

Allegheny County Hoarding Task Force
Hoarding Education Curriculum
Developed by the Education Workgroup
July 2017

Introduction

The Allegheny County Hoarding Task Force is a collective group of individuals working to accomplish the mission of the Task Force. The Task Force does not have and cannot accept funding and does not engage, intervene or consult on individual hoarding cases, concerns or situations.

The mission of the Allegheny County Hoarding Task Force is to better understand the nature and extent of hoarding, increase education and awareness and coordinate community resources in Allegheny County, so community services are better able to respond to individuals with hoarding disorder.

Combating and mitigating hoarding in our community requires a multi-disciplinary approach and cannot be overcome by any single agency or discipline.

This document has been created by members of the Hoarding Task Force Education Workgroup. Information in this document has been developed by its members through professional experience and research. This document is not meant to replace professional or legal advice. It is a first step to learn a bit more about hoarding and hoarding disorder and the complex issues that are faced by people with this disorder.

Target Audience: Professionals and clinicians that do not exclusively work with individuals with a hoarding disorder and are seeking more information about hoarding disorder.

Purpose: Examine multiple components of hoarding, including hoarding disorder basic definitions, diagnosis and assessment, stages of hoarding, risk factors, safety and interaction.

Sincerely,

The Allegheny County Hoarding Task Force

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Section 1 – Background and Definitions

Section Introduction

This section provides a basic history of hoarding disorder and introductory definitions

What is Hoarding Disorder?

Hoarding is the excessive acquiring and accumulation of items along with a persistent inability to discard items because of a perceived need to save. These items may have little value or utility. The thought or action of discarding an item will cause discomfort and distress.

History of Hoarding

Prior to May of 2015 there was no way to diagnosis an individual with this disorder. It had been listed under Obsessive Compulsive Personality Disorder (OCPD) as a single undefined bullet. As public awareness of the disorder increased so did our understanding, leading to a diagnosable disorder in the DSM-5. Individuals suffering with hoarding disorder can now seek treatment and receive protection under the American with Disabilities Act (ADA).

Definitions

- **Collecting** – A person who collects items of a specified type, professionally or as a hobby.
- **Hoarding** –Hoarding is the excessive acquiring and accumulation of items along with a persistent inability to discard items because of a perceived need to save. These items may have little value or utility. The thought or act of discarding an item will cause discomfort and distress.
- **Squalor** – Unhealthy and unsanitary conditions. This may include rotting food, vermin or insect infestation, large collection of trash and items, as well as a strong odor. The home owner is typically unbothered by their surroundings.
- **Diogenes syndrome**, also known as senile squalor syndrome, is a disorder characterized by extreme self-neglect, domestic squalor, social withdrawal, apathy, compulsive hoarding of garbage or animals, and lack of shame. Sufferers may also display symptoms of catatonia.

(Snowden, Halliday and Banerjee, 2012)

Collecting vs. Hoarding

- A collector differs from a hoarder in that a collector displays and cherishes their items while being able to set boundaries on their acquisitions and fully understand their collections actual value.
- An Individual suffering from hoarding disorder has persistent difficulty discarding or parting with possessions, regardless of their actual value.

Hoarding and Squalor

- Squalor and hoarding differ in that hoarding is the unrestrained acquiring of items and failure to discard unneeded items. Not all hoarding situations are unsanitary. Many hoards can be considered clean hoards. The visible surfaces are clean, the dishes are washed, bathrooms scrubbed, they simply just have too many items. Squalor is the unsanitary conditions that may come from a hoarding situation. If the person suffering from hoarding disorder finds their items in dumpsters or is unable to discard perishable food items or fast food containers a clean hoard can very quickly turn into squalor.

Section 2 – Debunking the Myths of Hoarding

Section Introduction

This sections dispels common myths about individuals with hoarding disorder. In the left-hand column below a common stereotype about individuals with hoarding disorder is presented and the right-hand column provides a more common reality. Information in this section was developed based on discussion with professionals on the Hoarding Task Force Education Workgroup based on their experiences.

