#### **ABSTRACT**

# A POLICY TO PROTECT HOARDERS: AN ANALYSIS OF FAIR HOUSING AMENDMENTS ACT, 1988

By

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This is a policy analysis of the Fair Housing Amendments Act of 1988 (also known as FHAA). In an attempt to provide protection from the legal consequences likely to be suffered by individuals with mental disabilities including those who exhibit the hoarding behavior, the FHAA requires housing providers to provide reasonable accommodations to the needs of these people in order to prevent unnecessary evictions and homelessness. To make use of these protections, task forces have been developed to create solutions that will protect the city from the hoarder, as well as the hoarder from the city.

This study uses secondary sources to analyze the FHAA. The background and history of this policy were explored as well as its effectiveness and impact. This study concludes that FHAA protects the hoarding population. The task forces, mental health professionals, and social workers are able to help with the mental health issues of hoarders even though the FHAA was obviously not intended to deal with the mental health issues, but only to help those who were in need of housing.

# A POLICY TO PROTECT HOARDERS: AN ANALYSIS OF FAIR HOUSING AMENDMENTS ACT, 1988

## A THESIS

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#### CHAPTER 1

#### **INTRODUCTION**

#### Statement of the Problem

Most individuals are able to determine their need for an object, however many

Americans suffer from a mental disorder, commonly known as hoarding, that heightens
their desire to buy, obtain and keep objects (Ronin, 2011). In their study, Frost and Hartl
(1996) found that the clinical definition of hoarding contains three main features:

(1) the acquisition of, and failure to discard a large number of possessions that appear to be useless or of limited value; (2) living spaces sufficiently cluttered so as to preclude activities for which those spaces were designed; and (3) significant distress or impairment in functioning caused by the hoarding. (p. 341)

Hoarding behavior can escalate to severe levels when clutter begins to prevent the normal use of space to complete typical activities, such as cooking, cleaning, moving through the house, and even sleeping (Steketee & Frost, 2003). When hoarding begins to interfere with these functions, it becomes a dangerous problem that puts people at risk for fire, falling, poor sanitation, and illness (Frost, Steketee, &Williams, 2000). It is estimated that hoarding impacts 3%-5% of the American population (Samuels et al., 2008). These numbers are just an estimate for the simple reason that hoarding is many times a hidden problem that is greatly underreported and very often misdiagnosed (Saltz, 2010).

There has been a significant shift in how hoarding is classified in the *Diagnostic* and Statistical Manual of Mental Disorders (DSM). Most recently, hoarding is in the

DSM-IV-TR (Diagnostic and Statistical Manual of Mental Disorders, 4<sup>th</sup> ed., text rev., 2000) under the heading of obsessive-compulsive personality disorder (Tolin, Frost, & Steketee, 2007). A large percentage of people with hoarding problems do not experience other OCD (obsessive compulsive disorder) symptoms (Frost, Steketee, Tolin, & Brown, 2006). Furthermore, many individuals with the hoarding behavior express little distress or recognition of the problem (Steketee & Frost, 2003). According to the DSM-V (American Psychiatric Association [APA], 2013), "people with hoarding disorder have a conscious, ongoing urge to accumulate possessions, as well as corresponding feelings of anxiety or mental anguish whenever those possessions are thrown away" (para. 2). To qualify for this diagnosis the individual has to experience a disruption in their lives, such as work, home life, and social interaction as the direct result of the hoarding behavior (APA, 2013, para. 3).

The Fair Housing Act of 1968 (FHA), also known as Title VIII of the Civil Rights Act of 1968, was enacted to protect tenants from housing discrimination on the basis of sex, color, race, religion, or national origin (Fair Housing Amendments Act [FHAA], 1988, § 3604(f)(3)(B), para. 1; Ronan, 2011, p. 253). In 1988, Congress extended the Fair Housing Act by enacting the Fair Housing Amendments Act of 1988, which protects tenants from any form of housing discrimination based on familial status or disability (FHAA, 1988, § 3604(f)(3)(B), para. 1; Ronan, 2011, p. 253). The purpose of the FHAA is to end the unnecessary exclusion of persons with handicaps from housing available to non-handicapped persons and to recognize that the right to be free from housing discrimination is essential to the goal of independent living (Ronan, 2011).

Hoarders can utilize their protections under FHAA against a possible eviction by arguing their disability requires the landlord to offer them a reasonable accommodation (Ronan, 2011). When the disability is hoarding, a reasonable accommodation would utilize a remedy plan to preserve tenancy, provide support services, and create a schedule for cleanup and inspections. The housing provider does not have to agree to this plan if it would impose a financial burden or change the nature of the housing program. The housing provider might be spared the cleanup expense if one of the support services secured an actual clean up that would be paid for by the tenant or by the tenant's representative (Ligatti, 2013). With the landlord not being held responsible for cleanup, the tenant must ensure the lease violations will be corrected. With a comprehensive agreement in place, the landlord must agree to the reasonable accommodation.

For many hoarders, a reasonable accommodation is the last possible remedy before eviction (Ligatti, 2013). In order to work, a reasonable accommodation should be based on a collaborative intervention model. This collaborative approach should involve mental health professionals, social workers, housing providers, and the tenant (Ligatti, 2013). The success of a reasonable accommodation plan is not just avoiding immediate eviction; it should also improve the ability of the client to maintain their housing, recognize their own problem, and put a support system in place. This collaborative approach can create improved success for the hoarder; however for this technique to work there must be an acknowledgement that those who are dealing with this compulsion will have a life long struggle.

## Statement of Purpose

The purpose of this study is to conduct a policy analysis of the Fair Housing Amendments Act, 1988, U.S.C. § 3604(f)(3)(B). This act amends Title VIII of the Civil Rights Act of 1968, which was passed to prohibit any discrimination based on race, color, religion, sex, or national origin in housing, sales, rentals or financing. The passing of the FHAA extends the protection of Title VIII to people with disabilities and to families with children. The study will explore the role of the FHAA in the lives of hoarders and on the safety and economic wellbeing of the community. The study will also provide an analysis on whether or not hoarders are protected under the housing laws.

Individuals with disabilities have always been mistreated and have never been considered quite good enough to receive the same benefits as abled individuals. The FHAA helps to eliminate some of the barriers that would prevent disabled persons from receiving their full civil rights (Ronan, 2011). With the passage of the FHAA, social workers are now able to recommend a reasonable accommodation that would allow the client to stay where they want to live limited by the applicable rules, policies, practices and available services (Bratiotis, 2013). By enforcing the FHAA, social workers will help eliminate the barriers that lead to isolation from the rest of society and encourage integration of these individuals with disabilities into all areas of society (Ronan, 2011). With these goals in mind, social workers may be able to develop and coordinate goals for their client that will improve intervention outcomes (Bratiotis, 2013). Even though the FHAA offers only a partial solution to protecting people with disabilities, it offers social workers another tool to help their clients and give them time to can find additional ways

and solutions to keep their clients protected and to keep the possibilities of interventions growing.

#### Social Work and Multicultural Relevance

Present research and future research of the hoarding behavior not only create an understanding of the behavior, but illuminate the best practices in working with hoarders, and the development of new treatment methods (Saltz, 2010). Social workers who are on the front line of this social problem are able to see that there is no real easy solution to this social problem, and there is no real guarantee of success (Metropolitan Washington Council of Governments, 2006; Saltz, 2010). Social workers will not be able to solve the hoarding behavior, but they can help find solutions for the hoarder's behavior and help the hoarder to see their problem (Bratiotis, 2013). Given that social workers are directly involved with the hoarders they become the link between the hoarder and the community (Saltz, 2010). The social worker's role does not just stop at the linkage, but starts at educating others, sharing knowledge with other professionals, helping hoarders understand their rights under the FHAA, and helping hoarders understand their diagnosis. A social worker's role for a hoarder is a continuous role that can be the most helpful for the hoarder, and which will help other professionals to see that this is not just a mental health issue, but a community issue (Ronan, 2011).

Hoarding behavior has been seen in people varying in age, sex, education, and socioeconomic level, and the time of onset has been seen to vary from person to person (Barksdale, Berry, Leon, & Madron, 2006). Hoarding is a very complex social problem that includes a number of public health and safety issues (Bratiotis, 2013). The behavior is characterized by the acquisition of objects and inability to use living spaces for the

intended purpose (Frost & Hartl, 1996). It has been estimated that hoarding impacts 3-5% of the American population, and the numbers appear to be similar in the countries of Germany and the United Kingdom (Bratiotis, 2013). Hoarding does not affect one area or one country; it is a behavior that needs more research to really understand the prevalence of this behavior and those affected by this behavior (Steketee & Frost, 2003).

## **Key Definitions**

FHA (Fair Housing Act of 1968): This act was created to prohibit the discrimination of sale, rental, and financing of housing based on religion, race, national origin, and sex (FHAA, 1988, § 3604(f)(3)(B), para. 1). This amendment was created to include people with disabilities or families under the protection of the FHA (Ronan, 2011).

Hoarding behavior: Is a problematic behavior in which the individual acquires a large number of possessions, will not discard or dispose of these items, and stores the items in such ways that affects the individual's life (Frost & Hartl, 1996).

*DSM-IV-TR* and *DSM-V*: *Diagnostic and Statistical Manual of Mental Disorders* (4<sup>th</sup> and 5<sup>th</sup> ed.), are the APA's classification and diagnostic tools. These resources are used for psychiatric diagnosis and treatment recommendations (APA, 2000; APA, 2013).

Reasonable accommodation: A reasonable accommodation is a change, adaptation or modification to a policy, program, service, or workplace which will allow a qualified person with a disability to participate fully in a program, take advantage of a service, or perform a job. Reasonable accommodations may include, for example, those which are necessary in order for the person with a disability to use and enjoy a dwelling, including public and common use spaces. Since persons with disabilities may have

special needs due to their disabilities, in some cases, simply treating them exactly the same as others may not ensure that they have an equal opportunity to use and enjoy a dwelling (Ligatti, 2013).

#### CHAPTER 2

#### LITERATURE REVIEW

## **Understanding Hoarding Behavior**

In the past 25 years hoarding has gained much attention among mental health clinicians, academic researchers, and in American society in general (Bratiotis, 2013; Frost & Hartl, 1996; Frost et al., 2000; Saltz, 2010). Hoarding is characterized by the acquisition of objects that are of limited value, inability to use living spaces for their intended purpose and functional impairment or distress (Frost & Hartl, 1996). The problem is that hoarders perceive themselves to have a special relationship with their belongings as if they were an extension of themselves (Saltz, 2010). If their things are removed or touched without their permission, they feel violated (Saltz, 2010). When hoarders perceive themselves or their belongings, in this manner, their behavior can lead to serious and life-threatening situations (Frost et al., 2000).

#### History

The case of the New York Collyer brothers brought wide attention to the issues and problems of hoarding. The Collyer brothers became famous for their reclusiveness and hoarding lifestyle even before the extent of their collecting became known. They became known as the Hermits of Harlem (Lidz, 2003). They lived in a four-story mansion on Fifth Avenue in Harlem that on the inside was filled with mostly useless possessions, newspapers, and just plain junk (Weiss, 2010). Their home was so packed

that Homer and Langley Collyer had to create a maze of tunnels out of magazines and old newspapers to be able to move around, and booby traps were set up to keep intruders at bay (Weiss, 2010). They both passed in 1947 when Langley was suffocated by his own booby trap; and Homer, who was blind, starved to death when his brother no longer brought him food. Even after their deaths the famous Collyer brothers' disorder captured the imaginations of New Yorkers as iconic hermits and hoarders (Weiss, 2010).

Even though their hoarding behavior was not a new phenomenon (Ligatti, 2013), the Collyer brothers were of persons of interest only to the police, utility companies, and banks, but their behavior was never brought to the attention of psychiatry or mental health professionals (Weiss, 2010). Hoarders and hermits have continued to provide a source of fascination in our society. When the person is famous, our society looks at them as if their issue is a simple matter, but when they are not famous they are deemed dangerous to themselves and others (Weiss, 2010). The difference with the Collyer brothers is they were the privileged class who were able to stay a step ahead of the law (Weiss, 2010). This could be why their behavior was not brought to the attention of mental health professionals (Weiss, 2010). In 1947 and in the mid-1950s, many did not really understand the behavior or how to even describe the behavior other than saying "clean up your room or you'll end up like the Collyer brothers!" (Weiss, 2010). Today the Collyer brothers have become iconic with firefighters, and psychiatrists, with the courts describing the hoarding behavior as Collyer Brothers Syndrome (Ronan, 2011). Now, as time has passed and awareness of the behavior is growing, there is a great need to study and understand the behavior, not just to label it as the Collyer Brothers Syndrome (Ronan, 2011; Weiss, 2010).

While hoarding is not a new phenomenon, empirical research of hoarding behavior is creating much attention and is increasing awareness of the issues surrounding this behavior. According to Fromm (1947) an individual whose security is dependent on the collection and saving of objects would be known as having the hoarding orientation. Jens Jansen (1962) referenced the term collector's mania as the expression to describe someone who collects junk of no value, which fills their living spaces. Many early psychiatrists would agree that "compulsory, panic collecting of hoarding and hoarding of many different objects, useful or useless" can lead to decreased mental functioning, most often senility (Jansen, 1962, p. 1351). It is evident by these early references; that hoarding has been of great interest in the mental health profession for many years, but now with more awareness, more research can be done.

## Hoarding in Older Adults

Hoarding has been characterized as a disorder of older adults (Steketee, Frost, & Kim, 2001). Of older adults who are struggling with hoarding behavior, most of them admit to lifelong struggle with this issue (Frost et al., 2000). Much of the empirical literature focuses on the hoarding behavior in students, subclinical, and clinical adult populations, but the case reports that have been published about this problem are predominately concerned with the elderly (Thomas, 1998). The empirical literature focus should not be taken to imply that hoarding behavior rarely occurs in the older age groups (Steketee et al., 2001). According to Frost et al. (2000), their study results showed that more than 40% of the hoarding complaints to health departments have involved elder services agencies. Research has come far, but there needs to be more research done with

elderly hoarders compared with younger hoarders, and with elderly non-hoarders to better understand the hoarding behavior in older adults (Steketee et al., 2001).

