the hoarding task force model. It provides a mechanism whereby elderly hoarders are able to establish a professional relationship with social workers, who then act a conduit to other services. There are limitations though, not least of which is often a lack of available resources.

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**Figure 16 – Social work model of case management coordination**
Studies of hoarding behavior suggest the response to it varies considerably across the county and between urban and rural communities. In addition, there is a paucity of information to determine the effect the economic recession has had on state and local governments’ ability to devote money and resources to address the problem. It is theorized that reductions in tax revenue has reduced the ability for local governments’ to respond, particularly in rural communities. At the same time it is unclear how willing local governments’ are to intervene in what could be viewed as a private matter brought on by an individual’s own behavior. In discussions with a community development permitting and inspection official it was indicated that in order for the county to consider intervening, they would first have to determine what, if any, advantages there would be (David Cooper, personal communication, Oct 2012).

In a study conducted by Steketee et al. (2001) of 62 elderly hoarders in the Boston area, the involvement of various forms of intervention comprised:

- Agencies, including cleaning services (59%)
- Elder services (38%)
- Building management (21%)
- Public health department (10%)
- Court (7%)

However, the same study indicated that most of the intervention strategies appeared ineffective with 43% showing no signs of improvement; 15% worsened; and 8% showed initial signs of improvement then relapsed. Only 15% showed any sign of sustained improvement (Steketee, Frost & Kim, 2001). It is figures such as these that can cause smaller and less populated communities to be cautious about investing money and resources for limited returns. The case of the small health department that spent most of its $16,000 budget clearing out a hoarding house, illustrates the cautious approach, particularly as the same hoarding problem re-emerged 18 months later (Frost et al., 2000).

Anecdotal knowledge indicates that despite the financial limitations under which many rural communities operate, local politics and community pressure can cause county agencies to intervene in selected hoarding cases. Evidence suggests this is not for philanthropic reasons, but has more to do with the value of real estate.

Hoarding Task Forces
The intervention strategies adopted by large urban communities differ considerably, and the development of hoarding task forces is slowly increasing across the county. An isolated elderly hoarder living in rural community may go unnoticed for many years, and is likely to have minimal impact on neighbors. In contrast, an elderly hoarder living in an urban area is more likely to be noticed and their behavior is likely to have a greater impact on the health and safety of neighbors and property.
The first hoarding task force (HTF) was created in Fairfax County, Virginia, in 1998 following the death of four homeless persons in an abandoned house. An open fire was used to provide heat and lighting in a house that was littered with debris (Fairfax County Hoarding Task Force 2011 Annual Report). The HTF developed by Fairfax County has become a template for the growing number of task forces being developed across the country. In 2006 the Fairfax County HTF was one of five in the country; a number that increased to more than 85 by 2011 (White, 2011). It is unclear why there has been such an upsurge in the development of HTFs over the past 5 years, but it is theorized that a growing fascination about hoarding, television programs, books on the subject and a plethora of studies and reports may be contributing factors.

The stated objectives of the Fairfax County HTF are to “develop and maintain procedures for dealing with moderate to severe hoarding that assertively uses the various County codes to deal with properties which, because of hoarding behavior of occupants, may be in violation of codes” (Fairfax County Hoarding Task Force 2011 Annual Report).

The model of intervention associated with HTFs is a multi-agency coordinated approach that differs considerably from the social work model of case management coordination. Further research is required to determine the efficacy of HTFs, particularly in relation to the psychological and emotional impact on elderly hoarders. In the model depicted in Figure 16, the social worker was the primary contact source and point of reference for the elderly hoarder. This model promoted the development of trust and, although time consuming from a case management perspective, was person centered. This is in contrast with the HTF model (Figure 17) where multi-agency involvement could be occurring simultaneously. In the Fairfax County HTF model, social services are a supporting agency. According to the Department of Code Compliance, it is to this agency that all initial reports of hoarding are made (Michael Congleton, Code Authority/Strategic Initiatives Manager, personal communication, Oct 2012).

Figure 17 – Fairfax County HTF, sample agencies: (Fairfax County Hoarding Task Force 2011 Annual Report)
It is unlikely that all of the HTF associated agencies would be involved simultaneously, but the model does suggest the potential for this occurring on a case-by-case basis. Each agency will be operating within its own guidelines and policies, and this can result in inter-agency conflict and misunderstanding. It also raises questions about priorities and agenda setting. For example, social services will be focusing on the elderly hoarder, and should be advocating on their part. Whereas the Department of Code Compliance might be insisting the home be brought into compliance with local codes within a specified period of time, without necessarily taking account of the social, emotional and psychological effects the elderly hoarder will be experiencing.