Hoarding Stereotype	Hoarding Reality
Hoarded homes are filthy.	Not all hoarded homes are filthy. Many hoarded homes are organized and clean.
All hoarding homes have bugs and vermin.	Many hoarded homes do not have an infestation.
People who hoard are poor.	Hoarding affects people of all socio-economic status and backgrounds
People who hoard are lazy.	Individuals who suffer from hoarding disorder often struggle with depression. This makes doing everyday tasks very difficult.
People who hoard are agoraphobic and/or anti-social.	A lot of people who hoard have a community and family who love them.
People who hoard are overweight.	Individuals who suffer from hoarding disorder come in all shapes and sizes.
People who hoard are uneducated.	Most individuals who hoard not only have an education but often have had well-paying jobs either in the past or present.

Section 3 - Common Characteristics of an Individual with hoarding disorder

Individuals with hoarding disorder are often stigmatized. The Hoarding Task Force Education Workgroup has reflected on their experiences working and supporting with individuals with hoarding disorder and has developed the follow list of common characteristics about individuals with hoarding disorder. Individuals with hoarding disorder are often...

- Visual learners
- Highly educated
- Creative
- Passionate
- Have strong environmental concerns
- Enjoy giving to others
- Enjoy reading literature
- Strive for knowledge

Section 4 - Diagnosis and Assessment

Introduction

This section addresses diagnosis and assessment of hoarding disorder. The diagnostic criteria from the Diagnostic and Statistical Manual, 5th edition is presented, including who should diagnose hoarding disorder and common assessment themes.

Diagnostic and Statistical Manual – Diagnostic Criteria.

The following is direct diagnostic criteria from the Diagnostic and Statistical Manual 5th edition. (DSM – 5), published in 2013. The DSM provides standardized diagnostic criteria of psychological disorders.

1. Persistent difficulty discarding or parting with possessions, regardless of their actual value.
2. This difficulty is due to both a perceived need to save the items and distress at the thought of discarding them.
3. The difficulty discarding possessions results in the accumulation of possessions that congest and clutter active living areas and substantially compromises their intended use. If living areas are uncluttered, it is only because of the interventions of third parties (e.g., family members, cleaners, or the authorities).
4. The hoarding causes clinically significant distress or impairment in social, occupational, or other important areas of functioning (including maintaining an environment safe for oneself or others).
5. The hoarding is not attributable to another medical condition.
6. The hoarding is not better explained by the symptoms of another mental disorder (e.g., obsessions in obsessive-compulsive disorder, decreased energy in major depressive disorder, etc.)
7. Specifiers
 1. With excessive acquisition
 2. With good or fair insight
 3. With poor insight
 4. With absent insight/delusional belief

(Diagnostic and Statistical Manual V, 2015)

Diagnosis

- It is recommended that a doctor or mental health professional diagnose the person with hoarding disorder. Being clinically diagnosed with hoarding disorder enables the individual to access treatment that is covered by their health insurance plan and places them in a protected class under the American's with Disabilities Act (ADA).

Assessment

Assessment of the disorder can be difficult if you are meeting outside of the client's home. Clients suffering from hoarding disorder are often very gifted at hiding their illness from the outside world. A complete assessment of an individual with hoarding disorder will cover multiple areas of functioning: psychiatric, social, and occupational. The assessment will also evaluate the safety and sanitation of the home as well as how the individuals hoarding affects their Activities of Daily Living (ADL). Additionally, the Clutter Image Rating Scale is an excellent way to gain insight into a client's living situation as well as their level of insight into their disorder.

When entering a client's home for the first time, there are several assessment components that should be kept in mind:

- How the client interacts with their belongings?
 - Is the client very loving towards their items or are they indifferent to the care of the items?
 - Does the client have a system for maintaining, storing and sorting their items?
 - Does the client have general knowledge of where things may be around their house?
- How the client describes their situation?
 - Does the client feel they just need to organize the items that they have?
 - Does the client feel overwhelmed or embarrassed with their level of clutter?
 - Does the client identify a problem with their living situation?
- How the client reacts to the idea of item removal?
 - Is the client strongly resistant to reducing or discarding items?
 - Is the client open to the reducing or discarding items, but hesitant?
 - Is the client more willing to part with their items if they know their items are going to be donated?
- Is the client's home dangerous and how does the client respond if the home is dangerous?
 - Is there a high risk of injury to the client due to the items and the way they are stored?
 - Is there a high risk of fire?
 - Are emergency personnel able to enter the home with ease?
 - When an area of concern is discussed does the client accept that there might be a hazard or do they justify the situation?