Older adults have longstanding eccentric personal habits that can be severe enough to impair their activities of daily living and their relationship with others (Andersen, Raffin-Bouchal, & Marcy-Edwards, 2008). Older hoarders are difficult when it comes to helping them to resolve the clutter or filth; they will resist the change and are unmotivated to discard any possessions (Grisham, Steketee, & Frost, 2008). According to Andersen et al. (2008), their study revealed that older hoarders acquire possessions because it is reassuring to their anxieties and helps them feel connected, socially engaged, needed by others, proud and productive, and in control of their living situation. In the hoarders' mind, acquiring more and more possessions gives them a sense of purpose and meaning to their lives (Andersen et al., 2008). Therefore, one cannot just tell an older adult hoarder to address their issue with hoarding by forcing them to adjust to society's standards of what cleanliness is, but must work to develop trust and to help them develop an understanding that their behavior is not normal (Andersen et al., 2008).

#### **National Hoarding**

The prevalence of hoarding behavior is greatly unknown due to the lack of research (Brown & Meszaros, 2007). Hoarding is hidden by those who exhibit the behavior because of pressures of self-preservation, shame, and isolation (Ligatti, 2013). Previously this behavior was considered a symptom of the Obsessive Compulsive Disorder (OCD; Saxena & Maidment, 2004). As research has developed, hoarding behavior is starting to show little or no relation to OCD (Steketee & Frost, 2003). A 2008 study done by Samuels et al. (2008) found between 3% to 5% of the general

population exhibit hoarding behavior. This was the first study to actually evaluate the general public's prevalence, demographics, and co-morbidities so as to provide understanding of the magnitude of this issue (Samuels et al., 2008).

According to Samuels et al. (2008) the socio-demographic characteristics evaluated in their study revealed that hoarding behavior increases as the hoarder ages. This study is consistent with Steketee and Frost's (2003) study, which indicates hoarding behavior begins early in life and then increases with time. Samuels et al.'s (2008) study revealed that gender, employment, marital status, and income levels were also found to be significant factors when it came to the hoarding behavior. This extensive study revealed that men were 2 times more likely than women to hoard, those who were unemployed or widowed were twice as likely to hoard as those who were not, and hoarding seemed to be inversely related to household income (Samuels et al., 2008). This study's research of the hoarding behavior revealed that the previous assumptions of the prevalence of hoarding behavior were great underestimations (Eckfield, 2010; Saltz, 2010).

## **Legal Problems**

Hoarding behavior harms people regardless of gender, socioeconomic status, ethnicity, or age. People's right to their independence and self-governance allows the individuals to act as they would like as long as the actions are within the confines of the law or they will suffer the consequences if they choose to not act within the law (Ligatti, 2013; Saltz, 2010). Hoarding can be a huge burden on the individual especially when it comes to the clutter and it has been reported, the risk of fire, falling, poor sanitation, and various health risks (Tolin et al., 2008). According to Tolin et al. (2008) health

department officials have indicated that hoarding poses a most substantial health risk; and has contributed directly to the hoarder's death. Even though these are constant battles that many communities face with hoarders, there is not enough community policies designed to really help the hoarder (Frost et al., 2000).

Severe hoarding has dramatic effects on the individual and the community (Frost et al., 2000). Hoarders are often reported to the health department and can face eviction due to health code violations (Frost, Steketee, Youngren, & Mallya, 1999). According to Frost et al. (1999), the hoarding behavior could lead to violation of local health, housing, and sanitation laws. There is a need for the community and federal to develop a way to solve this issue and to protect the individual and the community (Frost et al., 2000).

Frost et al. (2000), in their study, are able to describe the frequency and nature of the hoarding behavior. These researchers were able to create an awareness of the problematic behavior of hoarding and how infrequently this problem is reported to the health department (Frost et al., 2000). Many times a hoarders' problem will be recognized because their possessions are exceeding the confines of their home and this will then come to the attention of the police or fire department and health agencies (Frost et al., 2000). When these agencies come into contact with a hoarder they need to understand that the hoarder's possessions are related to a belief of their need and the hoarder's fears of lost opportunities (Frost & Hartl, 1996). The effects of this disorder are obviously very problematic, but for there to be an effective solution to legal problems, a thorough understanding of the issues needs to be developed by those who are trying to help the hoarders (Frost et al., 2000).

Dealing with hoarding behavior is always an ongoing process with some tension between mental health and public health systems (Saltz, 2010). The public health and safety professionals are primarily more concerned with the broader public safety and in enforcing a quick resolution to solve the public's problem (Saltz, 2010). In contrast, the mental health professionals resist the idea of an immediate resolution in order to reach out to the hoarder about the behavior and establish a trusting relationship that will lead to a resolution that will actually benefit and help the hoarder (Saltz, 2010). Somehow, these two groups need to find a way to come together to protect the rights and autonomy of the individual while responding to public health and safety issues (Saltz, 2010).

## DSM-IV-TR and DSM-V

Hoarding, in the *DSM-IV-TR*, is categorized under obsessive-compulsive personality disorder, although some professionals consider it as a subtype or dimension of OCD (Tolin et al., 2007). According to Frost et al. (2006), people who have hoarding problems experience no other OCD symptoms. Hoarding behavior has also been reported in a wide variety of Axis I disorders including: schizophrenia, social phobia, organic mental disorders, eating disorders, depression, and dementia (Steketee & Frost, 2003). However, as of May 2013, the APA had decided that hoarding behavior should be designated as a distinct form of mental illness.

Hoarding behavior has been found to occur with some cases of OCD, but the numbers are most likely an underestimate (Steketee & Frost, 2003). Interestingly, genetic studies found a significant chromosome linkage to OCD in families with relatives who hoard (Samuels et al., 2006), and research also shows that the hoarding behavior affects a multiple of family members with at least one first degree relative with the

hoarding problem (Pertusa et al., 2008; Samuels et al., 2006; Winsberg, Cassic, & Koran, 1999). This behavior has emerged as an unresolved challenge in understanding and treating OCD (Steketee & Frost, 2003). Hoarding behavior is known to result in serious and life-threatening pathology (Frost et al., 2000), and appears to increase with age (Steketee et al., 2001). A finding of hoarding correlates with treatment dropout and; failure or worse outcomes from the pharmacological and behavioral treatments for OCD (Black et al., 1998; Mataix-Cols, Marks, Greist, Kobak, & Baer, 2002; Mataix-Cols, Rauch, Manzo, Jenike, & Baer, 1999; Winsberg et al., 1999).

The debate between those who believe hoarding is a symptom of OCD and those who see it as a completely separate disorder is ongoing (Ligatti, 2013). Psychologists have discovered that roughly one quarter of OCD patients suffer from hoarding symptoms (Cobb et al., 2007). An epidemiological study found that between 2%-5% of people suffer from the hoarding behavior (Grisham & Norberg, 2010). While hoarding is possibly related to other conditions, it is in some ways the more complicated problem to treat (Ligatti, 2013). In the *DSM-IV-TR* hoarding behavior is not listed as a mental disorder, which could be why it is so complicated to treat (Pertusa, Frost, & Mataix-Cols, 2010). In the *DSM-IV-TR*, hoarding behavior is designated under OCD if the behavior is extreme; however, evidence suggests this behavior is distinct from other OCD symptoms (Grisham & Barlow, 2004). There is evidence that hoarding should constitute as a separate factor from other obsessions and compulsions (Calamari, Wiegartz, & Janeck, 1999; Mataix-Cols, Rauch, Manzo, Jenike, & Baer, 1999; Samuels et al., 2002).

The lack of epidemiological studies makes the diagnosis of hoarding as a subtype condition or an independent syndrome even more difficult (Steketee & Frost, 2003). As

of May of 2013, the *DSM-V* does not provide guidelines for treatment, but it will help in measuring the effectiveness of treatment, as dimensional assessments will assist in assessing the changes in severity levels in response to treatment (American Psychiatric Association, 2013). Even with hoarding behavior as its own diagnosis, there will still be a battle to prove the benefits of therapy for hoarders (Ronan, 2011). According to Saxena (2004) when comparing individuals who hoard compared with individuals with OCD, hoarders are less likely to respond to the traditional OCD treatment. Hoarders also exhibit personality features of behavioral inhibition and harm avoidance and demonstrate more personality disorder symptoms (Frost, Steketee, & Grisham, 2004). Finally, hoarders are distinguished from those with OCD when it comes to co-morbid mental health conditions and family history (Saxena, 2007). These findings support for why the hoarding behavior needs to be its own diagnosis and not part of OCD (Saxena, 2007).

Based on the research with mild to severe hoarders, Frost and Hartl (1996) created a cognitively based model of the hoarding behavior. The model shows that hoarding behavior will arise from a variety of information processing deficits, emotional attachment problems, behavioral avoidance, and the belief in the importance of their possessions (Franks, Lund, Poulton, & Caserta, 2008). The benefit of seeing this disorder as an independent disease is that there can then be a more effective and efficient way to help hoarders and to possibly prevent others becoming hoarders, as well as to stimulate research on this neglected topic (Franks et al., 2008).

#### Hoarding as a Social Problem

While there are many substantial problems that are experienced by a society, only a small portion impacts the public consciousness (Higartner & Bosk, 1988). The fierce

competition for public attention and how society acknowledges, and responds to the problem largely determines the status of the social problem (Higartner & Bosk, 1988). The prevalence of hoarding data suggests up to 5% of the American population suffers from a hoarding problem (Samuels et al., 2008). This evidence supports the view that hoarding is a serious problem that is impacting many lives, especially if we include not just the person with the hoarding problem, but also the families, neighbors and communities that are affected (Bratiotis, 2013).

Classifying hoarding as a social problem does not mean that hoarding has worsened (Saltz, 2010). Instead, it is more likely that hoarding is simply now entering the public consciousness (Saltz, 2010). Hoarding has progressed from social topic recognition to a social problem status, not because of its impact, but because of the conflict between public and private values (Nelson, 1984). Hoarding behavior elicits strong moral conflicts as well as conflicts among professional groups (Saltz, 2010). Until recently, hoarding was treated exclusively as a private mental health problem (Franks et al., 2008).

Even with the primary impact of hoarding on the hoarder and the potential secondary impact on multiple others, hoarding still remains an individual concern (Gusfield, 1989). With the number of cases increasing, there begins a journey from an individual problem to the public problem wherein the victim and villain become recognizable to society (Bratiotis, 2013). When this problem presents itself to the public as a problem, it has now become a potential harm for others (Bratiotis, 2013). The hoarder is now the villain for creating the threat of harm while at the same time becoming the victim to health and safety threats from their own actions (Bratiotis, 2013). When

these cases consistently present public health and safety concerns, then hoarding emerges as the social problem of greater importance and interest (Gusfield, 1989).

Emotional family support is a powerful protective factor against individual maladaptive behaviors, such as hoarding. Social support constructs what is defined as the comfort, assistance, and/or information one receives through formal or informal contacts with individuals or groups (Wallston, Alagna, DeVellis, & DeVellis, 1983). Research has studied hoarding behavior as the outcome for afflictions like mental health comorbidity (Lunhins, Goldman, & Hanrahan, 1992; Mataix-Cols, Baer, Rauch, & Jenike, 2000; Samuels et al., 2006; Samuels et al., 2008) or information-processing deficits (Frost & Hartl, 1996), while focusing less attention on hoarding as the potential response to the other types of contextual influences, such as family dynamics and past relational experiences.

When it comes to older adult hoarders and their families who want to help them, it can be very complex to keep the hoarder aging in place (Koenig, Chapin, & Spano, 2010). Aging in place is not simple and is-especially so for those who hoard because they want to remain living in their own homes, neighborhoods, and communities even though their own actions make it difficult (Whitfield, Daniels, Flesaker, & Simmons, 2011). According to Whitfield et al. (2011), aging in place is an ideal where people can age in their homes, neighborhoods, and communities where their quality of life is at their total disposal. The whole point of aging in place is about belonging to a community that will support one's needs (Bookman, 2008). Aging in place might not always be possible, but the realization of community-level social and health-related supports can maximize the quality of aging at home (Institute for Life Course and Aging, 2008).

## Public Health and Safety Problem Versus Autonomy

In our society, individuals are rewarded when they carefully assemble a complete collection and save valuable possessions (Grisham & Barlow, 2004). When the acquiring and saving becomes irrational or extreme, then, the behavior can become maladaptive and possibly dangerous (Grisham & Barlow, 2004). Even though the accumulation of possessions can make the individual feel more secure, it can also create risks from falls, fires, and sanitation problems (Frost et al., 2000; Steketee et al., 2001). Even in the less severe cases, hoarding can interfere with the individual's ability to work, interact with others, and perform the basic activities of life (Grisham & Barlow, 2004). The ideal of individualism is the drive of our American social response and is challenged when the issue of hoarding requires a compassionate social response (Lantz & Booth, 1998).

However, as a society, we are often able to be compassionate towards the problem when there still exist a level of individual vulnerability (Lantz & Booth, 1998).

According to Loeske's (1989) study, when an individual trouble moves to becoming a social problem, a professional group will identify itself and become equipped to respond to the social problem. Because hoarding is so complex, it requires a response that can address the mental and physical health issues, threats to physical and emotional safety, and impact on family and friends, as well as the threats to health and safety (Frost et al., 2000). A question one will always have is whether the professional intervention is successful in addressing the myriad individual and societal difficulties associated with the behavior while fulfilling the response to the problem in order to be considered socially constructive (Frost et al., 2000).

## <u>Policy</u>

The passage of the FHAA can be seen as a way to provide a solution to the tension created by the differing purposes of the public health and safety professionals and the mental health professionals who work with hoarders. With the FHAA in place, the hoarders' team or the hoarder can request a reasonable accommodation for the person's disability (Ligatti, 2013). Usually this accommodation consists of delaying and in the long run avoiding eviction by giving the hoarder enough time to remedy the situation (Fair Housing Amendments Act, 1988, § 3604(f)(3)(B); Ligatti, 2013). If the hoarder has made a request for reasonable accommodation, the landlord must comply and adjust the lease to allow for the hoarder's needs (Ronan, 2011). This is an opportunity for the landlord and hoarder to discuss a reasonable accommodation that would suit both of their needs (Ronan, 2011). Usually with a hoarder, the request is for time (Ligatti, 2013).