A major advantage of the HTF model is the pooling of resources, something smaller communities are less able to achieve. The ability to draw upon a variety of resources potentially spreads the financial burden across a number of agencies. But for this to take place the community in which the HTF operates has to be able to generate sufficient income to sustain this level of involvement. Fairfax County, situated on the fringes of Washington D.C., reported a population of 1,096,798 in 2011, and a mean family income of $122,189 (Demographic Reports 2011 County of Fairfax, Virginia (a)). The same report also reported that in January 2011 the market value of owned housing units ranged from below $350,000 to greater than $850,000 (Demographic Reports 2011 County of Fairfax, Virginia (b)).

In such a highly populated urban community that attracts high incomes and property values, the consequences of hoarding behavior and its resultant impact (e.g., economically, environmentally, social) is considerably greater than on smaller and less affluent rural communities. This again raises the question of whether HTFs are a philanthropic response to increased awareness of hoarding behavior, driven by economics or a combination of the two.

A review of six HTFs across the country revealed some commonality with the Fairfax County model, but also considerable variations. This is another example of how different states and communities view and respond to hoarding behavior. The six include:

- Detroit (MI) Hoarding and Cluttering Task Force
- Atlanta (GA) Hoarding Task Force
- Arizona (AZ) Hoarding Task Force
- Morgantown (WV) Hoarding Task Force
- Orange County (CA) Hoarding Task Force
- San Francisco (CA) Task Force on Compulsive Hoarding

The San Francisco HTF is similar to the one developed by Fairfax County, and also encompasses a large metropolitan area. In a 2009 report produced by the San Francisco HTF, it was estimated that over a one year period (April 1, 2007 – April 30, 2008) the city spent almost 2,400 hours on hoarding clean-up operations, at a cost of nearly $64,000 (San Francisco Task Force on Compulsive Hoarding, 2009). It is unlikely this amount of time and expenditure would be sustainable by small local government authorities. Examples of the different models and how they approach hoarding behavior are illustrated in Figure 18.
COMPARISON OF HOARDING TASK FORCE MODELS

<table>
<thead>
<tr>
<th>HTF</th>
<th>STRUCTURE</th>
<th>PARTICIPATING AGENCIES &amp; SERVICES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Detroit</td>
<td>Public-private partnership.</td>
<td>Neighborhood organizations, adult well-being foundation, legal services. Seeks to educate, raise public awareness, and preserve safe housing and early detection.</td>
</tr>
<tr>
<td>Atlanta</td>
<td>Non-profit coordinated response team.</td>
<td>On-site therapeutic assessment, ongoing CBT supplemental support services, community education.</td>
</tr>
<tr>
<td>Morgantown</td>
<td>Public organization headed by a Code Enforcement Officer.</td>
<td>Aim is to completely address hoarding cases that each department of the city experienced. Includes representatives from social services, police, fire, animal control, health department, Homeland Security and Emergency Management.</td>
</tr>
<tr>
<td>Orange County</td>
<td>Volunteer advisory group that meets monthly to review existing residential hoarding situations.</td>
<td>Comprised of agencies and programs that are able to offer assistance. Includes social services, animal control, code enforcement, health and mental health professionals, fire, housing, and professional organizers and cleaning companies.</td>
</tr>
</tbody>
</table>

Figure 18 – Sources: Detroit Hoarding and Cluttering Taskforce, [www.hannan.org](http://www.hannan.org); Atlanta Hoarding Task Force, [http://atlantahoardingtaskforce.com](http://atlantahoardingtaskforce.com); Arizona Hoarding Task Force, [www.azhoarding.com](http://www.azhoarding.com); City of Morgantown, Sullivan (2012); Orange County Hoarding Task Force, [www.mhaoc.org/hoarding](http://www.mhaoc.org/hoarding).

These examples illustrate the different approaches some communities have taken, and range from volunteer advisory groups, public-private partnerships, publicly controlled and, in the example of Arizona, a state-wide information source. It is unclear what role the Department of Homeland Security plays in cases of hoarding.

Clean-up companies
Companies specializing in cleaning and organizing the contents of homes and businesses have existed for a number of years; and approximately 4,200 nationwide belong to the National Association of Professional Organizers ([www.napo.net](http://www.napo.net)). However, there is a lack of research about the number of companies that added ‘hoarding clean-up’ to their list of existing services, or the number of new companies that started operations in response to the publics’ increased awareness of hoarding behavior.