Section 5 – Stages of Hoarding

Section Introduction

There are different models that categorize level of hoarding. The *Clutter Rating Scale* from the Institute for Challenging Disorganization (ICD) is a well-known and a widely utilized scale. Hoarding severity is broken down into five stages, with stage one being least profound and stage five being most severe.

The categories below outline the stages of hoarding. Click the link below to access the Institute for Challenging Disorganization *Clutter Rating Scale* for more detail:

<https://challengingdisorganization.org/resources/clutter-8211-hoarding-scale>

Stage 1

Stage 1 following *the Clutter Rating Scale* is the least advanced level of hoarding. At this stage hoarding behavior and habits become solidified.



Below are common characteristics that may present in stage 1

- All doors and stairways are accessible
- All building systems (Plumbing, electrical, HVAC, etc.) are fully functional.
- Pet behavioral and sanitation is appropriate
- Number of pets are in compliance with local regulations
- No excessive clutter
- All amenities are accessible and working
- Functioning bathroom and clean clothes
- All rooms are being used for their intended purposes.
- All family members and pets are healthy, clean, and well nourished
- Safe, maintained sanitation condition
- Maintained finances
- Invites friends' over
- Not generally viewed as a hoarder
- Feelings of anxiety about their clutter, with minimal effects

Stage 2

In stage 2, indicators of hoarding become more identifiable. Safety issues are starting to arise and impaired functioning is starting to present, including accessibility and mobility constraints.



- One exit to the house is blocked or one room is unusable
- One major appliance is not in working order because it is too difficult to access
- Less attention is being paid to housekeeping. (e.g. Dishes are piling up and shelves remain dusty)
- Some plumbing or electrical systems are not fully functional.
- Non-existent or non-functioning smoke alarms or CO alarms.
- Pet odors becoming noticeable.
- Shift in focus from life to clutter.
- Diminished social and family interaction
- Clutter and obstruction in some living areas.
- Reduction in the number of guests they have over because of embarrassment
- Mild anxiety and depression
- Shifting from embarrassment to justification
- Clean-up requires light Personal protective Equipment (PPE) as needed.

Stage 3

Stage 3 is the mid-point on the *Clutter Rating Scale* and signs of hoarding are starting to become evident to outsiders.



- Indoor items may be stored or tossed outside
- Minor structural damage
- Evidence of excessive extension cord use and phone lines when outlets get blocked off
- Pets may have fleas
- The kitchen sink may be full of dishes and standing water
- Stairs and walkways are generally extensively cluttered and difficult to navigate
- Outside storage (shed or garage) is overflowing
- Personal care is neglected
- Consuming reheated, precooked, or fast food because the kitchen is only borderline functional
- Decreased physical activity
- Family has attempted to intervene numerous times and is faced with rejection and withdrawal.
- Work place problems
- Audible evidence of pests
- Inadequate and/or inappropriate pet sanitation
- Light structure damage to the home
- Growing financial concern
- Obvious presence of accumulated dirt, dust and debris
- Clean-up requires a medium level of PPE.
- Substandard household maintenance and/or housekeeping.

Stage 4

Stage 4 consists of advanced structural damage in several areas, including sagging floors and ceilings. Major appliances are no longer working properly or at all. The house and contents pose a significant safety risk to occupants. Additionally, individuals will not have access to fresh foods and safe/workable food preparation area and utensils.



The following may also be present

- Mold, bugs, and cobwebs may be present
- Contents are stored in uncommon places such as clothes hanging on the shower curtain rod or important documents in the oven
- Individuals who hoard will remain in very small area of the house, “The Cockpit”
- Bathe in the sink or not at all
- Struggle to get to work on time or no longer working
- Significantly behind on bills and other serious financial troubles
- Utilities may be shut off
- Water damaged floors
- Expired or leaking canned goods, jars, etc.
- Dishes and utensils unusable
- Rooms cannot be used for their intended purpose
- Rotting food
- Sleeping on mattress or sleeping somewhere other than in bed.
- Rodents are audible and visible
- Pets may have run away or died in the house
- Individuals may have shut everyone out of their lives
- Individual is focused mostly on the past or an unrealistic future

Stage 5

Stage 5 is the most advanced and profound stage. Hoarding is evident and the property is highly unsafe and inhabitable.