Despite the landlord having agreed to the accommodation and the hoarder having agreed to fix any lease violations, there is no guarantee the problem will not arise again (Barksdale et al., 2006; Ligatti, 2013). The most difficult aspect of hoarding is there is no magic pill to cure this behavior and the hoarder will continue to suffer with this problem for their entire life (Barksdale et al., 2006; Ligatti, 2013). Relapses do not signal an absolute failure for the hoarder for not sticking to the accommodation plan, but such relapses are expected when dealing with a serious mental illness (Ligatti, 2013).

The shame of hoarding is one of the prominent aspects of this disorder. Keeping the behavior hidden; prevents treatment; keeping the individual in a state of isolation; leads to the lessening of social interaction; and then reinforces the behavior itself (Bratiotis, Schmalisch, & Steketee, 2011; Frost & Steketee, 2010; Rodriguez, Panero, &

Tannen, 2010). Due to the very nature of hoarding, the individual will go to great lengths to hide the problem; or at least the extent of it (Ligatti, 2013). The health and safety risks created by this issue have serious legal implications (Ligatti, 2013). The needs of the mentally ill for safe and affordable independent living must be weighed against the needs of the housing providers and the numerous local health laws designed to protect the public at large (Ligatti, 2013). Now, not only are these individuals dealing with their disabling condition and trying to find affordable housing, but they are also dealing with the pervasive stereotypes that are just as disabling as the condition itself (Ligatti, 2013).

In most cases hoarding behavior will create conditions that violate federal, state and local laws (Ligatti, 2013). When the hoarding behavior is taking place in an individual's home it can lead to fines and nuisance proceedings, and, when it takes place in an apartment, there are tenant laws, as well as private leases, which impose the responsibilities and duties that a tenant must fulfill (Ligatti, 2013). Subsidized housing, the last resort for these people, is the only thing standing between individuals or families and homelessness (Cobb et al., 2007).

Housing providers and mental health advocates struggle with how to balance the housing needs of the mentally ill with the needs of their neighbors and landlords (Ligatti, 2013; Saltz, 2010). Therefore, local municipalities, agencies, and landlords need to find a way to collaborate to stop the destructive consequences of hoarding behavior (Frost & Hartl, 1996). Due to the magnitude of the danger that hoarding can create, it is likely that hoarders will lack sufficient protection from eviction at the local level (Ronan, 2011). When state and municipal law fails, hoarding behavior should be recognized as a mental

disability under the Fair Housing Amendments Act (FHAA; International OCD Foundation, 2011).

It is clear that a reasonable accommodation law will not require the housing provider to do everything possible to accommodate the tenant (Eisner, 1997). The requirement is only for a "reasonable" accommodation. A request can be considered reasonable unless it will result in the fundamental alteration to the program or place an undue financial burden on the landlord (Ligatti, 2013). In addition, the landlord can reject a requested accommodation where the tenant might pose a threat to the health or safety of other residents or when the property might be subject to substantial physical damage (Douglas v. Kriegsfled Corp., 844 A.2d 1109, 1125-26 (D.C. Cir. 2005). There is a current split regarding which party bears the burden of proving that a tenant or their behavior constitutes a direct threat (Groner v. Golden Gate Gardens Apartments, 250 F.3d 1039, 1044-45 (6<sup>th</sup> Cir. 2001). In our court system when a reasonable accommodation is presented, its reasonableness is determined on a case-by-case basis and the law also requires the landlord to engage in an interactive process with the hoarder who is requesting the accommodation (Ligatti, 2013). However, the Department of Justice has determined that the disabled person is the best judge of what accommodations are needed (Ligatti, 2013).

The legal challenges to providing adequate reasonable accommodations for hoarders are: (1) the legal system's lack of knowledge about the disorder impairs the ability to properly treat hoarders fairly, and (2) there is no established solution to deal with hoarding (Ronan, 2011). Until hoarding is truly recognized as a disability, courts will not see an accommodation involving treatment, rather than a cleanout, as a

reasonable solution, and the courts will not recognize the importance of maintaining the hoarder's ability to remain in their restored living areas (Ronan, 2011). Nonetheless, the hoarding populations who can assert their rights to reasonable accommodation are those individuals who are receiving federal housing through Section Eight Housing (Ronan, 2011). The individuals who are in this program are in a better position because Section Eight rules contain due process safeguards for the tenants and the landlords in this program are mandated to help their tenants (Ronan, 2011).

The FHAA is a medium to protect hoarders (Ronan, 2011). The FHAA is what hoarders can use to resist landlords' eviction attempts when their tenancy constitutes a threat to the health and safety of the individuals around them (Bratiotis, 2013). Even so, tenancy may be denied if the person poses a direct threat and risk of harm to health and safety of others. If the risk can be eliminated with a reasonable accommodation, entities covered under the FHA are required to agree to such accommodation (Radecki v. Joura, 8<sup>th</sup> Cir. 1997; Howard v. City of Beavercreek, S.D. Ohio 2000; Roe v. Housing Authority of Boulder, D. Colorado 1995; Roe v. Sugar River Mills Association (D.N.H. 1993). Another problem is that if the court sides with the hoarder and gives the person additional time to de-clutter the dwelling unit, the amount of time that is given to the hoarder to clean up might not be sufficient to actually clean a hoarders apartment and may show no recognition of the reality of the continuous treatment the hoarder needs (Pittman, 2010). The direction that courts are going in is still being determined, but interestingly one court decided the exception requiring amelioration of risk to others might not apply to hoarders (Ronan, 2011). Clifford Fried, a lawyer and editorialist of the San Francisco Apartment Magazine, reported the decision in a local superior court eviction trial, Trophy Properties

v. Taylor (Fried, 2006). A jury decided that, although the defendant created a nuisance by hoarding and cluttering her apartment, the tenant could not be evicted because she suffered from a disability and the landlord had failed to accommodate her (Fried, 2006). Even though the jury found the defendant had created the nuisance by keeping her apartment in the dangerous and unsanitary condition, she had not been offered a reasonable accommodation. The jury agreed she could stay in her apartment because she had not been offered the required reasonable accommodation (Fried, 2006). This case could be just an outlier on this issue, but it could also be the new realization that the health and safety exception of the FHAA does not really apply to hoarders (Ronan, 2011).

## Community

Hoarding is a community health problem that needs a community solution (Ronan, 2011). Samuels et al. (2008) reported that further research into hoarding behavior might provide insight for developing interventions for treatment and prevention of hoarding with-in the community. As complex as hording is, it will require coordination of care (Bratiotis, 2013). The work that goes into coordination of hoarding services allows the cross-pollination of information and ideas, collegial support, and a comprehensive treatment of an individual's hording issue from many professional perspectives (Bratiotis, 2013). Although the impact of professionals working together, passage of the FHAA, and recent research on hoarding behavior have increased the attention paid to this disorder, the study of hoarding still remains a developing field (Steketee & Frost, 2003).

In the past decade several communities have developed task forces to address the complex issues exhibited by the hoarding behavior and the attention from the cases that come to the public's attention. The development of the task force will determine if this mechanism is beneficial for the social networks and other community practices and policies (Bratiotis, 2013). So far, the development of the task force is the most promising intervention when it comes to hoarding behavior (Frost et al., 2000). Utilizing the task force as a response to the social problem of hoarding is an innovative strategy. As these groups take the lead in organizing and developing a community response to this social problem of hoarding, the results can be used to develop community policies focusing on intervention, collaboration and resource utilization (Bratiotis, 2013). If the communities throughout the United States used task forces as an intervention towards hoarding, then just maybe more systematic changes could be created (Bratiotis, 2013; Frost et al., 2000).

Some areas have taken on the obligation of creating task forces in their communities; here are five communities which are utilizing task forces as a community response/intervention:

1. Fairfax County, Virgina: This entity developed its task force in 1999. It became, the first task force known for dealing with hoarding in the United States. This task force meets monthly with 15-20 employees from different departments within the county structure. These employees come from environmental health, zoning, building code services, fire, animal control, mobile crisis, and adult protective services. They have one goal in mind: how to help hoarders in their community. Now in their fifteenth year, their presence in their community is still strong, creating education, solutions, and help for hoarders and those around the hoarder (Bratiotis, 2013).

- 2. Hampshire, Hamden and Franklin Counties, Massachusetts: This task force was formed in 2003. Their membership consists of representatives from the departments of public health, housing, code enforcement, mental health, protective services, and education. In the last 11 years, their membership has diminished from the seven to eight agencies they started with to only two or three agencies attending. It is reorganizing slowly and is doing its best for hoarders in their communities, and has been able to gain some support to keep up their efforts in the community (Bratiotis, 2013).
- 3. Orange County, California: This task force was established in 2004. This task force meets monthly with agencies and organizations from environmental health, code enforcement, mental health, adult protective services, fire authority, senior service providers, and individuals with hoarding problems. To educate the community and other professionals they have educational material including brochures, and power point presentation, creating awareness of how to respond to the hoarding behavior. Their office hosts community hoarding summits to promote public awareness. This task force's goal is to provide community education, case consultation, resource identification, and networking (Bratiotis, 2013).
- 4. Sedgwick County, Kansas: This task force was formed in 2006. Their meetings are held monthly with attendees from the agencies of the department on aging, code enforcement, environmental services, mental health, adult protective services, fire, professional organizer and law enforcement. To help further educate the community they have created a brochure, a website, business cards with their contact info, and a power point presentation to create more awareness. Their goal is to gain referrals from other

professionals, triaging, intervening and staying updated on the cases that pertain to hoarding (Bratiotis, 2013).

5. San Francisco, California: This task force was formed in 2007 and is in partnership with the Mental Health Association of San Francisco and the San Francisco Department of Aging and Adult Services. They meet every other month with other members from the following organizations public health, adult protective services, housing, mental health, law enforcement and individuals with the hoarding behavior. This task force educates the community about hoarding through educational materials, brochures, resource guide, and they also host hoarding support groups and annual hoarding conferences. It is known that this task force meets with the intention of studying the impact of hoarding in the City of San Francisco. With this in mind, they were able to fund a two-year study, the results of which will be reported to the local policy makers (Bratiotis, 2013).

The established task forces are dealing with the disorder on the community level. Obviously public policies do not exist in many communities throughout the United States, but the formation of these task forces provides a promising avenue for addressing hoarding on a community and personal level (Frost et al., 2000). Task forces are also known as collaborates, as collectives, and as networks; to describe a fusion of the efforts that involve social planning, community organizing and development, and policy advocacy (Roussos & Fawcett, 2000). Tolin, Kiehl, Worhunsky, Book, and Maltby (2007) reported that a small town health department spent \$16,000 to clear out one house, to later face the problem recurring 18 months later. Many cities have established task forces to help deal with the individuals who hoard (Frost & Steketee, 2003). Hoarding

has the highest rates of psychiatric comorbidity; in a study of 104 hoarding participants, 57 % met diagnostic criteria for major depressive disorder, 29% for social phobia, and 28% for generalized anxiety disorder (Frost et al., 2006). The data suggests the impact of hoarding on a per-person basis exceeds many psychiatric disorders (Tolin et al., 2007). The costs appear to affect not only the individual who hoards, but also society as a whole in the way of lost work productivity, mental health service utilization, non-psychiatric, costs and community agency involvement. Further research and evaluation needs to be done to really see the overall costs and impact of hoarding in the population (Tolin et al., 2007).

## **Ecological Theory**

The ecological theory posits that the causes and solutions of the health and social problem are beyond the control of the individual and are instead imposed by the quality of the community (Mikkonen & Raphael, 2010). According to Higartner and Bosk (1988), the rise of the social problem (hoarding) in one area will likely indicate embracing the social problem in another area. According to Germain (1979), the ecological theory refers to the actions between people and their environments, nested at multiple levels. Professionals will be able to understand that the most appropriate intervention within the particular environment is crucial (Germain, 1979). The establishment of task forces to assist with the social problem of hoarding has led task forces to see the need for the multi-level environmental system intervention, which will assist with hoarding at all environmental levels originally proposed by Bronfenbrenner (1979).

## Solution to Hoarding

People with hoarding behavior are the most underrepresented when it comes to treatment because their refusal of treatment makes the development of an effective treatment exceptionally difficult (Steketee & Frost, 2003). In fact, there have been negative case reports regarding the treatment of hoarding (Saxena & Maidment, 2004). Saxena and Maidment (2004) recommend the class of medications that have been used with hoarders who also have other mental health issues, that respond well to SSRI's such as; fluoxetine, sertraline and citalopram and anti-obsession medications such as fluvoxamine. Earlier clinical research trials found that pharmacological treatments did not produce any significant improvement when it came to hoarding (Mataix-Cols, Rauch, Manzo, Jenike, & Baer, 1999). According to Clairborn (2006), this may have occurred because people with OCD have anxiety despite engaging in avoidance and ritual behaviors, where hoarders experience less anxiety than those with OCD. The hoarders' lack of response to medications serves as evidence to help separate hoarding from OCD.

The research that has been done on the various forms of psychotherapy has found to be very beneficial. According to Christensen and Griest (2001), hoarding had the worst outcome when it came to behavioral therapy when compared to other disorders. Abramowitz, Franklin, Schwartz, and Furr (2003) found that (CBT) cognitive behavioral therapy when using the traditional exposure and the response prevention method was 63% effective for OCD clients vs. 31% for hoarders. There were two studies done to research the effectiveness of medication and therapeutic intervention, which showed slight improvement for hoarders (Winsberg et al., 1999).

There is no easy solution when it comes to hoarding (Saltz, 2010). There are different treatment options that exist, some of which are in development and can offer a great potential for future treatment (Saltz, 2010). Currently there are three major forms of intervention for hoarders including cognitive behavior therapy (CBT), harm reduction, and motivational interviewing (Saltz, 2010). CBT developed by Steketee and Frost, involves skill building in the areas of decision-making, categorizing and de-cluttering (Saltz, 2010). Harm reduction concentrates on trying to help the hoarder live more safely rather than to stop hoarding (Eckfield, 2010; Saltz, 2010). Motivational Interviewing is combined with a cognitive-behavioral model utilizing motivational strategies to promote readiness change for the client (Saltz, 2010). There is little evidence to show that medication or psychotherapy, have been the most effective in treating individual hoarders (Eckfield, 2010; Saltz, 2010). However, no matter which treatment is chosen, it is crucial to recognize that denial is the biggest issue of this disease and it presents a substantial barrier for an effective treatment (Saltz, 2010).