When one thinks of hoarding clean-up companies, it is easy to conjure up images of an army of workers descending upon a hoarding house, unceremoniously removing the clutter and taking it to the local landfill. As studies have shown this form of intervention is likely to cause severe emotional distress, possibly exacerbate existing mental health disorders, and can result in suicide. This form of intervention is draconian and demonstrates a total lack of sensitivity toward the elderly hoarder. It is also theorized that such behavior is not the norm, and that companies specializing in hoarding clean-up have staff trained in sensitivity awareness.
An internet search for ‘hoarding clean-up companies’ will return numerous hits for organizations specializing in this form of work. Two companies were chosen at random; SI-Restoration (www.si-restoration.com) and Steri-Clean, Inc (http://1800hoarders.com or www.steri-clean.com). In addition, I spoke with Maria Spetalnik of Conquer the Clutter to gain further insight on the subject (Maria Spetalnik, CEO, COO, Conquer the Clutter – personal communication, Oct 2012).

A common theme across all three agencies is the claim to utilize staff that has been trained to be non-judgmental, sensitive toward the individual and their possessions and to assist the elderly hoarder identify items to keep and items to discard. The companies also claim to use unmarked vehicles to try and minimize unwanted publicity for the elderly hoarder.

There is no doubt that as a form of intervention clean-up companies are a useful resource. The lack of time experienced by most social workers often prevents them from engaging directly in clean-up operations; although I would suggest their presence during the actual operation could be beneficial in providing emotional support.

Another factor is cost and whether elderly hoarders have the financial resources to pay thousands of dollars for a company to clean-up their home. This is a strong disincentive, but a reality for many elderly hoarders living on a small fixed income. SI-Restoration and Steri-Clean, Inc offer free in-home estimates, whereas Conquer the Clutter charges $275 for an initial visit (Maria Spetalnik – personal communication, Oct 2012).

Local government agencies might be unwilling or hesitant to pay the costs unless they perceive some benefit to the community, and may also be fearful of recidivism occurring. The latter is always a strong possibility in cases of hoarding which reinforces the need for ongoing case management through regular contact to minimize this risk. In large urban communities, particularly those with HTFs, it is conceivable that contracts exist with hoarding clean-up companies that would spread the cost among a number of agencies. However, even this approach can be expensive as the city of San Francisco found when it spent nearly $64,000 over a one year period on clean-up operations (San Francisco Task Force on Compulsive Hoarding, 2009).

ASPCA, Humane Society, local animal control agencies
Developing appropriate intervention strategies in cases of animal hoarding is more complex, and challenging than cases involving only object hoarding. Studies indicate that the level of squalor in homes of animal hoarders is nearly 100% (Patronek, et al., 2009), primarily as a result of the presence of animal feces, urine soaked surfaces, unhealthy, dead and decomposing animals. In addition, studies by the Occupational Safety and Health Administration indicate that prolonged exposure to ammonic environments above 35ppm over an 8 hour period (CDC, 2011) could have a harmful effect on the respiratory system, nose, eyes, and skin (OSHA, 2003). This raises concerns for the health of elderly animal hoarders, but also presents health implications for social workers and other professionals.
Intervention is rarely one-dimensional (i.e. social services) and will invariably require coordination with other local agencies (e.g., ASPCA, animal control, zoning, health department). As with other cases of hoarding, intervention strategies will vary considerably, and social workers need to be aware of the protocols as they apply to their community. In some localities the social worker is likely to take the lead in coordinating services; whereas in communities with HTFs the social worker’s role may be supplementary.

Cases involving animal hoarding can be emotive and subject to conflict between ‘animal protection agencies’ and social workers. Differing agendas and values is the main reason. Animal protection agencies are likely to focus on preventing further suffering to the animals, and may seek to intervene and remove them as soon as possible; whereas the focus of APS is to advocate on behalf of the elderly hoarder and take steps to reduce the risk of the behavior and its impact on the individual (Patronek, et. al., 2006). When there are competing interests social workers’ can act in a conciliatory role, while ensuring they maintain professional integrity. Adult Protective Services is charged to serve the client, not the animals (Patronek, et. al., 2006). In reality, APS social workers are usually local government employees, and there will be community expectations that some form of intervention will occur.

Deciding on the most appropriate form of intervention is perhaps the biggest challenge, and animal hoarding, in most cases, is likely to require the involvement of other agencies and possible legal action. Studies of object hoarding clearly indicate that removing possessions and clean-up operations does not solve the underlying problem. This also applies to animal hoarding which is commonly regarded as a problem, as opposed to being a symptom of the problem (Patronek, et. al., 2006).