- Major structural damage to the house
- Severe mold, strong odors, bugs, rodents, and cobwebs
- Entire floors of the house might be blocked off
- Walls of items in every room
- Struggling to complete simple tasks like eating, sleeping, using the restroom
- Limited to consuming soft drinks, fast-food or expired foods
- Family and friends (if they are still in contact with them) are deeply concerned
- Serious financial problems
- Severe, debilitating depression
- Confusion
- Isolated to their house, unless it is to move into their car or a homeless shelter
- Unreliable electrical, water or plumbing systems
- Structure issues deemed unsafe and/or not repairable
- All rooms not used for their intended purpose
- Hidden hazards obscured by clutter and content
- Human urine and excrement present
- Overgrown vegetation/foliage
- Extreme indoor/outdoor clutter

Section 6 – Risk Factors for Developing Hoarding Disorder

Section Introduction

The purpose of this section is to identify risk factors (antecedents) that may lead an individual to hoard. These factors may be a combination of physical, psychological and environmental. Information in this section is developed through a literature review of hoarding risk factors and reviewing professional experiences working with individuals with a hoarding disorder.

- Section 6(a) – Risk factors
- Section 6(b) – Emotional factors

Section 6(a) – Risk Factors of Developing Hoarding disorder

Heredity and Family History

Initial research into hoarding behavior and disorder indicates there may be a hereditary link. In 2007 results from the *OCD Collaborative Genetics Study* indicated that individuals with hoarding behaviors have different levels of regional brain activity compared with individual with other types of OCD diagnoses. The study also revealed that families with two or more relatives who hoard had a strong signal of chromosome 14, indicating this chromosome may contribute to an individual's hoarding compulsions.

The *OCD Collaborative Genetics Study* was conducted before the addition of hoarding disorder in the DSM - 5.

(Samuels, et al, 2007)

Age

Hoarding appears more commonly in older individuals, as the disorder is progressive. Hoarding is likely to have started at a much earlier period of life; however, the effects may not have been observed until later in the individual's life. The Mayo Clinic reports hoarding usually starts around age 11 to 15 and progresses throughout life.

Samuels et al reports that hoarding is three times more common in individuals age 54 and older, indicating hoarding is progressive and chronic.

(Mayo Clinic, 2014)

Dementia

Dementia creates changes in the brain that can lead to hoarding, according to the Alzheimer's Association. They also report hoarding may develop in the early and middle stages of dementia. Like other individuals that hoard, individuals with dementia...

- May forget to discard things
- Believes they are holding onto items for people that they don't remember have passed away
- Have difficulty distinguishing items that should be kept or discarded
- Have difficulty remembering where items are stored, placed or hidden

(Alzheimer's Association, 2015)

Obsessive Compulsive Behaviors and Disorders

Individuals with hoarding disorder display linkages between Obsessive Compulsive Disorder (OCD) or OCD-like behaviors. According to the National Institute of Mental Health (NIMH), OCD actions are uncontrollable, reoccurring thoughts (obsessions), and behaviors (compulsion), that an individual feels the need to repeat over and over again.

- Obsessive Compulsive Disorder (OCD) is closely linked, but separate from hoarding disorder.
- Rates of hoarding in OCD cases range from 18% – 42%. (Grisham and Baldwin, 2015)
- If an individual is suffering from OCD they may put off cleaning up or putting things away if they do not have the time needed to satisfy their compulsion.
- Individuals may be compelled to buy things to satisfy a compulsion but may not be able to throw items away that are worn out or ruined for the same reason.
- Individuals are often focused on the "What If" scenario (What if I need this and don't have it? What if my family/friends need this and I don't have it to lend to them?)

(National Institute of Mental Health, 2016 & Grisham and Baldwin, 2015)

Depression and Anxiety

Depression and anxiety are common mental health diagnoses in our society. According to Frost, Steketee, and Tolin, 2011, 50% of clients with hoarding disorder have a major depressive disorder as well.

- Generally, depression and anxiety go hand in hand with hoarding disorder.
- “Things” become their safety
- Having or acquiring items reduces anxiety
- Many clients use retail therapy to help with their anxiety and depression, feeling an emotional “high” at finding a great deal/sale. Unfortunately, many times after the purchases the client suffers from buyer’s remorse and will soon need to go back out to feel that high again.