# CHAPTER 3

#### **METHODS**

# Research Design and Framework

Data will be gathered from several sources, including legislation, government documents, court cases, personal accounts and (Fair Housing Amendments Act, 1988, § 3604(f)(3)(B) will be performed using selected components of Gil's (1992) policy analysis framework. The specific components of the analysis will include: a detailed description of the social problem and the key issues the policy addresses, the objectives, value premises, theoretical positions and effects of the policy, and implications of the policy for social structure and the social system (Gil, 1992). A copy of the framework is included in the Appendix of this document.

# Sampling

This study will use a variety of primary and secondary sources of literature as data to research the FHAA. Scholarly articles will be reviewed and will include "Age of Onset of Compulsive Hoarding" by Grisham, Frost, Steketee, Kim and Hood, "Older Adults with Hoarding Behavior Aging in Place: Looking to a Collaborative Community-Based Planning Approach for Solutions" by Whitfield, Daniels, Flesaker and Simmons, "Treatment of Compulsive Hoarding" by Saxena and Maidment, "Formation of Attachment to Possessions in Compulsive Hoarding" by Grisham, Frost, Steketee, Kim, Tarkoff, and Hood, "Community Hoarding Task Forces: A Comparative Case Study of

Five Task Forces in the United States" by Bratiotis, "Hoarding a Community Health Problem" by Frost, Steketee, and Williams, "Compulsive Hoarding: Current status of the Research" by Steketee and Frost, "Compulsive Hoarding, or Collyer Brothers Syndrome, and the Legal Reality of Clutter" by Ronan, "Hoarding and Elders: Current Trends, Dilemmas, and Solutions" by Saltz, "Evaluating and Selecting Interventions for Older Adults with Hoarding and Cluttering Behaviors" by Eckfield and Candidate, "Home-Based Intervention for Elderly Hoarders: What Really Works?" by Bratiotis and Flowers, "Fair Housing and Hoarding and Sanitation Fact Sheet" by Metropolitan Boston Housing Partnership, "Cluttered Apartments and Complicated Tenancies: A Collaborative Intervention Approach to Tenant "Hoarding Under the Fair Housing Act" by Ligatti. Statistical data will be gathered from resources such as "The Economic and Social Burden of Compulsive Hoarding" by Tolin, Frost, Steketee, Gray, and Fitch. This data will display the geographical and ethnic backgrounds of those people who hoard, with a focus on national and global hoarding statistics.

# **Data Collection Procedure**

Primary and secondary sources of literature suitable for use in this policy analysis will be identified using a variety of methods. Electronic databases, such as EBSCO, Lexis-Nexis, Jstor and Illuminations, Social Services Abstracts, will be used to access articles from scholarly journals and law reviews. The California State University, Long Beach library and its electronic catalog will also be used to locate books and articles. Internet search engines, such as Google Scholar and government websites, such as Bureau Justice of Statistics and Thomas, will be used to locate government documents and legislation to be used in this policy analysis.

# Data Analysis

All sources of literature gathered will be used to construct a policy analysis using a modified version of Gil's (1992) framework of policy analysis. A focused content analysis will be used to determine the meaning, objectives, effects, and values associated with the literature and legislation reviewed. This technique will be used to complete a policy analysis of the (Fair Housing Amendments Act, 1988, § 3604(f)(3)(B) focusing on issues related to hoarders.

#### **CHAPTER 4**

# **POLICY ANALYSIS**

# Section A: Issues Dealt With by the Policy

# Nature, Scope, and Distribution of the Problem

In the past 25 years hoarding has gained much attention among mental health clinicians, academic researchers, and in American society in general (Bratiotis, 2013; Frost & Hartl, 1996; Frost et al., 2000; Saltz, 2010). It is estimated that 3%-5% of Americans are affected by the hoarding behavior (Samuels et al., 2008). Hoarding can have debilitating consequences for older adults who hoard, as well as for their families and the community in which they live (Koenig et al., 2013). It is known that social services and other agencies do as much as they can in addressing the public health and safety problems resulting from hoarding (Koenig et al., 2013). Due to the complex nature of hoarding and the many agencies that are needed for a single hoarding case, many believe a multidisciplinary approach is needed and can be successful in responding to the problems of hoarding (Abramson, 2005; Franks, Lund, & Poulton, 2004; Frost et al., 2000; Steketee et al., 2001).

The multidisciplinary approach will need the involvement of a variety of public and private agencies representing human, animal, health, legal, and environmental concerns (Abramson, 2005; Anetzberger et al., 2000; Dyer & Prati, 2006; Teaster, Nerenberg, & Stansbury, 2003). A mental health professional would be the most

important member of this multidisciplinary approach and can contribute to control hoarding behavior (Koenig et al., 2013). However, due to limited funding there is little possibility of having a mental health professional on the team. Having a mental health professional on the team would not only increase the awareness, but the mental health professional would also provide the maximum possible benefit for the hoarders who could really benefit from the mental health treatment and services (Koenig et al., 2013).

There is still a great debate on whether or not hoarding is a symptom of OCD or if hoarding is its own diagnosis (Abramowitz, Wheaton, & Storch, 2008; Pertusa et al., 2008). Researchers from various fields are investigating the relationship between hoarding and the various etiologies, such as brain function and impairment (Anderson, Damasio, & Damasio, 2005; Grisham, Brown, Savage, Steketee, & Barlow, 2007), genetics (Alonso et al., 2008; Matthews et al., 2007, Samuels et al., 2007), gender differences (Samuels et al., 2007), and traumatic life events (Cromer, Schmidt, & Murphy, 2007). With this collective knowledge and our rapidly increasing knowledge of the causes of hoarding, the current uncertainty leaves the field without definitive statements on what hoarding is, what exactly causes it, or how to treat it (Koenig, Leiste, Spano, & Chapin, 2013).

# Hypothesis Concerning the Issues

Hoarding is a community health problem in need of a community solution (Ronan, 2011). Samuels et al. (2008) reported that further research into hoarding behavior might provide insight for developing interventions for treatment and prevention of hoarding within the community. As complex as hoarding is, it will require coordination of care (Bratiotis, 2013). The work that goes into the coordination of

hoarding services allows the cross-pollination of information and a comprehensive treatment of an individual's hoarding issue from the many professional perspectives (Bratiotis, 2013). Although the impact of professionals working together to solve the issue of hoarding, the passage of the FHAA, and recent research on hoarding behavior have increased the attention paid to this disorder, the study of hoarding still remains a developing field (Steketee & Frost, 2003).

The creation of the FHAA is seen as a way to provide a solution to the tension created by the differing purposes of the public health and safety professionals and the mental health professionals who work with hoarders. With the FHAA a hoarder or a task force working with a hoarder can request a reasonable accommodation for the disability of the hoarding behavior (Ligatti, 2013). This accommodation usually consists of delaying and eventually avoiding eviction by giving the hoarder enough time to remedy the situation (Fair Housing Amendments Act, 1988, §3604(f)(3)(B); Ligatti, 2013).

Despite the accommodation being requested, and the landlord agreeing to the accommodation, and the hoarder agreeing to fix the violations, there is no guarantee the problem will not arise again (Barksdale et al., 2006; Ligatti, 2013). There is no magic pill to cure this behavior and it is most likely that the hoarder will suffer with this problem their entire life (Barksdale et al., 2006; Ligatti, 2013).

Section B: Objectives, Value Premises, Theoretical Positions, Target Segments, and Substantive Effects of the Policy

# Policy Objective

The Fair Housing Act of 1968, also known as Title VIII of the Civil Rights Act of 1968, was enacted to protect tenants from housing discrimination on the basis of sex,

color, race, religion, or national origin (Ronan, 2011, p. 253). In 1988, Congress extended the Fair Housing Act by enacting the Fair Housing Amendments Act of 1988, which protects tenants from any form of housing discrimination based on familial status or disability (Fair Housing Amendments Act, & Ronan, 2011, p. 253). The purpose of the Fair Housing Amendments Act is to end the unnecessary exclusion of persons with handicaps from housing available to non-handicapped persons and to recognize that the right to be free from housing discrimination is essential to the goal of independent living (Ronan, 2011).

### Overt Objective

Hoarding behavior by tenants creates unsafe, unsanitary conditions that will impact both the hoarding tenant and the other tenants in the building while at the same time risking significant damage to the housing provider's or landlords property (Bratiotis, 2013). Housing providers, landlords, and mental health advocates are constantly struggling with precisely how to balance the housing needs of the mentally ill with the needs of the neighbors, landlords, and housing providers (Ligatti, 2013). Stable housing is particularly vital for the mentally ill since these are individuals who desperately need to maintain close contact with their physicians, social services providers, and other treatment professionals (Kanter, 1994). Thus the acquisition of stable housing and the quality of that housing is a very serious challenge facing the mentally ill (Carter, 2010).

The Fair Housing Amendments Act (42 U.S.C. § 3604(f)(3)(B), 2006) requires a reasonable accommodation in the form of a change in the housing provider's or landlord's policy or practice only when it is medically necessary. The FHAA, passed and signed into law in 1988, amends Title VIII of the Civil Rights Act of 1968, also known as

the Fair Housing Act, to add protections for the disabled (42 U.S.C. § 3604(f)(3)(B), 2006). Landlords and housing providers are required to grant reasonable accommodations when a request is made by the disabled individual and the landlord or housing provider knows or should have known of the disability (Ligatti, 2013). The reasonable accommodation request is a request that is made by the disabled individual in order to acquire an equal opportunity to enjoy their home (Schwemm, 1990).

In order for a person to be qualified as a disabled individual, there must be proof of a person's physical or mental impairment and that the impairment impacts a major life activity. The impairment definition is quite broad and expressly includes mental or psychiatric disabilities, the term major life activities is not clearly defined (Millar, 2012). The courts have agreed that major life activities will include: working, sleeping, concentrating, self-care, and interacting with others (Stephenson, 2004). This disabled person needs to show only that the desired accommodation will affirmatively enhance the individual's quality of life by ameliorating the effects of the disability (*Bronk v. Ineichen*, 1995). It is well known and accepted that the reasonable accommodation law will not require the housing provider or landlord to do everything humanly possible to accommodate the individual (Eisner, 1997). Typically, the requests are reasonable unless they result in a fundamental alteration of the housing provider's or landlords program or entailing an undue financial burden (Schwemm, 1990).

It is known that a housing provider or a landlord may reject the accommodation request if the individual poses a direct threat to the health or safety of the other residents or even if the individual's tenancy results in physical damage to the property of others (*Douglas v. Kriegsfeld Corp*, 2005). There is a current judicial split regarding whether or

not the plaintiff or the defendant has the burden of proving the reasonableness, but it is clear that on the question of whether the individual's behavior constitutes a direct threat, the burden rests upon the housing provider or landlord (Schwemm, 1990).

There are no formal requirements for accommodation requests. They can be written or oral and do not need to use any specific language (Ligatti, 2013). There is also no particular time requirement (Cobb, 2007). When it comes to eviction cases, reasonable accommodation requests can be made any time before the actual physical eviction (*Radecki v. Joura*, 1997). Housing providers and landlords are required to engage as much as they can in an interactive process with the individuals requesting the reasonable accommodations (*Auer v. Robbins*, 1997). However, the Department of Justice is clear that when it comes to determining whether the proposed accommodation will meet that individual's need, the individual understands their needs better than any landlord or housing provider (Ligatti, 2013). Therefore, the determination on the issue is influenced by the disabled individual's view of the accommodation (Widmer, 2007). The failure of the housing provider or landlord to make the accommodation will lead to the court awarding economic damages, as well as emotional distress damages, and even punitive damages or penalties (*Krueger v. Cuomo*, 1997).

# **Explicit Value Premises**

There are studies that indicate that the legal situation of hoarders varies considerably according to state laws, local ordinances, and, to some extent, community standards and values (Bell, 2012). The interesting paradox is that while hoarders generally will not seek or welcome intrusions into their life or home, they often attract

this intrusion by falling to pay utility bills and rent (Bell, 2012). Ultimately, the utilities are cut off, and the non-payment of rent can result in eviction (Bell, 2012).

When it comes to fines, their imposition is a reflection of community standards toward hoarding (Bell, 2012). However, the imposition of fines is not necessarily limited to the physical condition of the homes, but also to the casual factors of the hoarding behavior (Bell, 2012). A study by Tolin et al. (2007) found instances of hoarders who had failed to file income tax returns in at least one of the previous five years. Tax arrears increase the financial burden on hoarders and highlight the hoarders' intense emotional attachment to their possessions, their impaired executive functioning, and their great lack of insight regarding their hoarding behavior (Bell, 2012).

The need to hoard increases the social burden on communities and creates a severe psychological impact on displaced hoarders (Bell, 2012). The strong attachment that hoarders experience to their possessions means that watching as these possessions start to be removed and thrown into a dumpster will make them feel violated (Bell, 2012). When eviction occurs as the result of compulsory clean-up, the opportunity to obtain rental properties becomes more difficult because of the prior poor rental history (Bell, 2012). For hoarders who are on low, fixed incomes, homeless shelters might be the only option (Bell, 2012).

However, laws are in place to protect the tenants and prevent evictions (Bell, 2012). The Fair Housing Act of 1968, as amended, prohibits housing discrimination (www.FEMA.gov) and landlords cannot begin eviction procedures without providing notice (Bell, 2012). The fair housing laws' ending tenancy vary from state to state (Ronan, 2011).

The consequences of hoarding in the community vary according to the severity and environmental damage (Bell, 2012). Hoarders do not seek any form of attention, but risk attracting attention from the community as a result of their behavior (Bell, 2012). When their behavior becomes noticed, then multiple agencies become involved (Bell, 2012). When these agencies become involved, the hoarder's anonymity comes to an end, and they start to lose control of what their lives were (Bell, 2012).

Depending on state and local ordinances, health and fire departments often have broad powers to condemn properties for health and safety violations and this condemnation, can lead to evictions (Bell, 2012; Ronan, 2011). These departments have the legal power to require that the homes be brought into compliance with health and safety codes (Schmalishch, 2012). This type of action places the responsibility on the hoarder to comply with the applicable codes, but it is theorized that without additional support the actual likelihood of compliance is limited (Bell, 2012). Hoarders will be resistant to any form of change; they will fail to acknowledge the consequences of their actions and their lack of finances, and they are likely to lack the cognitive abilities necessary to comprehend the remedial actions (Bell, 2012). According to Schmalisch (2012) there is evidence that judges and lawyers across the U.S. are starting to recognize that the legal system can also be very powerful in supporting changes to better understand hoarding as a social and personal problem. This understanding is a positive and humane response to people who hoard and shows the beginnings of respect and protection of the rights of hoarders (Bell, 2012).