Each case is different and has to be approached from this perspective. Establishing and building trust with animal hoarders is still necessary in order for intervention to be effective, irrespective of any moral or personal feelings concerning the fate of the animals. Equally important is the need to assess the person’s capacity to determine their level of understanding regarding the situation and also their motives. If the animals were acquired actively there is likely to be a stronger reluctance to cooperate and accept intervention, as opposed to the elderly animal hoarder who acquires passively, but is unable to keep up with a steady influx of cats. In the latter example intervention could focus on developing a plan to reduce the number of cats by encouraging the elderly hoarder to donate some of the animals to rescue organizations. A concurrent plan would be to have the remaining cats spayed and neutered, thereby reducing the risk of further breeding. The cost of such action can be prohibitive for an elderly hoarder, but programs do exist to address this issue. The ASPCA operates a Trap-Neuter-Return (TNR) program whereby feral cats are humanely trapped, spayed, neutered, vaccinated against rabies, and then returned to their colony or owner (ASPCA, 2010 (b)). The elderly hoarder is not charged for this service and although helpful in reducing the number of animals, it does not address the squalor associated with animal hoarding, nor prevent the arrival or acquisition of additional animals. Consequently, the need for ongoing case management and monitoring remains extant.
Initiating legal action in cases of animal hoarding is generally not a social worker’s responsibility, and would be a conflict of interest that could potentially impede further relations with the elderly hoarder. Studies of legal action taken in cases of animal hoarding indicate that when prosecution does occur it often fails to halt the behavior, and the risk of it resuming again is high (Patronek, 1999).

Only two states, Illinois and Hawaii, have laws specifically addressing animal hoarding (Hayes, 2010), while other states use general animal cruelty laws. According to Berry et. al., (2005) the lack of specific animal cruelty laws has led to many communities utilizing ordinances (e.g. licensing of animals, dangerous animal restrictions, rabies vaccinations), and codes (e.g. health, zoning, fire, wildlife statutes) in an attempt to address the problem. The most obvious weakness to this approach is non-compliance. An animal hoarder is unlikely to voluntarily register all their animals or have them vaccinated, for fear of drawing attention to their behavior.

The cost of legal action can also be prohibitive for smaller communities, thereby acting as a deterrent to prosecuting cases of animal hoarding; in the knowledge that the behavior might resume. There is also the additional expense of boarding and caring for the animals in the event of protracted legal proceedings. One approach to address this problem has been the use of civil forfeiture and bonding laws (Patronek, et. al., 2006).

Civil forfeiture laws enable animals to be removed from a home and held in custody without compromising due process, because it only requires a preponderance of evidence of animal abuse, as opposed to establishing guilt beyond reasonable doubt.

Bonding laws operate in a similar manner in that a bond is set for the care of the animals pending the legal outcome of the case. If the owner fails to post the bond within a specified period of time their right of ownership to the animals is forfeited.

It is theorized that many low income elderly animal hoarders may lack the financial resources to post a bond, thereby risking the loss of all their animals. Not only does this increase the financial burden on animal rescue organizations, something the bond was supposed to avoid, the action is likely to have a profound impact on elderly hoarders’ mental health status. This in turn could require more intensive case management by social workers’ to ameliorate the situation.

Mental health
The probable causes of hoarding behavior, objects and/or animals, have been extensively researched, and recent studies suggest that hoarding behavior may constitute a diagnosis in its own right as opposed to a component of OCD. Although treatment for hoarding behavior exists, it is unlikely that ‘front-line’ social workers will be the ones providing it. In cases where elderly hoarders are willing to accept mental health intervention, the appropriate course of action would be to refer them to mental health services to receive treatment. This assumes the elderly hoarder acknowledges the impact of their behavior and wishes to take action to combat it. Implicit in this statement is high capacity and a willingness to cooperate. The reality is that many elderly hoarders may be unwilling to change their behavior and part with their possessions, or negotiate a compromise and take limited corrective steps to avoid possible legal action (e.g., eviction).
The barriers to seeking treatment by elderly hoarders are multifarious and include:

- Denial of their behavior as being a problem that requires treatment.
- Seen as an infringement of their civil liberties and right to self-determination.
- Social stigma among the elderly cohort in general of receiving mental health services.
- Lack of transport to attend therapy sessions, particularly in rural communities.
- Poor health and physical impairments.
- Lack of health insurance.
- Limited financial resources to afford co-payments for treatment.
- Lack of mental health clinicians trained specifically in treating hoarding behavior.

The majority of published research about mental health interventions suggests the behavior begins in childhood or adolescence and increases gradually with age (Grisham, et. al., 2006). Therefore, by the time APS or other agencies become aware of an elderly hoarder the behavior will be deeply ingrained. It is also theorized that major life changing events can also act as a trigger (e.g., divorce, death of parents/spouse).