(Frost, Steketee and Tolin, 2011)

Social Phobia and Isolation

Individuals past experiences MAY cause them to distrust people and interacting with people could cause emotional or physical pain. Individuals who hoard may prefer material comfort. Common examples include:

- Fears of a past event happening again
- Having a negative interaction with one or more people that has caused a deep distrust of others
- A major loss, such as a death, has caused them emotional suffering that they fear reliving.

Personality and Decision Making

- According to the Mayo Clinic, individuals that have hoarding disorder may be more indecisive.
- One study identified that individuals with hoarding disorder took longer to make a decision to throw away an item or keep it.
- Individuals may suffer from chronic disorganization which makes deciding very difficult, since they are unable to clearly outline a purpose and need for an item

(Source: Szalavitz, 2012 & Mayo Clinic, 2015)

Trauma and Stress

Some Individuals who struggle with hoarding disorder may have a history of trauma. As a means of coping with the past, individuals may seek comfort in possessions. These possessions serve multiple purposes depending on the trauma. Sometimes these possessions create a physical barrier between them and the persons or world that harmed them. Other times folks who have suffered abuse, neglect, or rejection turn their affections towards items and the joy that they bring serves as a substitute for healthy interpersonal relationships. To a person who has experienced housing instability and/or economic hardship, it makes sense to save everything in the event that there is or may come a time when they will need something and will be unable to afford to purchase a similar on item.

Section 6(b) – Emotional Factors

Preservation of a Perfect Past

- Individuals with hoarding disorder may feel there is no end in sight to their situation
- May prefer to live in a time where things were better or easier for them
- If they had a traumatic past they may hold onto one positive and believe that was the norm
 - i.e. Dad took me fishing every weekend. In reality their father only took them fishing once.

Addiction

- A need to have another object
- Experience a “high” when they acquire or find an item
- May display manipulative behaviors and justification for the need of those items
- Sense of temporary relief when they can acquire or keep an item
- Unable to decide between the people they love and their items

Easy Love

- May feel people cannot be trusted, seeking another outlet for social interaction and connection
- Concept that “stuff” will always be there for them and “stuff” will never ask them to do anything that they do not feel comfortable doing
- If individual hoards animals, they will always have the sense of being needed because animals rely on their owners for survival
- Animals will give a quick dose of love every time they see their owner

Fake Future, Avoiding Reality and Boundaries

- Stuff can be an escape
- They will submerge themselves in the items that make them feel the best, such as clothing or craft supplies, when their lives feel unmanageable
- Individuals with a hoarding disorder may spend time trying to clean or organize and get lost in the process rather than coping with an unpleasant experience
- May have a difficult time processing between an item that is needed or an items that is wanted.

Section 7 – Interacting and Engaging Individuals Who Hoard

Section Introduction

This section reviews some best practices about interacting and engaging someone with hoarding disorder. An individual with hoarding disorder will not change until they are ready, able and willing. A third party cleaning out a hoarded property will not correct the underlying causes of hoarding and the hoarding will return.

Interaction and Engagement

- Make sure the individual that hoards feels in control
- Set obtainable and realistic goals (e.g. an individual with an advanced case of hoarding disorder may never live in a perfectly clean house)
- Be patient and maintain trust.
- Stay focused on the individual with hoarding disorder, not the family's needs
- Late-stage hoarding disorder clients will be in denial. Remain positive and supportive
- Focus on love and concern
- Offer to help and assist in clean up

Level of self-Insight
<p>Insight is the level of understanding and recognition one has about their situation. The following three levels provide a basic definition and description of insight.</p> <p style="text-align: right;"><i>(Sources: Miller and Rollnick & DSM 5)</i></p>
<p>No insight</p> <ul style="list-style-type: none"> • No awareness; denial and justification of one’s hoarding situation. • Believes hoarding behavior and situation is not problematic <p style="text-align: right;"><i>(DSM 5, 2015)</i></p>
<p>Poor insight</p> <ul style="list-style-type: none"> • Some awareness of one’s situation, causes and consequences. • Mostly believes hoarding behaviors are not problematic. <p style="text-align: right;"><i>(DSM 5, 2015)</i></p>
<p>Good Insight</p> <ul style="list-style-type: none"> • Good awareness of one’s situation and causes, effects and consequences. Person can accurately explain and describe their situation. • Recognizes hoarding behavior is problematic and understands difficulty discarding unneeded items.