# **Covert Objectives and Implicit Value Premises**

Legal cases dealing with hoarding have arisen when the hoarding behavior has created conditions that violate federal, state, or local laws (Ligatti, 2013). Most of time the issue of hoarding will typically arise in apartment buildings or other rental housing, but individuals who hoard in their own homes can also fines or nuisance proceedings (Cobb et al., 2007). When it comes to the terms of rental housing, landlord tenant laws and private leases all impose certain responsibilities upon the tenants (Ligatti, 2013). These responsibilities include disposing waste in a timely manner, not defacing, destroying, or impairing any part of the premises, not disturbing the peaceful enjoyment of neighbors, and abiding by all the building and housing codes (Unif. Residential Landlord and Tenant Act § 3.101). Furthermore, the state public-health codes that apply to rentals make any unsanitary conditions an offense (Bratiotis et al., 2011). These health and safety codes deal with improper storage of garbage, presence of pests, and fire hazards such as blocking access to and storing large amounts of flammable materials near fire dangers in the home (Bratiotis et al., 2011). When it comes to a possible eviction action, hoarding behavior can not only lead to fines, but to the condemnation of the property (Cobb et al., 2007).

Most forms of subsidized housing, whether publicly or privately owned, also have very similar requirements when it comes to health and safety (Ligatti, 2013). This is a very important issue because subsidized housing is very often the last chance housing, the only thing standing between the individuals and homelessness (Cobb et al., 2007; Carter, 2010; Bratiotis et al., 2011). Federal regulations require that health and safety provisions to be included in the leases between the tenant and the housing provider. Some forms of

subsidy, require that annual inspections showing that the unit will meet the Housing Quality Standards. Therefore any violations of these regulations are grounds for immediate lease termination.

The legal regulations are based on legitimate health and safety concerns (Ligatti, 2013). First responders need to be able to gain access for themselves and the necessary medical equipment but with hoarders; this access is consistently a problem (Bratiotis et al., 2011). Furthermore, rotting and moldy food often results in insect and rodent infestations and creates unhealthy conditions not just for the hoarder, but also the tenants around them (Weiss, 2010). When it comes to the general filth resulting from the hoarding, conditions can not only affect the hoarder's health, but the health of the other tenants living around them (Tolin et al., 2008).

# **Underlying Theories**

Hoarding is the community health problem that obviously requires a communal solution (Ronan, 2011). The standards and tools that are used for measuring hoarding are progressing as psychologists better understand the behavior of hoarding (Pertusa et al., 2010). Being able to utilize these tools for a better understanding of hoarding, clinicians are making positive headway towards pharmacological and psychological treatment (Pertusa et al., 2010). Cognitive Behavior Therapy (CBT) is a therapy that is very promising for hoarders (Pertusa et al., 2010). This treatment consists of office and inhome sessions that will focus on motivational interviewing, skills training, exposure to sorting, discarding, not acquiring, and cognitive restructuring (Pertusa et al., 2010). CBT which requires patients to adhere to homework assignments, such as cleaning in between their therapy sessions, seems to show greater symptom improvement (Gilliam & Tolin,

2010). Case studies using CBT shows hoarding symptoms improve by 23-37%; overall CBT seems to be a very promising treatment for hoarding (Pertusa et al., 2010). There still needs to be some long-term studies of the use of CBT for hoarding behavior, but at this point CBT is the best treatment option when it comes to helping the hoarding individual (Gilliam & Tolin, 2010).

Listing hoarding as its own psychological disease in the DSM-V, rather than listing it as part of a symptom of obsessive compulsive disorder, will provide guidance for the court system to understand the scope of the illness and how better to deal with eviction proceedings (Mataix-Cols et al., 2010; Ronan, 2011). Without this validation of the diagnosis being published in the DSM-V, hoarding defendants would lack credibility as to the severity of their disease and, more importantly, the proof that their symptoms are treatable (Ronan, 2011). Hoarding obviously has severe enough to impact on the hoarder's work, family, home, and community to grant its inclusion as a mental disorder (Mataix-Cols et al., 2010). Furthermore, inclusion in the DSM-V will lead to more specific diagnostic criteria for hoarding behavior, which could help to increase the awareness of hoarding, which will increase the number of reported cases (Ronan, 2011). Although hoarding is known as to be a very substantial burden on the sufferers, families, and the communities, it is the most underreported and undertreated disease (Mataix-Cols et al., 2010). Including hoarding as a separate disorder in the DSM-V will increase public awareness and improve identification of cases, accuracy of diagnosis, and the tailoring of treatment to the individual (Mataix-Cols et al., 2010). In the last decade hoarding has become a popular topic (Mataix-Cols et al., 2010). The lack of awareness by the public has led to several patients receiving no diagnosis (Ronan, 2011). Hoarders are often

treated for OCD rather than for their own behavior of hoarding, obviously leading to frequent treatment failure (Mataix-Cols et al., 2010).

To control hoarding housing disputes effectively, municipalities must develop hoarding task forces (Ronan, 2011). Eviction is not the solution and does not confront the hoarding behavior, and evicting an individual without an attempt at accommodating the disabled individual is not in harmony with the FHAA (Ronan, 2011). Task forces bring stakeholders together to help create a solution on individual hoarding cases (San Francisco Task Force, 2009). They provide support not only for the hoarders themselves, but they also provide education and training for courts, the public, and public agencies (San Francisco Task Force, 2009). The most important feature of task forces is that they can facilitate interagency coordination (San Francisco Task Force, 2009). Task forces provide guidelines for the assessment of hoarding situations, techniques for the cleanout, and guidance on who should help physically with the de-clutter (San Francisco Task Force, 2009). To really make sure that hoarders can receive actual help with the decluttering, municipalities must provide the affordable resources that will assist the hoarders (Ronan, 2011). Hoarding is a shared problem that is not easily resolved unless society accepts its responsibility for the process (Ronan, 2011).

#### Characteristics

The target population directly affected by the Fair Housing Amendments Act is anyone who might be discriminated against on the basis of race, color, religion, sex, sexual orientation, marital status, national origin, ancestry, familial status, source of income, or disability. As described in the previous literature, there are many characteristics that are associated with the hoarding behavior; issues in depression and

anxiety, along with a family history of hoarding, difficulties in processing information, attention problems, memory, categorization, decision-making, forming intense emotional attachment to the variety of possessions being hoarded, and the belief of the necessity of not wasting objects (Samuels et al., 2008). The prevalence of hoarding is 4% and is greater in older adults than younger adults, greater in men than in women, and is related to the hoarder's household income (Samuels et al., 2008). The hoarding behavior is also associated with alcohol dependency; paranoia, schizotypal disorders, avoidant, and obsessive-compulsive personality disorder traits, insecurity from home break-ins, and excessive physical discipline before the age of 16, and parental psychopathology (Samuels et al., 2008). The behavior can lead to very significant cluttered living space in the home and causes considerable distress and impairment in functioning for the individual and their family members (Tolin et al., 2008).

To date, hoarding behavior has been studied primarily in samples of individuals that were not selected from the community, such as the individuals were responding to advertisements for hoarding research studies. These individuals were coming from hoarding self-help groups, were referred to clinics specializing in the treatment of obsessive-compulsive disorder, or were participating in family studies of obsessive-compulsive disorder (Samuels et al., 2008). The results from these studies show that individuals who hoard have more symptoms of anxiety and depression, a greater prevalence of anxiety disorders, especially generalized anxiety disorder and social phobia, and poor functioning (Frost et al., 2000; Samuels et al., 2002).

There is little known about the prevalence, and sociodemographic and clinical correlates, of hoarding behavior in the community samples (Samuels et al., 2008). It has

been reported that hoarding behavior occurs in approximately 30% of the individuals with OCD in clinical and family samples (Rasmussen & Eisen, 1992; Samuels et al., 2002), and it is estimated in the population prevalence of OCD is about 1-2% (Karno, Golding, Sorenson, & Burnam, 1988). The overall population prevalence of hoarding behavior is estimated at approximately 4%; however, since the hoarding behavior can occur in individuals without OCD, this could be an underestimate (Steketee & Frost, 2003). Knowledge about the demographic and clinical characteristics of the individuals with the hoarding disorder is restricted to the particular samples of the individuals who really do not reflect the wider range of the hoarding disorder in the community (Samuels et al., 2008).

From inquiry into the biological basis of the development of the hoarding behavior, it is suggested from the case reports that hoarding emerges from traumatic brain lesions (Anderson et al., 2005). A genetic etiology of the hoarding behavior supports the hypothesis that the hoarding behavior can be part of genetic syndromes (Prader-Willi syndrome and velocardiofacial syndrome; Samuels et al., 2007). However, in these cases, precipitating factors in the development of the hoarding behavior have not been identified (Samuels et al., 2008).

Recently there have been two studies that found that traumatic life events are associated with hoarding behavior (Samuels et al., 2008). Hartl et al. (2005) found that participants who exhibited hoarding reported having experienced a greater number of various types of traumatic events, especially where an object was taken from them by force, being physically handled roughly in childhood or adulthood, or being forced in a sexual activity in childhood or adulthood.

A study that was done recently to find the prevalence of the hoarding behavior in the community revealed that nearly 4% of the population exhibit hoarding behavior in the community (Samuels et al., 2008). The demographic characteristics show there is more evidence of impairment in individuals with the hoarding behavior. Several participants reported the kinds of childhood adversities associated with their hoarding behavior due to the lack of security from home break-ins and excessive physical discipline (Samuels et al., 2008). The study provides the evidence that the hoarding behavior is more prevalent in the community today than it was a decade ago (Samuels et al., 2008). The study also revealed that hoarding behavior is greater in older adults, those with limited household income, and that there should be a push to focus on community interventions (Samuels et al., 2008). Further research on the impact of the behavior should provide the insight needed to develop programs for treating and preventing hoarding in the community (Samuels et al., 2008).

# <u>Size</u>

Evictions of hoarders are on the rise (Ligatti, 2013). Between March 1, 2010 and February 28, 2011 alone 1,370 evictions were filed in San Francisco, which an 8% rise from 1,269 evictions in the previous year (Mann, 2011). There is no information on how many of the evictees were hoarders, but since an estimated 3% to 5% of Americans suffer from the hoarding disorder (Hoffman, 2013). The impact of hoarding, though, extends beyond the afflicted individual and family members who are in the home; this behavior can also put neighbors at risk, by creating conditions for explosive house fires and infestations of vermin and disease (Hoffman, 2013).

# **Short and Long-Term Effects**

The intended short term and long term effects of the policy are to prevent hoarders from losing stable housing (Cobb et al., 2007). It seems that hoarding tenants are constantly facing the severe consequential threat of private judicial eviction (Douglas v. Kriegsfeld Corp, 2005). Eviction from one's home can be devastating for any individual, but it can be truly catastrophic for those who hoard (Cobb et al., 2007). To a hoarder, their personal belongings are their life and who they are, and accepting the possible idea of sudden homelessness is unfathomable to the hoarder (Cobb et al., 2007). From a legal point of view, hoarding behavior violates all housing codes and health and safety codes when it comes to occupancy of leased residential property (Cobb et al., 2007). The individual, who decides to take advantage of being able to preserve their home, can be given the opportunity and a civil right to continue their tenancy (Cobb et al., 2007).

The studies that have been done to measure short term success are concerned with how well the treatment resolves the disorder's symptoms. Eliminating or at least diminishing the hoarder's mass of possessions is a resolution important to the housing advocate's point of view rather than the hoarder's point of view (Cobb et al., 2007). When reviewing these studies one might get the impression that the hoarding behavior is untreatable, especially in the short term (Steketee & Frost, 2003). These studies also show that even short-term treatments, 10 to 12 weeks, are effective for some hoarders, depending on the type of therapy that each client needs to get their situation somewhat solved (Cobb et al., 2007). The newer studies also suggest with the right support hoarders can make progress in decluttering their homes (Cobb et al., 2007).

Mental health providers are the important resource not only for helping hoarder clean up their homes, but also for developing long-term strategies to prevent the recurrence of the hoarding behavior (Cobb et al., 2007). When a hoarder is working with an attorney, the attorney can have better results with the hoarder if they make sure to ensure the hoarder receives adequate mental health treatment and are involved in clearing their clutter (Cobb et al., 2007). There have been some cases where the landlords or housing providers have taken extraordinary measures to help the hoarder cure their conditions brought on by the behavior to only discover the problem reoccurs; showing that handling these cases using the usual court directives and timelines may not always be adequate (Zipper v. Haroldon Court Condominium, 2007). When it comes to individualized treatment for hoarders, treatment which is often expensive and not generally available, there are still options of less formal community-based groups that can provide an effective treatment (Frost, 2004).

Another solution for long-term handling of hoarding behavior is found in the many states that have made a concerted effort to integrate the legal, social services, and mental health services to form interagency city, county, or regional task forces (Cobb et al., 2007). There are one or more task forces in the following states California, Wisconsin, Kansas, Minnesota, Massachusetts, New York, and Virginia (Bratiotis, 2012). The city of San Francisco has a support group known as The San Francisco Compulsive Hoarding and Cluttering Project, which provides regular support for people who hoard and clutter; it has an information and referral line, and customized training for legal and social service providers on hoarding and cluttering (Cobb et al., 2007). This group sponsors an annual conference on hoarding to raise the awareness and to educate the

community (Cobb et al., 2007). The task force in the Washington, D.C. metropolitan area provides crisis response teams and intervention services to ameliorate the threats to the community, prevent eviction, and provide support to the hoarder in attempting to resolve the problem long term (Metropolitan Washington Council of Governments, 2006).

The legal situation currently facing hoarders is a very difficult one, with traditional legal remedies that may not fully resolve the problem facing these individuals (Cobb et al., 2007). Attorneys can work with landlords or housing providers and courts to stop eviction proceedings and obtain time extensions to cure the lease violations as reasonable accommodations under the Fair Housing Amendments Act (Cobb et al., 2007). It is generally known that the attorney cannot ensure that the hoarding clients will be able to cure lease violations within the time extensions nor to receive the treatment necessary to ensure the lease violations will not recur (Cobb et al., 2007). Ultimately the success of this approach really depends on whether the attorney can postpone or prevent eviction long enough to allow the clients to participate in the mental health treatments, and whether social services or community organizations can provide the immediate assistance needed to reduce the risks to the community resulting from the behavior (Cobb et al., 2007).