Research is also beginning to indicate that the results from intervention methods used to commonly treat OCD, such as CBT (Cognitive-Behavior-Therapy) and Selective Serotonin Reuptake Inhibitors (SSRIs) are exhibiting fewer benefits than those reported for OCD (Mataix-Cols et.al., 1999). Selective serotonin reuptake inhibitors are commonly used in the treatment of depression and anxiety, major symptoms associated with hoarding behavior. Serotonin, a chemical in the brain that is known to affect mood, is blocked by the use of SSRIs (Hu, 2004).

Examples of how SSRIs might affect OCD based hoarding and non-OCD based hoarding are illustrated in Figures 19 and 20. The left hand picture (Figure 19) shows typical OCD based hoarding behavior in which both acquisition and organization are evident. The bottles and cans are arranged in an organized manner, and any disruption to the collection could trigger feelings of intense anxiety. In contrast, Figure 20 illustrates a typical hoarding situation in which there is no perceived organization, although a hoarder may disagree, claiming they are able to locate an object within a specific area; suggesting the use of spatial awareness compensatory methods.

Figure 19 – Rows of cans and bottles
Source: www.krackedkillers.wordpress.com

Figure 20 – Inside a hoarder’s home
Source: http://izismile.com
A person with OCD based hoarding tendencies is likely to find this scene disturbing and contra to their need for order and could equally trigger intense feelings of anxiety. The use of SSRIs in the treatment of OCD based hoarding seeks to enable hoarders to become less anxious and develop coping and compensatory strategies that reduce the obsessive tendencies. There is no apparent symmetry in Figure 20, which might partly explain why studies of non-OCD based hoarders are finding them less responsive to SSRIs. Another significant factor related to stress and anxiety highlighted by the pictures is pleasure. The OCD based hoarder is likely to derive pleasure from their collection and this can often drive them acquire more of the same objects. The non-OCD based hoarder may also experience feelings of pleasure simply by being surrounded by their possessions.

In an attempt to develop alternative protocols that might be more effective in treating non-OCD based hoarding, a new model focuses on community based in-home therapy, as opposed to the more sterile environment of a mental health clinician’s office. Concerns have been raised about potential ethical and boundary issues associated with visiting clients’ in their homes (Gibson, et. al., 2010). I would suggest this argument may be more related to culture changes and protectionism, rather than embracing and adopting different work practices that are person centered. Social workers’ routinely visit and work with elderly hoarders in their homes, and are equally subject to codes of ethics and professional standards.

The community based model focuses on CBT and exposure and response presentation (ERP). Over a 9 to 12 month period hoarders’ receive 26 weekly sessions and are visited in their homes on a monthly basis for 1 to 2 hours by a mental health clinician (Steketee and Frost, 2007). During the home visits clinicians are able to conduct accurate assessments, and work with clients to teach them skills aimed at reducing the excessive accumulation of possessions. This includes learning how to sort, categorize and organize their possessions. Standardized assessment tools exist that are helpful in determining the level of insight hoarders have to their living conditions and hoarding activities (Figure 21).

Another standard treatment of this protocol is ERP. This involves deliberately exposing hoarders to public places or environments they routinely frequent, and teaching them how to resist urges to acquire additional items (Steketee and Frost, 2007). Examples of this might include taking a shopaholic to their favorite department store or yard sales, and encouraging them to utilize coping strategies to resist the urge to purchase items. I would theorize that a particular challenge to ERP is the widespread availability and convenience of internet shopping.

A further component is the use of coaches who work in similar ways to clinicians, and may also involve family members, spouses, friends and professional organizers (Steketee and Frost, 2007). Involving family members could have both negative and positive consequences. Family members and spouses frequently express frustration and a feeling of impotence in trying to work with a hoarding relative. Feelings of resentment could be counterproductive in establishing a working relationship. Conversely, a combination of therapy and support from family members could potentially achieve positive outcomes. The use of coaches is an attractive feature of this model. All too often social workers’ case loads’ prevent them from devoting the time that is necessary and this can result in a lack of any concrete progress.
A multi-agency approach would enable social workers’ to focus on other areas (e.g., negotiating with landlords, health department, zoning). Involving professional organizers is more problematic with this model, and hoarding cases in general. Concern about the handling and disposal of possessions might be one factor, as well as cost. For those on low fixed incomes, engaging the services of a professional organizer could be beyond their financial means. The same applies to clean up companies. Additional potential barriers include the lack of health insurance or ability to afford co-payments.