Section 8 – Therapy, Engagement and Remediation

Section Introduction

Treating hoarding disorder is a twofold approach. An individual must be ready, willing and able to engage in therapy and engage in clean-up activities. A person cannot be forced to change; however, it is possible to properly motivate an individual to innately desire change. Additionally, discarding possessions without the individual with hoarding disorders involvement, participation and consent will be counterproductive, causing trauma, stress and distrust of the individual.

Information in this section have been gathered through conducting literature review and looking to common interventions. This section provides a high-level overview of potential components. Use of therapeutic approaches requires intervention by a trained professional

Section 8(a): *Therapy*

- Motivational Interviewing (MI)
- Cognitive Behavioral Therapy (CBT)
- Exposure Response Prevention (ERP)
- Support groups

Section 8(b): *Clean up and Remediation*

Section 8(a) – Therapy

Motivational Interviewing

Motivational Interviewing is a person-centered approach used to enhance a person's intrinsic motivation to create change. Motivational interviewing works to increase a person's insight and break through a person's ambivalence about change.

Miller and Rollnick, the primary theorists behind Motivational Interviewing developed their model based on the five theories below:

- Change occurs naturally
- Change is influenced by the interactions between people
- The expression of empathy is a means of effecting change
- The best predictor of change is confidence on the part of the patient or the practitioner, that the patient will change
- Patients who say they are motivated to change do change

Strategies to create change:

- Show the disadvantages of the status quo
- Show the benefits of change
- Show that change is possible
- Support individuals in their intention to change.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2231547/>

(Source: Miller & Rollnick)

Cognitive Behavioral Therapy (CBT)

The National Alliance on Mental Illness (NAMI) defines Cognitive Behavioral Therapy (CBT) as:

“Focusing on exploring relationships among a person's thoughts, feelings and behaviors. During CBT a therapist will actively work with a person to uncover unhealthy patterns of thought and how they may be causing self-destructive behaviors and beliefs”. (NAMI, 2016)

Therapists and clients will work together as a team to identify, develop and reinforce positive thoughts, thereby creating healthier thoughts and behaviors.

According to NAMI, CBT seeks to identify negative or false beliefs and test or restructure those negative thoughts and beliefs.

Homework is also an important part CBT, which requires the patient to actively work on improving their situation in small doses.

<http://www.nami.org/Learn-More/Treatment/Psychotherapy#sthash.WWhfJkz9.dpuf>

(Source: NAMI, 2016.)

Exposure Response Prevention (ERP)

The American Psychiatric Association (APA) defines Exposure Response Prevention Therapy as:

A treatment that must involve *both* exposure and ritual prevention. Exposure involves confronting situations, objects, and thoughts that evoke anxiety or distress because they are unrealistically associated with danger. Response (ritual) prevention is conceptualized as blocking avoidance or escape from feared situations. By encouraging the individual to remain in the feared situation without any avoidance behaviors, exposure and response affords patients the opportunity to learn that their fears are unrealistic.

When patients were exposed to obsessional cues, but were prevented from engaging in rituals, anxiety and discomfort was at first profound, but decreased over time. When patients were then exposed to their obsessional cues again, the urge to ritualize had decreased as compared to the previous trial. This decrease in urge to ritualize did not occur if patients continued to engage in rituals in response to obsessional cues.

(Huppert, & Roth, 2003)

Support Groups

Support groups are an effective means of increasing a person's self-insight. Irvin Yalom is well known for his work related to group therapy. The following elements are some examples identified by Yalom that may prove helpful to individuals attending support groups.

- **Self-understanding** – Human interaction with other human beings is vital to positive mental health functioning. How one interacts with others effects one's mental functioning. Individuals that have the opportunity to interact with others will learn more about themselves. Through interaction in a support group, individuals can learn better about their functioning and increase self-insight into their behaviors
- **Universality** – Hoarding individuals often feel isolated and suffer with their own feelings, thoughts and situations. By attending a support group, individuals understand they are not alone. They have the opportunity to confide and identify with other individuals in similar circumstances.
- **Instillation of hope** – When individuals with hoarding disorder interact and identify with others that have overcome and improved on their situation, those new to support groups and the change process will improve their own situation by observing the improvement others have experienced.