# Overall Costs and Benefits

Hoarding behavior is characterized by the acquisition of and failure to discard possessions, clutter that blocks the activities for which the living spaces were designed, and significant distress or impairment in functioning caused by the behavior (Frost & Hartl, 1996). Housing providers and mental health advocates have always struggled with

how to satisfactorily balance housing needs of the mentally ill with the needs of the landlord or housing providers and neighbors (Ligatti, 2013). Stable housing is the most essential prerequisite to education and employment, and is especially vital for the mentally ill, as these individuals must have constant contact with physicians, social services, and other treatment professionals (Kanter, 1994). The acquisition of quality stable housing is one of the most serious challenges that face the psychiatrically disabled (Carter, 2010).

Reasonable accommodation is required when medically necessary under the Fair Housing Amendments Act. This act was passed and signed into law in 1988, amending Title VIII of the Civil Rights Act of 1968, known as the Fair Housing Act, to include disability protections (Fair Housing Amendment Act, Pub. L. No. 100-430, § 5-6, 102 Stat. 1619, 1988). Housing providers or landlords are required to grant accommodations when the request is made by the disabled individual, the housing provider or landlord knows or should be aware of the known disability, the request made might be necessary to provide the individual and equal opportunity to enjoy their home, and the request is reasonable (Schwemm, 1990).

To qualify for the accommodation the disabled person must show they suffer from a physical or mental impairment and the impairment impacts their life activities. The requirement is quiet broad and expressly includes mental or psychiatric disabilities (Millar, 2012), but the term "affecting life activities" is less clearly defined (Ligatti, 2013). The courts have said that major life activities include working, sleeping, concentrating, self-care and interacting with others (Ligatti, 2013). The requirement is

only to show that a desired accommodation will enhance the disabled individual's quality of life by ameliorating the effects of the disability (Bronk v. Ineichen, 1995).

A hoarder's home likely violates multiple municipal housing codes and lease agreements (Frost et al., 2000). In many of the circumstances, the corrective action for these violations involves proceedings to evict the hoarder (Frost et al., 2000). When it comes to evicting the tenants and condemning homes it can be very costly for the municipalities, and at times eviction will not correct the behavior that is causing the hoarding (Frost et al., 2000).

The involvement of multiple service providers with hoarding cases is the best accomplished by the establishment of the community hoarding task forces (Bratiotis, 2012). In 2011, Bratiotis et al. reported approximately 75 multidisciplinary community hoarding task forces throughout the United States (Bratiotis, 2012). In these urban and rural communities, representatives from various human services agencies are working together to coordinate service delivery for the hoarding cases, and many of these cases are of nonvoluntary clients (Bratiotis, 2012). Mental health practitioners are often part of the coordinated community response to hoarding (Bratiotis, 2012).

Some communities recognize that complex and multisystemic nature of hoarding requires much coordination across the human service disciplines beyond mental health (Bratiotis et al., 2011). However, many task forces have agency constraints that make it very difficult to provide mental health services for older adult hoarders (Koenig, Leiste, Spano, & Chapin, 2013). The constraints these task forces face consist of funding limitations, the time consuming nature of providing mental health services, and a lack of mental health providers able or willing to provide in-home services (Koenig, Leiste,

Spano, & Chapin, 2013). Individuals with hoarding behaviors and older adults with other mental health issues do not do well going to a mental health center, but they do well when someone can come into their home (Koenig, Leiste, Spano, & Chapin, 2013). Older adult hoarders and individuals who hoard challenge existing mental health service delivery systems that are not set up to provide long-term, in-home, and cost-intensive services (Koenig, Leiste, Spano, & Chapin, 2013).

It is known that hoarding behavior puts a strain on the community agency's fiscal and personnel resources (Bratiotis, 2012). A Massachusetts health department spent \$16,000 to clear possessions from a hoarded home to eliminate health and safety risks (Frost et al., 2000). Even individuals who are not big hoarders can require considerable staff time, depleting resources, and costing the communities large sums of money (Bratiotis, 2012). This behavior also represents a significant general public health burden through occupational impairment, poor overall physical health, and social service involvement (Tolin, Kiehl et al., 2007).

According to a Tolin et al. (2008) study, the data is consistent with the high rate of agency involvement in the cases of hoarders, and the associated high cost of involvement. This study does not permit the estimation of the dollar amount of economic burden of hoarding (Greenberg, Kessler et al., 2003; Greenberg, Sisitsky et al., 1999; Wu et al., 2005). However, the data that is available suggests the impact of hoarding on a per-person basis exceeds many psychiatric disorders (Tolin et al., 2008). These high costs seem to affect not just individuals, but also society as a whole in terms of lost work productivity, mental health services, non-psychiatric medical costs, and community agency involvement (Tolin et al., 2008). The evaluation of the overall costs and the

impact of hoarding behavior in our society await epidemiologic research (Tolin et al., 2008).

# Section C: Implications of the Policy for the Operating and Outcome Variables of Social Policies

Changes in Development and Allocation of Resources, Goods, and Services

Little is known about the prevalence of hoarding behavior in the community (Samuels et al., 2008). Hoarding behavior, also called pathological collecting, is characterized by the acquisition of, and unwillingness or inability to discard, large quantities of seemingly useless objects (Greenberg et al., 1999; Frost & Gross, 1993). Hoarding behavior has been studied primarily in samples of individuals who were selected from the community, such as respondents to advertisements for hoarding research studies, individuals in self-help groups, individuals referred to clinics specializing in the treatment of OCD, and individuals participating in family studies of OCD (Samuels et al., 2008). The results of these studies suggest that individuals who exhibit hoarding behavior have more symptoms of anxiety and depression, a greater prevalence of anxiety disorders, especially generalized anxiety disorder and social phobia, and poorer functioning (Frost et al., 2000; Samuels et al., 2002).

The presumption that hoarding behavior is a symptom of OCD is contradicted by more recent theory and research on the behavior (Grisham et al., 2008). There is strong evidence suggesting that hoarding patients display an excessive sentimental attachment to possessions (Frost & Gross, 1993; Frost & Hartl, 1996). It is also known hoarders will usually report the same reasons for saving (Frost et al., 1999). The past research and literature on the meaning of possessions and motivation behind saving in the Western

cultures might shed light on the attachment to their possessions (Grisham et al., 2008). Furby suggests people save for sentimental and instrumental motives (Grisham et al., 2008). Furby also suggests that the core idea of saving is the need to bring about desired outcomes in the environment (Grisham et al., 2008). Individuals define themselves, express to others who they are, enable them to maintain a sense of continuity, and enable them to stay connected to the past (Grisham et al., 2008). These findings imply that once an attachment is formed, it does not increase differently for individuals with greater or lesser hoarding symptoms, and that the initial attachment is the best indicator of hoarding (Grisham et al., 2008).

Hoarding behavior is an unrecognized problem, but it is one that is increasing among older adults and poses threats to their quality of life (Franks et al., 2004). The prevalence of hoarding behavior by older adults in their homes or places of residence appears to be increasing nationally (Steketee et al., 2001; Thomas, 1998). There are very serious consequences from this behavior in costs to the individual's quality of life, including deterioration in physical health, safety, and psychological, emotional and social well-being (Steketee et al., 2001; Thomas, 1998). There are also significant community health risks if the hoarding behavior is neglected or ignored (Ligatti, 2013). The difficulty in studying hoarding behavior is that it is a very complex problem with multiple contributing causes that take many diverse forms and is largely undetected for many years (Franks et al., 2004). The main questions when working with individuals who hoard is when to intervene and how to intervene (Franks et al., 2004). Often people who hoard do not see their behavior as a problem, but as a lifestyle choice or as just normal behavior (Franks et al., 2004).

The acquisition of excess items was found to be reassuring for the older hoarder, because the possessions relieved their anxieties, helped them to feel proud and productive, needed by others, connected, socially engaged, and in control (Andersen et al., 2008). An older person may have longstanding eccentric personal habits that can become severe enough to cause impairment in their activities of daily living and their relationships with others (Andersen et al., 2008). When it comes to providing care for older hoarders, how we interpret the value of their hoarded possessions is worthy of notice since we are quick to strip hoarders of their personal possessions because we do not understand the value of the items from their perspective (Andersen et al., 2008). To achieve better care for hoarders, it is necessary that consider the whole person, and how their symptoms might be worsened by how we approach them and care for them (Andersen et al., 2008). The community health professionals who can understand the emotional issues of hoarding will be better able to resist the pressures from families, neighbors, landlords, and care agencies who want to dispose of the excess immediately, by being in a position to explain why some older hoarders should be granted their egocentricities rather than insisting on unnecessary involuntary interventions or relocation (Andersen et al., 2008).

Although older hoarders who exhibit hoarding behavior often live alone, are detached socially, and have the higher scores on social and family disability indices, (Saxena et al., 2002), they generally do not come to the attention of community health professionals unless there is a need for them to require home care for chronic medical conditions (Andersen et al., 2008). When the hoarder is receiving provided home care, their care providers might find themselves in a quandary when frustrated families,

landlords, neighbors, or care agencies pressure them to intervene (Andersen et al., 2008). It is necessary to have rational, unbiased, supportive, and informed nursing care in order to prevent undue stress in the older client and help community health professionals to understand the emotional issues that underpin the hoarding behaviors (Andersen et al., 2008).

The research shows that hoarding related complaints to the public health departments occur in 26 per 100,000 over 5 years, but this figure undoubtedly underestimates the frequency of hoarding, since many individuals with this behavior have never had a public complaint filed against them (Steketee & Frost, 2003). The existing case reports suggest that hoarding runs a chronic and unchanging course (Steketee & Frost, 2003). According to Greenberg (1987) the onset occurs in the early 20's, but a study of 32 pack rats or chronic savers from the community indicated that the age of onset of saving occurs most often in childhood or early adolescence. Extreme levels of hoarding behavior typically occur at about the age of 35 (Steketee & Frost, 2003). The acquisition problems have a slightly later onset than clutter or the difficulty to discard (Steketee & Frost, 2003). The course of the hoarding behavior symptoms tend to be chronic, with very few individuals reporting improvement between the onset and the development of the extreme symptoms, but the degree of variability over time is unclear (Steketee & Frost, 2003).

Even though there is only limited recognition of the severity and impairment caused by hoarding, the behavior is a problem that is very troublesome for family members and service providers (Frost et al., 1999). Research and case reports indicate that many people who hoard do not consider their hoarding unreasonable or as a problem

(Frost & Gross, 1993; Frost et al., 2000; Thomas, 1998). This limited insight is due to the delayed recognition of the hoarding problem (Grisham et al., 2008). Social service providers report that most elderly clients with serious hoarding behavior show very little insight into their problem, despite the absence of cognitive impairment, and this lack of insight interferes with the provision services needed to address the cluttering and health-related complications (Steketee et al., 2001). Although the research on the hoarding behavior has increased in recent years, it still remains a nascent field with more research needed (Steketee & Frost, 2003).

During the past decade many community task forces have been established to address the hoarding problems that have come to the public's attention (Briatiotis, 2012). These task forces provide a societal-level intervention to assist people with the most severe cases of hoarding, who are not voluntarily seeking help for their hoarding behavior (Briatiotis, 2012). It is estimated that hoarding behavior is exhibited by 2%-5% of the American population (Samuels et al., 2008). There are many questions remaining about this behavior and its etiology, phenomenology and treatment, but it seems to impact men more than women (Samuels et al., 2002), although women participate more in the research than men (Frost & Gross, 1993). The studies reveal the onset of the hoarding behavior occurs most often in the teenage years (Samuels et al., 2008), although the average age of when individuals seek treatment is approximately 50 (Samuels et al., 2008).

The face that hoarding behavior adversely impacts not just those who hoard but also their families and communities, suggests that there is a need for the community to respond (Bratiotis, 2013). A collaborative partnership, which is best when forming a

group to coordinate task forces or coalitions, is very useful in the approach for resolving community problems through a multidisciplinary approach (Roussos & Fawcett, 2000). These groups provide a way for community members to work collectively to advance community-level change (Bratiotis, 2012).

More often than not, hoarders have compromises in the areas of functioning. This then requires professionals to collaborate to assure the compliance with health and safety regulations (Bratiotis et al., 2011). Agencies that share the responsibility for the various tasks can do much when it comes to maximize the efficient division of labor and to manage with limited budgets (Bratiotis, 2013). In addition, how the hoarder perceives the role of the service providers can be very effective in attaining positive outcomes (Bratiotis, 2013). Some disciplines can take the role of friendly helpers, while other disciplines can serve as regulators (Bratiotis, 2013). When these roles are coordinated, there is more likelihood of an effective resolution of the hoarding behavior (Bratiotis et al., 2011). Being able to see the person who is hoarding through different professional lenses will produce a more successful outcome that will address the important needs in each case (Bratiotis, 2013).

It is essential to the community for people who are diagnosed as seriously mentally ill to have adequate housing (Petrila, 1994). Without the proper housing, people may have to be hospitalized longer than would otherwise be necessary (Petrila, 1994). One survey of mental health consumers and families suggested that, for individuals who are mentally ill, adequate housing is a more pressing need than the need for treatment (Petrila, 1994). Mentally ill individuals still face discrimination when trying to obtain housing (Petrila, 1994). In an attempt to counter this discrimination, Congress enacted

the Fair Housing Amendments Act of 1988. The law amended the 1968 Fair Housing Act, which prohibited discrimination on the basis of race (Petrila, 1994). Congress had in two goals in mind with this amendment: first to enable people with disabilities to obtain housing without worry of discrimination in communities of their choice, and second to utilize housing to integrate people with handicaps into the mainstream of American life (Petrila, 1994).

To effectively control hoarding housing disputes, municipalities must develop hoarding task forces (Ronan, 2011). Necessarily eviction does not actually confront the hoarding behavior, and eviction without an attempt to accommodate disabled persons is not allowable under the FHAA (Ronan, 2011). The FHAA is one of the major civil rights statues designed to eliminate discrimination on the basis of mental illness (Petrila, 1994). The FHAA is emerging as an important tool for mentally disabled individuals to use to obtain housing (Petrilia, 1994). The courts are becoming more receptive to using the amendment to challenge the laws and practices which are creating the barriers to housing for those that are mentally ill (Petrila, 1994).