There are other factors to be considered in relation to this community based model, and hoarding behavior in general. First, studies are increasingly pointing toward hoarding behavior being a specific mental health disorder as opposed to a sub-type of OCD. This raises the question of whether there are adequate numbers of clinicians trained to respond to a diagnosis of hoarding behavior. Second, it is unknown how many people regularly visit clinicians to be treated for anxiety, MDD or other mental health disorders, but have undisclosed or unidentified hoarding tendencies. Implicit in the literature relating to the in-home model is the fact that clients have disclosed their hoarding behavior. Anecdotal knowledge indicates that many elderly hoarders go undetected until an event occurs that causes their situation to become public. If mental health clinicians visit clients in their homes on a regular basis, it is feasible that causal effects of their symptoms could be detected earlier and appropriate services offered.

Legal
The consequences of hoarding behavior, object and/or animals in relation to legal intervention reveals a disparate approach across the county, and between counties and municipalities to this problem. This in turn makes it particularly challenging for social workers’ and their role could focus more on advocacy than direct legal intervention. An example is the Washington D.C. woman who was evicted along with 30,000 pounds worth of possessions (p. 17). According to the article the hoarder had been unemployed for two and a half years, owed back rent and was unable to keep up with a repayment plan (Vargas, 2010). This suggests the landlord knew there was a problem but allowed it to continue. The involvement of social services, if the hoarder agreed, and which then raises questions about capacity, could have possibly ameliorated the situation by providing advocacy and support, thereby averting the eviction that occurred. State laws do exist that protect the rights of tenants with disabilities, and can be used to fight eviction notices by requesting ‘reasonable accommodation’ (Caitlin, 2011). This could involve a plan in which a specified period of time is given to take corrective action to avoid the risk of eviction.

There is a lack of research to indicate whether fines and/or liens on property are effective in addressing hoarding behavior. Anecdotal knowledge of cases in which fines and liens have been imposed suggests them to be punitive measures that fail to address the underlying causes and, without adequate follow-up intervention, the hoarding continues.

The increasing growth of HTFs across the country is suggestive of a more coordinated response to hoarding behaviors that appear to adopt and utilize a variety of codes as enforcement measures. An example is Part III of the Virginia Uniform Statewide Building Code, commonly known as the Virginia Maintenance Code. It contains “regulations for the maintenance of existing structures which is enforced at the option of local governments” (Virginia Department of Housing and Community Development, 2006).
Of significance is the word ‘option’ as this implies that counties and municipalities are not required to adopt the code, and may choose not to because adoption implies enforcement. Section 105.1 of the code states “this section shall apply to existing buildings or structures which are classified as unsafe or unfit for human occupancy. All conditions causing such structures to be classified as unsafe or unfit for human occupancy shall be remedied or as an alternative to correcting such conditions, the structure may be vacated and secured against public entry or razed to the ground” (Virginia Department of Housing and Community Development, 2006).

Community standards and willingness to adopt such codes has implications, not least of which is the cost of enforcing non-compliance with the regulations. It is not uncommon to find older homes in rural communities without indoor plumbing, water supply, and still have dirt floors. Environmental Health would be more concerned about the disposal of waste products outside that home, than conditions inside it. (Roy Anderson – Environmental Health Specialist Supervisor, personal communication, Oct 2012).

The existence of statewide fire regulations does not imply that the detection of hoarding behavior will automatically result in legal action. Section 109.1 of the Virginia Statewide Fire Prevention Code (SFPC) (2009) allows a fire official the right of entry to “inspect all structures and premises for the purpose of ascertaining and causing to be corrected any conditions liable to cause fires, contribute to the spread of fire, interfere with firefighting operations, endanger life, or any violations of the provisions or intent of the SFPC.” Hoarding homes typically encompass these risks, but according to Darren Stevens (Assistant Chief, Department of Fire, Rescue and Emergency Management, personal communication, Nov 2012), single family homes and up to three adjoining townhouses are exempt from the regulations. However, in the multi-agency HTF model is it conceivable that intervention by other agencies under different codes could result in the subsequent enforcement of fire codes.

Social work practice and intervention should be based on a ‘least restricted’ approach, juxtaposed with balancing capacity, risk, and the rights of the individual to self-determination. Occasions will arise when working with elderly hoarders, or as in the case of Mary Northern (pg. 30), when legal action is considered necessary. However, a diligent approach would ensure that all other avenues have been explored before resorting to legal intervention.

The most draconian form of legal intervention is guardianship which can effectively strip an individual of all their rights, or the order can be written to provide guardians with specific duties and powers. As with all other forms of intervention described in this paper, guardianship laws will vary from state to state, and social workers need to be aware that differences exist. For an individual to be determined in need of a legal guardian, they generally have to be declared incapacitated by a court of law. This reflects low capacity and high risk on the risk-capacity model.