#### CHAPTER 5

# **CONCLUSION**

#### Introduction

The purpose of this study was to create a policy analysis of the Fair Housing Amendments Act of 1988. The background and history of the policy leading to its enactment, as well as its effectiveness and short and long-term impact were explored. The particularly negative effects hoarding behavior has on individuals who exhibit the behavior were discussed in this analysis. The analysis of this policy was conducted using components of David Gil's social policy analysis framework (1992). By following this framework, the policy analysis included a description of the social problem and the key issues of the problem that the policy addresses, the overt and covert objectives, both the explicit and implicit values premises, theoretical positions and effects of the policy and implications of the policy for the social structure and system (Gil, 1992).

#### Summary of Findings

To be effective, housing law needs to balance the interests of the individual with that of the general public (Ronan, 2011). Because of the magnitude of the problems that hoarding behavior can create, there is the danger that hoarders lack sufficient protection of their housing rights at the local level (Ronan, 2011). When the state and municipal law fails to protect hoarders' rights to be free from housing discrimination, it is important that hoarding should be recognized as a mental disability under the Fair Housing

Amendments Act. As a result, landlords and housing providers would be required to provide a reasonable accommodation to the hoarder in a fashion that is consistent with the Act (Ronan, 2011). Hoarders require an accommodation that can be tailored to their serious, long-term mental disability, not just a transitory solution (Ronan, 2011). It is to be hoped that with the Act in place there can be recommendations and solutions for municipalities and agencies that are struggling with hoarders that can reduce the recidivism, streamline problem-solving, and be consistent with the requirements of the Fair Housing Amendments Act (Ronan, 2011).

The passage of the FHAA in many ways can be seen as a solution for the public health and safety professionals and mental health professionals who are working with hoarders. The needs of these individuals for safe and affordable housing must be weighed against the needs of the housing providers and the local health laws that were designed to protect the public at large (Ligatti, 2013). The most difficult aspect of this behavior is that there is no magic pill to cure it, and hoarders will continue to suffer with this issue for their entire lives (Barksdale et al., 2006; Ligatti, 2013). While there is always the possibility of relapses, that does not necessarily signal a failure for the hoarder because such relapses can be expected when working with serious mental illnesses (Ligatti, 2013).

As complex as the hoarding behavior is, it requires careful coordination of care (Bratiotis, 2013). Even with the impact of professionals working together, the passage of the FHAA, and the recent increases in research on the behavior, hoarding still remains a developing issue (Steketee & Frost, 2003). Many communities in the United States do not have a public policy on handling of hoarding, but the formation, when it occurs, of public services provides a very promising solution towards the problem of hoarding on

the community and personal level (Frost et al., 2000). The establishment of these public services to help assist with the social problems created by the behavior has led these professionals to see the need for a multi-level environmental system intervention, which can tackle hoarding at all environmental levels (Bronfenbrenner, 1979). Individuals with the hoarding behavior are the most underrepresented population, and there is no easy solution when it comes to working with this behavior (Saltz, 2010). However, it is most crucial to recognize this behavior and the barriers that come along with this mental health issue (Saltz, 2010).

### Limitations

There are still major limitations in the application of this policy. If no reasonable accommodation for a hoarding individual can be achieved and the hoarder's last-chance housing fails as a result the individual will end up being forcibly evicted without the necessary psychiatric treatment (Bratiotis et al., 2011). Another limitation is that intervention can only be done once eviction proceedings have begun, and this puts a great deal of pressure on the individual to make significant changes in a very short period of time, something a hoarder will find extremely difficult (Ligatti, 2013). There also needs to be more research that examines the etiology, contributing factors, and other contextual characteristics to help us understand hoarding (Koenig, Leiste, Spano, & Chapin, 2013). It is also necessary to remedy the current lack of training that social workers, legal personnel, police and fire professionals have when they approach individuals who are hoarding and enable them to find a way to arrive at a common understanding of the behavior (Koenig, Leiste, Spano, & Chapin, 2013). Task force members need to build trust with each other so they will be able to come together to address the policy barriers

that impede efforts to help hoarders (Koenig, Leiste, Spano, & Chapin, 2013). There are ethical dilemmas to be faced by the practitioners when trying to honor the hoarder's right of self-determination even when they see the dangers that are presented by the person's behavior (Koenig, Leiste, Spano, & Chapin, 2013).

# Future Research

Future research can be helpful in further exploring how revisions could be made to the Fair Housing Amendments Act of 1988 to address protection for hoarders.

Research and advocacy to develop new policies can be introduced that can lead to more appropriate treatment of hoarders by avoiding misunderstanding of their disorder by landlords and housing providers or family members or even the community. Research needs to continue to develop support for an effective means of working with hoarders and providing them with suitable treatment. Specifically, this research needs to consider the underlying causes of this behavior and what factors have contributed to the hoarding behavior. It is important for policy changes to be based on current related research instead of unfounded public opinion and political agendas.

# Social Work Implications

Social work professionals provide the services following the guidelines set by the National Association of Social Workers (NASW). The NASW mission states that it is the role of the social worker to advocate for and facilitate justice and social change in a way that maximizes the well-being of individuals, families, and communities (NASW, 2008). The social work field can have a very crucial role when it comes to promoting policies that help create social justice and change while upholding the NASW code of ethics and ethical standards, including cultural competency and commitment to clients.

According to the NASW, the federal, state and local government efforts should lead to the development of policies and services that will increase opportunities, aim for justice, and improve the quality of life and communities (NASW, 2008). Therefore, it is of the utmost importance that social workers be educated on how the Fair Housing Amendments Act can be useful in helping individuals, families, and communities. Social workers are the individuals who advocate for more positive and effective government efforts. It is so important that social work agencies and the profession as a whole unite and empower individuals, families, and the community who are working among the hoarding population, and advocate for research-based, comprehensive solutions for hoarding behavior populations that are not otherwise served.

REFERENCES

#### **REFERENCES**

- Abramowitz, J. S., Franklin, M. E., Schwartz, S. A., & Furr, J. M. (2003). Symptom presentation and outcome of cognitive-behavioral therapy for obsessive compulsive disorder. *Journal of Consulting and Clinical Psychology*, 71, 1049-1057
- Abramson, B. (2005). *The inter-disciplinary team approach to addressing hoarding cases.* Madison: Wisconsin Department of Health and Family Services.
- Abramowitz, J. S., Wheaton, M. G., & Storch, E. A. (2008). The status of hoarding as a symptom of obsessive-compulsive disorder. *Behavior Research and Therapy*, 46, 1026-1033.
- Alonso, P., Gratacos, M., Menchon, J. M., Segalas, C., Gonzalez, J. R., Labad, J., & Estivill, X. (2008). Genetic susceptibility to obsessive-compulsive hoarding. The contribution of neurotrophic tyrosine kinase receptor type 3 gene. *Genes, Brain, and Behavior*, 7, 778-785.
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text rev.). doi:10.1176/appi.books.9780890423349.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). doi.org/10.1176/appi.books.9780890425596.
- Andersen, E., Raffin-Bouchal, S., & Marcy-Edwards, D. (2008). Reasons to accumulate excess: Older adults who hoard possessions. *Home Health Care Services Quarterly*, 27(3), 187-216. doi 10.1080/01621420802319993.
- Anderson, S.W., Damasio, H., & Damasio, A. R. (2005). A neural basis for collecting behavior in humans. *Brain*, *128*, 201-212.
- Anetzberger, G. J., Palmisano, B. R., Sanders, M., Bass, D., Dayton, C., Eckert, S., & Schimer, M. (2000). A model intervention for elder abuse and dementia. *The Gerontologist*, 40, 492-497.
- Auer v. Robbins (95-897), 519 U.S. 452 (1997)

- Barksdale, B., Berry, L., Leon, R., & Madron, L. (2006). *Hoarding: A dangerous secret*. Retrieved from Metropolitan Washington Council of Governments website: http://www.mwcog.org/uploads/pub-documents/zllWXQ20061121162353.pdf
- Bell, R. A. (2012). Why do elderly hoarders present challenges for social workers and what intervention strategies can be used to address these challenges? Retrieved from http://cdn.umb.edu/images/mgs/mgs\_gerontology/BELL\_Aging\_Services\_Capstone.pdf
- Black, D. W., Monahan, P., Gable, J., Blum, N., Clancy, G., & Baker, P. (1998). Hoarding and treatment response in non-depressed subjects with obsessive-compulsive disorder. *The Journal of Clinical Psychiatry*, 59, 420-425.
- Bookman, A. (2008). Innovative models of aging in place: Transforming our communities for an aging population. *Community Work and Family*, 11(4), 419-438.
- Bratiotis, C. (2013). Community hoarding task forces, a comparative case study of five task forces in the United States. *Health and Social Care in the Community*, 21(3), 245-253. doi: 10.1111/hsc. 12010
- Bratiotis, C., Schmalisch, C. S., & Steketee, G. (2011). *The hoarding handbook: A guide for human service professionals*. New York, NY: Oxford University Press.
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Cambridge, MA: Harvard University Press.
- Bronk v. Ineichen, 54 F.3d 425, 428 (7<sup>th</sup> Cir. 1995)
- Brown, W. A., & Meszaros, Z. (2007). Hoarding. Psychiatric Times, 24(13), 50-52.
- Calamari, J. E., Wiegartz, P. S., & Janeck, A. S. (1999). Obsessive-compulsive disorder subgroups: A symptom-based clustering approach. *Behaviour Research and Therapy*, *37*(2), 113-125.
- Carter, M. (2010). How evictions from subsidized housing routinely violate the rights of persons with mental illness. *Northwestern Journal of Law & Social Policy*, 5(1), 119.
- Christensen, D. D., & Griest, J. H. (2001). The challenge of obsessive-compulsive disorder hoarding. *Primary Psychiatry*, *8*, 79-86.
- Clairborne, J. M. (2006). *Hoarding a successful compulsion*. Retrieved from http://home.att.net/~j-claiborn-phd/HOARDING.HTML

- Cobb, T. D., Dunn, E., Torres-Hernandez, V., Moroni-Okleberry, J., Pfefferkorn, R., & Spector, C. E. (2007). Advocacy strategies to fight eviction in cases of compulsive hoarding and cluttering. *Journal of Poverty Law and Policy*, 41, 427-441.
- Cromer, K. R., Schmidt, N. B., & Murphy, D. L. (2007). Do traumatic events influence the clinical expression of compulsive hoarding? *Behavior Research and Therapy*, 45, 2581-2592.
- Douglas v. Kriegsfled Corp., 844 A.2d 1109, 1125-26 (D.C. Cir. 2005)
- Dyer, C. B., & Prati, L. L. (2006). Self-neglect: On the crest of new discoveries. *Journal of Elder Abuse & Neglect, 18*(4), 1-3.
- Eckfield, M. B. (2010). Evaluating and selecting interventions for older adults with hoarding and cluttering behaviors. *Journal of Geriatric Care Management*. Retrieved from www.caremanager.org
- Eisner, S. B. (1997). There is no place like home: Housing discrimination against disabled persons and the concept of reasonable accommodation under the Fair Housing Amendments Act of 1988. *NYL Sch. J. Hum. Rts*, *14*, 435.
- Fair Housing Act 1968, Pub. L. No. 90-284, Title VIII, 82 Stat 81(1968) (codified at 42 U.S.C. 3601 et seq.) Retrieved from the United States Department of Justice website: http://www.justice.gov/crt/about/hce/housing\_coverage.php#disability
- Fair Housing Amendments Act 1988, Pub. L. No. 100-430, 102 Stat. 1619. Section 804(f)(1)(1988). Retrieved from http://www.justice.gov/crt/about/hce/housing coverage.php#disability
- Franks, M., Lund, D. A., & Poulton, D. (2004). Understanding hoarding behavior among older adults: A case study approach. *Journal of Gerontological Social Work, 42*, 77-107.
- Franks, M., Lund, D., Poulton, D., & Caserta, M. S. (2008). Understanding hoarding behavior among older adults. *Journal Gerontological Social Work*, 77-107.
- Fried, C. (2006). *Sufferers have a right to create nuisance*. Retrieved from http://www.sfaa.org/0610fried.html
- Fromm, E. (1947). *Man for himself: An inquiry into the psychology of ethics*. Oxfordshire, England: Routledge.

- Frost, R. O. (2004). When hoarding causes suffering-working together to address a multi-faceted problem. Retrieved from www.environmentalgeriatrics.com/home\_safety/conference.html
- Frost, R. O., & Gross, R. C. (1993). The hoarding of possessions. *Behavior Research* and Therapy, 31(4), 367-381.
- Frost, R. O., & Hartl, T. (1996). A cognitive-behavioral model of compulsive hoarding. *Behavior Research and Therapy*, *34*, 341-350.
- Frost, R. O., & Steketee, G. (2010). *Stuff: Compulsive hoarding and the meaning of things*. Boston, MA: Houghton Mifflin Harcourt.
- Frost, R. O., Steketee, G., & Grisham, J. (2004). Measurement of compulsive hoarding: Saving inventory-revised. *Behaviour Research and Therapy*, 42(10), 1163-1182.
- Frost, R. O., Steketee, G., Tolin, D. F., & Brown, T. A. (2006). *Comorbidity and diagnostic issues in compulsive hoarding*. Paper presented at the Annual Meeting of the Anxiety Disorders Association of America, Miami, Florida (March).
- Frost, R. O., Steketee, G., & Williams, L. (2000). Hoarding: A community health problem. *Health and Social Care in the Community*, 8, 229-234.
- Frost, R. O., Steketee, G., Youngren, V. R., & Mallya, G. K. (1999). The threat of the housing inspector: A case of hoarding. *Harvard Review of Psychiatry*, 6, 270-278.
- Germain, C. B. (Ed.). (1979). *Social work practice people and environments*. New York, NY: Columbia University Press.
- Gil, D. (1992). *Unraveling social policy: Theory, analysis, and political action towards social equality* (rev. 5<sup>th</sup> ed.). Rochester, VT: Schenkman Books.
- Gilliam, C. M., & Tolin, D. F. (2010). Compulsive hoarding. 74 Bulletin of the *Menninger Clinic*, 93, 109-110.
- Greenberg. D. (1987). Compulsive hoarding. *American Journal of Psychothempy*, 41, 409-416.
- Greenberg, P. E., Kessler, R. C., Birnbaum, H. G., Leong, S. A., Lowe, S. W., Berglund, P. A., & Corey-Lisle, P. K. (2003). The economic burden of depression in the United States: How did it change between 1990 and 2000? *Journal of Clinical Psychiatry*, 64, 1465-1475.

- Greenberg, P. E., Sisitsky, T., Kessler, R. C., Finkelstein, S. N., Berndt, E. R., Davidson, J. R., . . . , Fyer, A. J. (1999). The economic burden of anxiety disorders in the 1990s. *Journal of Clinical Psychiatry*, 60, 427-435.
- Grisham, J. R., & Barlow, D. H. (2004). Compulsive hoarding: Current research and theory. *Journal of Psychopathology and Behavioral Assessment*, 27(1), 45-51. doi:10.1007/s10862-005-3265-z
- Grisham, J. R., Brown, T. A., Savage, S. R., Steketee, G., & Barlow, D. H. (2007). Neuropsychological impairment associated with compulsive hoarding. *Behavior Research and Therapy*, 45, 1471-1483.
- Grisham, J., & Norberg, M. M. (2010). Compulsive hoarding: Current controversies and new directions. *Dialogues Clinical Neuroscience*, 12, 233-235.
- Grisham, J. R., Steketee, G., & Frost, R. O. (2008). Interpersonal problems and emotional intelligence in compulsive hoarding. *Depression and Anxiety*, 25, E63.
- Groner v. Golden Gate Gardens Apartments, 250 F.3d 1039, 1044-45 (6<sup>th</sup> Cir. 2001)
- Gusfield, J. (1989). Constructing the ownership of social problems: Fun and profit in the welfare state. *Social Problems*, *36*(5), 431-441.
- Hartl, T. L., Duffany, S. R., Allen, G. J., Steketee, G., & Frost, R. O. (2005). Relationships among compulsive hoarding, trauma, and attention-deficit/hyperactivity disorder. *Behavior Research and Therapy*, 43, 269-276.
- Higartner, S., & Bosk, C. L. (1988). The rise and fall of social problems: A public arenas model. *American Journal of Sociology*, *94*(1), 53-78.
- Hoffman, J. (2013). Task forces offer hoarders a way to dig out. *New York Times*. Retrieved from http://www.nytimes.com/2013/05/27//health/when-hoarding-morphs-into-a-safety-hazard.html
- Howard v. City of Beavercreek, S.D. Ohio 2000
- International OCD Foundation. (2011). *Hoarding fact sheet*. Retrieved from www.ocfoundation.org
- Jansen, J. (1962). Collector's mania. Acta Psychiatrica Scandinavica, 119, 1351-1358.
- Kanter, A. S. (1994). A home of one's own: The Fair Housing Amendments Act of 1988 and housing discrimination against people with mental disabilities. *American University Law Review*, 43, 925.

- Karno, M., Golding, J. M., Sorenson, S. B., & Burnam, A. (1988). The Epidemiology of obsessive-compulsive disorder in five U.S. communities. *Arch Gen Psychiatry*, 45(12), 1094-1099. doi:10.1001/archpsych.1988.01800360042006
- Koenig, T., Chapin, R., & Spano, R. (2010). Using multi-disciplinary teams to address ethical dilemmas with older adults who hoard. *Journal of Gerontological Social Work*, 53(2), 137-147.
- Koenig, T. L., Leiste, M., Spano, R., & Chapin, R. K. (2013). Multidisciplinary team perspectives on older adult hoarding and mental illness. *Journal of Elder Abuse and Neglect*, 25, 1-20.
- Krueger v. Cuomo, 115 F.3d 487, 492 (7th Cir. 1997)
- Lantz, P. M., & Booth, K. M. (1998). The social construction of the breast cancer epidemic. *Social Science & Medicine*, 46(7), 907-918.
- Lidz, F. (2003). Ghostly men: The strange but true story of the Collyer brothers and my uncle Author, New York's Greatest Hoarders (An Urban Historical).
- Ligatti, C. (2013). Cluttered apartments and complicated tenancies: A collaborative intervention approach to tenant "hoarding" Under the Fair Housing Act. *Suffolk University Law Review, Cluttered Apartments and Complicated Tenancies, XLVI*(79), 79-109.
- Loeske, D. R. (1989). Thinking about social problems. New York, NY: Aldine De Gruyter.
- Lunhins, D., Goldman, M. B., & Hanrahan, P. (1992). Repetitive behaviors in chronically institutionalized schizophrenic patients. *Schizophrenia Research*, 8, 119-123. doi:10.1016/0920-9964(92)90027-3
- Mann, L. (2011). Excessive collection of stuff is a mental disability, but legal protections for these renters are often ignored. Retrieved from http://www.sfbg.com/2011/05/03/evicting-hoarders?page=0,2
- Mataix-Cols, D., Baer, L., Rauch, S., & Jenike, M. (2000). Relation to factor-analyzed symptom dimensions of obsessive-compulsive disorder to personality disorders. *Acta Psychitrica Scandinavica*, *102*, 199-202. doi:10.1034/j.1600-0447.2000.102003199.x
- Mataix-Cols, D., Frost, R. O., Pertusa, A., Clark, L. A., Saxena, S., Leckman, J. F., Stein, D. J., . . . , Wilhelm, S. (2010). Hoarding disorder: A new diagnosis for DSM-V? *Depression and Anxiety*, 27(6), 556-572.

- Mataix-Cols, D., Marks, I. M., Greist, J. H., Kobak, K. A., & Baer, L. (2002). Obsessive-compulsive symptom dimensions as predictors of compliance with and response to behaviour therapy: Results from a controlled trial. *Psychotherapy and Psychosomatics*, 71, 255-262.
- Mataix-Cols, D., Rauch, S. L., Manzo, P. A., Jenike, M. A., & Baer, L. (1999). Use of factor-analyzed symptom dimensions to predict outcome with serotonin reuptake inhibitors and placebo in the treatment of obsessive-compulsive disorder. *American Journal of Psychiatry*, *156*, 1409-1416.
- Matthews, C. A., Nievergelt, C. M., Azzam, A., Garrido, H., Chavira, D. A., Wessel, J., & Schork, J. C. (2007). Heritability and clinical fetures of multigenerational families with obsessive-compulsive disorder and hoarding. *American Journal of Medical Genetics Part B (Neuropsychiatric Genetics)*, 144B, 174-182.
- Metropolitan Washington Council of Governments. (2006). *Hoarding: A dangerous secret*. Retrieved from www.mwcog.org/uploads/pub-documents/zllWXQ20061 121162353.pdf
- Mikkonen, J., & Raphael, D. (2010). *Social determinants of health: The Canadian facts*. Toronto, Canada: York University School of Health Policy and Management.
- Millar, E. O. (2012). Hoarding and Fair Housing Law. *Life Span Network*. Retrieved from http://www.lifespan-network.org/docs/Hoarding-and-Fair-Housing-Law.pdf
- Nelson, B. J. (1984). *Making an issue of child abuse: political agenda setting for social problems*. Chicago, IL: University of Chicago Press.
- Pertusa, A., Frost, R. O., & Mataix-Cols, D. (2010). When hoarding is a symptom of OCD: A case series and implications for DSM-V. *Behaviour Research and Therapy*, 48(10), 1012-1020.
- Pertusa, A., Fullana, M. A., Singh, S., Alonso, P., Mechon, J. M., & Mataix-Cols, D. (2008). Compulsive hoarding: OCD symptom, distinct clinical syndrome, or both? *American Journal of Psychiatry*, *165*(10), 1289-1298.
- Petrila, J. (1994). An overview of Judicial Enforcement of the Fair Housing Amendments Act of 1988. Retrieved from http://www.oxfordhouse.org/userfiles/file/doc/fhapetrila.pdf
- Pittman, J. (2010). *Calling all clutterers*. Retrieved from http://www.sfaa.org/august 2010/1008 clutterers.html

- Radecki v. Joura, (8<sup>th</sup> Cir. 1997); Howard v. City of Beavercreek, S.D. Ohio (2000); Roe v. Housing Authority of Boulder, D. Colorado (1995); & Roe v. Sugar River Mills Association (D.N.H. 1993)
- Rodriguez, C., Panero, L., & Tannen, A. (2010). A Personalized Intervention for Hoarders at Risk of Eviction. *Psychiatric Services*, 61(2), 1-2. doi:10.1176/appi.ps.61.2.205
- Roe v. Housing Authority of Boulder, D. Colorado (1995)
- Roe v. Sugar River Mills Association (D.N.H. 1993)
- Ronan, F. (2011). Notes navigating the goat paths: compulsive hoarding, or collyer brothers syndrome, and the legal reality of clutter. *Rutgers Law Review*, 64(1), 235-266.
- Roussos, S. T., & Fawcett, S. B. (2000). A review of collaborative partnerships as a strategy for improving community health. *Annual Review of Public Health*, 21, 369-402.
- Saltz, E. B. (2010). Hoarding and elders: Current trends, dilemmas, and solutions. *Journal of Geriatric Care Management*. Retrieved from www.caremanager.org
- Samuels, J. F., Bienvenu, O. J., Grados, M. A., Cullen, B., Riddle, M. A., Liang, K., Eaton, W. W., & Nestadt, G. (2008). Prevalence and correlates of hoarding behavior in a community-based sample. *Behavior Research and Therapy*, 48(7), 836-844.
- Samuels, J. F., Bienvenu, O., Pinto, A., Fyer, A. J., McCracken, J. T., Rauch, S. L., . . . , & Nestadt, G. (2006). Hoarding in obsessive-compulsive disorder: Results from the OCD Collaborative Genetics Study. *Behaviour Research and Therapy*. doi:10.1016/j.brat.2006.05.008
- Samuels, J. F., Bienvenu, O. J., Pinto, A., Murphy, D. L., Piacentini, J., Rauch, S. L., & Nestdat, G. (2007). Sex-specific clinical correlates of hoarding in obsessive-compulsive disorder. *Behavior Research and Therapy*, 46, 1040-1046.
- Samuels, J., Eaton, W. W., Bienvenu, O. J., Brown, C. H., Costa, P. T., & Nestadt, G. (2002). Prevalence and correlates of personality disorders in a community sample. *British Journal of Psychiatry*, 180, 536-542.

- Samuels, J., Shugart, Y. Y., Grados, M. A., Willour, V. L., Bienvenu, O. J., Greenberg, B. D., & Nestadt, G. (2007). Significant linkage to compulsive hoarding on chromosome 14 in families with obsessive-compulsive disorder: Results from the OCD collaborative genetics study. *The American Journal of Psychiatry*, 164, 493-499.
- Saxena, S., & Maidment, K. M. (2004). Treatment of compulsive hoarding. *Journal of Clinical Psychology*, 63, 21-27.
- Saxena, S. (2007). Is compulsive hoarding a genetically and neurobiologically discrete syndrome? Implications for diagnostic classification. *American Journal of Psychiatry*, 164, 380-384. doi:10.1176/appi.ajp. 164.3.380
- Schmalisch, C.S. (2012). Hoarding and the legal system. *International OCD Foundation* http://www.ocfoundation.org/hoarding/legal\_issues.aspx
- Schwemm, R. G. (1990). *Housing discrimination: Law and litigation*. St. Paul, MN: West.
- Steketee, G., & Frost R. O. (2003). Compulsive hoarding: Current status of the research. *Clinical Psychology Review*, 23, 905-927.
- Steketee, G., Frost, R. O., & Kim, H. J. (2001). Hoarding by elderly people. *Health and Social Work*, 26, 176-184.
- Stephenson, B. P. (2004). I'm so lonesome I could cry...but could I sue? Whether 'interacting with others' is a major life activity under the ADA. *Pepperdine Law Review*, 773, 136.
- Teaster, P. B., Nerenberg, L. & Stansbury, K. L. (2003). A national look at elder abuse multidisciplinary teams. *Journal of Elder Abuse & Neglect*, 15(3/4), 91-107.
- Thomas, N. D. (1998). Hoarding: Eccentricity or pathology: When to intervene? *Journal of Gerontological Social Work*, 29(1), 45-55.
- Tolin, D. F., Frost, R. O., & Steketee, G. (2007). An open trial of cognitive behavioral therapy for compulsive hoarding. *Behaviour Research and Therapy*, 45(7), 1461-1470.
- Tolin, D. F., Frost, R. O., Steketee, G., Gray, K. D., & Fitch, K. E. (2008). The economic and social burden of compulsive hoarding. *Psychiatry Research*, *160*, 200-211.
- Tolin, D. F., Kiehl, K. A., Worhunsky, P., Book, G. A., & Maltby, N. A. (2007). A pilot study of the neural mechanisms of decision-making in compulsive hoarding. *PsycholMed*, *39*(2), 325-336. doi:10.1017/S0033291708003371

- Uniform Residential Landlord and Tenant Act § 3.101 (1972), (amended in 1974). Retrieved from www.law.upenn.edu/bll/archives/ulc/fnact99/1970s/ultra72.htm
- Wallston, B. S., Alagna, S. W., DeVellis, B. M., & DeVellis, R. F. (1983). Social support and physical health. *Health Psychology*, 2(4), 367-391. doi:10.1037/0278-6133.2.4.367
- Weiss, K. J. (2010). Hoarding, hermitage, and the law: Why we love the Collyer Brothers. *Journal of the American of Psychiatry and the Law*, 38(2), 251-257.
- Whitfield, K. Y., Daniels, J. S., Flesaker, K., & Simmons, D. (2011). Older adults with hoarding behavior aging in place: Looking to a collaborative community-based planning approach for solutions. *Journal of Aging Research*, 1-8. doi:10:1155/2012/205425
- Widmer, G. M. (2007). We can work it out: Reasonable accommodation and the interactive process under the Fair Housing Amendments Act. *University of Illinois Law Review*, 761, 764-766.
- Winsberg, M. E., Cassic, K. S., & Koran, L. M. (1999). Hoarding in obsessive-compulsive disorder: A report of 20 cases. *Journal of Clinical Psychiatry*. Retrieved from http://psychnet.apa.org
- Wu, K. D., & Watson, D. (2005). Hoarding and its relation to obsessive-compulsive disorder. *Behavior Research and Therapy*, 43, 897-921.
- Zipper v. Haroldon Court Condominium, 2007 N.Y. Slip Op. 03179, 835 N.Y.S 2d 43, 2007 WL 1120373, at \*2 (N.Y.A.D. 1 Dept. 2007).