The appointment of a guardian could enable a compulsory clean-up of the hoarder’s home to be initiated, but does not necessarily address the underlying causes of the hoarding behavior, or the additional risk to the hoarder’s cognitive state. It is a moot point but in situations such as this it is likely that the self-neglect and lack of capacity could require the elderly hoarder having to give up their home to live with family or be placed in a long-term care facility.
Family

The involvement of family members in cases of hoarding can be particularly challenging because of the emotive feelings it generates; including frustration and resentment toward the elderly hoarder. In a study by Tolin, Frost, Steketee & Fitch (2008), high degrees of rejection by family members was also noted, based on the severity of the hoarding and perceived lack of insight to the problem. These findings are consistent with other studies involving the impact of hoarding on families.

Social workers can play a key role in these situations by working with families to educate them about the underlying causes of hoarding behavior, identify support groups, and recommend treatment options. Anecdotal knowledge indicates that a lack of understanding is often the main barrier to effective family involvement. Families frequently regard the excessive accumulation of possessions as ‘junk’ and want to simply go into the home and throw it all away. Such action would be counterproductive and could lead to increased levels of anxiety, depression and resistance to change.

For intervention to have any hope of success families need to attempt to see the world for the hoarder’s perspective and ‘step into their shoes.’ Difficult as this might be, the chances of success are greatly improved with this empathetic approach that is both supportive and non-judgmental.

Intervention plans are also required and should, whenever possible, include the elderly hoarder. It is their possessions and they need to be part of the decision making process. Setbacks are inevitable, along with episodes of procrastination. An effective plan to help overcome this is the uses of labeled boxes (e.g., keep, discard, for sorting) and large trash bags. When the latter are filled they should be removed from the house to avoid the risk of the contents being retrieved and finding their way back into the home.

As with any type of hoarding case, there is no one-solution-fits-all answer. Families need to adapt to changing situations, but also be continually sensitive and aware of how difficult the experience of de-cluttering is likely to be and offer appropriate support and encouragement.

There are many positive aspects with associated with family intervention. It can lead to closer family ties, reunification with former friends who might have been too embarrassed to visit, and is less intrusive than employing private cleaning companies.
Conclusions
The aim of this paper sought to answer two questions. First “Why do elderly hoarders present challenges for social workers?” And second, “What intervention strategies can be used to address these challenges?” Personal experience of working with elderly hoarders, literature reviews, and personal communications have reinforced my theory that the principle reasons for the challenges social workers experience are attributable to:

- Unwillingness to change behaviors that have become ingrained over many years.
- Fear concerning the loss of possessions.
- Undiagnosed and/or untreated mental health disorders.
- Undiagnosed and/or untreated physical health conditions.
- Lack of insight as to probable causes of their hoarding behavior.
- Lack of insight regarding the impact their behavior has on their mental and physical health, and the health and wellness of animals.
- Lack of safety awareness regarding self and others.
- Freedom of choice and right to self-determination.
- Lack of effective community resources, finances, ordinances and policies.
- Lack of willingness by communities to invest in resources if there is no perceived return on investment.
- Lack of willingness by communities to devote time and resources to what is perceived as a private matter.
- Lack of coordination between local government agencies.
- Lack of time to devote to intensive case management.

The lack of time experienced by many social workers is an inhibiting factor that can delay attempts to effect change. However, there are also ethical considerations, particularly in cases involving elderly hoarders with capacity. Due diligence is a requirement of APS social workers, but if elderly hoarders continually refuse intervention and understand the consequences of their action, it would be unethical to try and ‘force’ services on them. If animal hoarding is also involved it then becomes questionable whether this should be reported to animal control and/or humane societies. The role of APS is to protect the adult, not the animals, which can create further ethical issues; notwithstanding the impact animal hoarding is likely to have on the health of the elderly hoarder.

I began with the theory that elderly hoarders present ongoing challenges for social workers and this view remain extant.

A number of intervention strategies discussed in this paper offer the potential for developing a more cohesive approach in addressing these challenges. However, there is a lack of evidence to indicate that rural communities are willing to respond to hoarding behavior in a concerted manner. In fact, the opposite appears to be the case. Consequently, involving community agencies and accessing their resources is likely to continue on an ad hoc basis.

In contrast the HTF model that is being increasingly adopted across the county does offer a more cohesive and concerted form of intervention. Nevertheless, I question the efficacy of them and have concerns for elderly hoarders and hoarders in general who come to their attention.
The ability to access resources from a number of agencies is a positive aspect of this model, but in the example of Fairfax County HTF, it is the Department of Code Compliance that is the lead agency as opposed to social services. The numerous studies referred to in this paper clearly identify the risk factors and consequences of hoarding behavior, as well as the impact unwanted attention can have on the mental health status of hoarders. The uninvited intervention by numerous agencies could have serious negative consequences. I suggest that early involvement of social workers in this model is paramount to ensure the rights of the individual are not being infringed, and to advocate on their behalf as they begin dealing with a bureaucracy that could ultimately result in fines and possible eviction. Although the risk to property and neighbors in urban built-up areas poses a greater threat than in rural communities, the potential for intervention based on economic grounds as opposed to philanthropy is a consideration. More in-depth research is required to determine the impact and subsequent outcomes of this model on elderly hoarders.

One area that offers considerable potential for developing cohesive intervention strategies is mental health services. Among all the professionals who might become involved in working with elderly hoarders, mental health services is the agency most closely aligned with social work. Both services are person centered and, together they have the potential to develop unified intervention strategies that complement each other’s role. Close cooperation between the two services will be necessary to enhance understanding of each agency’s role, as well as limitations. Issues involving ethics, confidentiality and privacy are likely to be raised, but these are not insurmountable obstacles.

The development of the in-home CBT and ERP protocol offers additional opportunities for social workers to observe new skills and intervention techniques they can incorporate into their case management, thereby offering a more enhanced level of service. However, at this time it is unclear how widely this protocol is in use and whether sufficient mental health clinicians exist that have been trained to implement it.

Another area that offers the opportunity to develop partnerships is with families of elderly hoarders. Studies suggest this is an under-used resource, primarily because of the frustration, embarrassment, and lack of understanding about the potential causes of hoarding. The creation of support groups to educate and train family members could have long-term positive consequences in addressing hoarding behavior.

Hoarding is a social problem, and one that the public is becoming increasingly aware of. Response to it is piecemeal and there is no evidence to indicate that policymakers intend producing legislation to address its effects, including legislation concerning animal hoarding.

But there is hope and assistance for elderly hoarders who are willing to accept it. Social workers are likely to continue playing a key role, and if mental health services and families can also be encouraged to participate in a partnership, these three elements have the potential for developing effective intervention strategies to address the challenges described in this paper.
**Additional resources**
Anxiety Disorders Association of America  
[www.adaa.org](http://www.adaa.org)

Association for Behavioral and Cognitive Therapies  
[www.abct.org](http://www.abct.org)

Boston University School of Social Work  

Children of Compulsive Hoarders  
[http://www.childrenofhoarders.com](http://www.childrenofhoarders.com)

Clutters Anonymous  
[www.cluttersanonymous.net](http://www.cluttersanonymous.net)

Hoarding of Animals Research Consortium  
[http://www.tufts.edu/vet/hoarding](http://www.tufts.edu/vet/hoarding)

Humane Society of the United States  
[http://www.hsus.org](http://www.hsus.org)

Institute for Challenging Disorganization  

Institute of Living  
[http://www.instituteofliving.org/ADC/compulsive_hoarding.htm](http://www.instituteofliving.org/ADC/compulsive_hoarding.htm)

International Obsessive Compulsive Disorder (OCD) Foundation  
[http://www.ocfoundation.org/hoarding](http://www.ocfoundation.org/hoarding)

List of Hoarding Task Forces by State  
[http://www.childrenofhoarders.com/hoardingtaskforce.org](http://www.childrenofhoarders.com/hoardingtaskforce.org)

National Association of Professional Organizers  
[www.napo.net](http://www.napo.net)

National Association of Senior Move Managers (NASMM)  
[http://www.nasmm.org](http://www.nasmm.org)

Obsessive Compulsive Foundation  
[www.ocfoundation.org](http://www.ocfoundation.org)

San Francisco Task Force on Compulsive Hoarding  
[www.mha-sf.org](http://www.mha-sf.org)
Understanding Compulsive Hoarding
http://understanding_ocd.tripod.com/index_hoarding.html
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Photograph, Figure 6. Hoarder’s toilet. Retrieved from http://izismile.com/2010/06/30/inside_a_hoarders_home.


Photograph, Figure 11. Example of a hoarder’s kitchen (a). Retrieved Nov 2012 from http://izismile.com/2010/06/30/inside_a_hoarders_640_12hoarderskitchen.


Photograph, Figure 20. Inside a hoarder’s home (b). Retrieved Nov 2012 from http://izismile.com/2010/06/30/inside_a_hoarders_640_07hoardershome.

Rosenthal, M; Stelian, J; Wagner, J; Berkman, P. (1999). Diogenes Syndrome and Hoarding in the Elderly: Case Reports. The Israel Journal of Psychiatry and Related Sciences; 1999; 36, 1; ProQuest pg. 29.