(Source: Yalom, 2005)

Section 8(b) – Clean up and Remediation

The concept of a clean-out can be a very stressful situation for an individual who hoards. Because of the emotional attachment to the items this can be a very vulnerable time for the client. When helping a loved one process their items it is important to allow the client to make the majority of the decisions on their own. This process requires compassion, patience, and understanding on the part of the individual assisting the client.

Unfortunately, if a clean-up requires professional services, these can often be costly. A clean-up could cost upward of \$5,000 or more, but is very situational

Some thoughts

- If biohazards are present
- Property size
- Property condition
- Property location
- Property/utility damage
- Level of client involvement

Section 9 – Road blocks and Barriers to Treatment

Section Introduction

There are many road blocks and barriers to client successfully accessing, receiving and progressing through the treatment and clean-up process. Information in this section was developed through common research and members of the Hoarding Task Force reflecting on common road blocks and barriers they have identified as part of their professional experiences.

Money and Finances

Money is a common barrier to treatment. Individuals that hoard may not be financially equipped to engage in an intensive clean out program. A clean-up could cost around \$5,000 or more.

If an individual is covered by health insurance, they may be able to access therapy services. Health insurance will not cover the cost of cleanup and remediation.

Client self-insight

Clients may lack full insight into the extent of their hoarding situation and may be unready and unwilling to improve their situation. Some may be unable to comprehend the size of their clutter and feel their issues are more related to a lack of space or lack of organization. Individuals may be unable to see how their hoarding is negatively affecting their life and relationships. Some may think they can solve their issues of clutter on their own when they might actually benefit from the support of loved ones and mental health care providers.

Physical Ability

Hoarding clients may not have physical ability to clean up because of advanced age, fragility or physical disability. A client should be encouraged to participate to their full potential and be an active member in the cleanup process.

Support

Hoarding is often isolating. Many individuals that hoard are ashamed and embarrassed and hide their situation from others. Lack of support can lead to isolation, depression, anxiety among many other issues.

Stigma and Discrimination

The stigma of having a hoarding disorder may be at the core of why an individual does not seek treatment. The way in which the disorder is negatively portrayed in the media may lead an individual to be more comfortable hiding the illness and withdrawing from those around them, rather than becoming vulnerable to critics.

Transportation and Community Access

Access includes not only transportation but also physical and community access. Individuals in rural areas may not have access to a public transportation system, preventing them from seeking medical/mental health treatment, socialization and basic needs. Hoarding clients without access to transportation have a higher likelihood of experiencing social isolation.

In rural areas, services are not always available, nor easily accessible. An individual may have to drive an hour or more to be able to receive support, treatment or socialization. A rural resident may also struggle to arrange for in-home services.

Section 10 – Safety

Section Introduction

Hoarding situations require special safety measures. This section discusses safety precautions that can be used to mitigate risks in a hoarding situation. Each hoarding situation is unique, so understanding the extent and degree of hoarding is important. Some hoarding situations may be advanced, with mold, dead or alive animals, including urine and droppings. Additionally, structural integrity issues and fire risks are increased.

Please note that hoarding clean up may require specialized services, such as mold remediation and hazardous waste management. It is important to seek these services when appropriate and not risk personal safety.

Possible safety issues depend on the type of hoard, extent and situation. The list below is meant to provide examples and may not be all inclusive.

This section is broken down into the following exposures:

- 10(a) – Infectious disease
- 10(b) – Animal/vermin
- 10(c) – Chemicals and particulates
- 10(d) – Structural dangers and safety

Information in this section was identified through primarily researching Centers for Disease Control and Prevention publications other web-site based resources.

Section 10(a) – Infectious Disease

Depending on the hoarding situation, it is possible that infectious diseases are present. This is certainly not the case in all situations, but the following infectious diseases *may* be present in a hoarding situation. They are most commonly found in situations involving no access to proper food preparation and storage and/or to those that demonstrate improper sanitation, handwashing and waste disposal, but are not exclusive to hoarding.

Pathogen	Description
Toxoplasmosis	<p>Illness from <i>toxoplasma gondii</i> parasite, which may cause flu-like symptoms and is found in the following areas</p> <ul style="list-style-type: none"> • Cat feces • Contaminated water • Contaminated surfaces (knives, counters) • Unwashed fruit/vegetables <p style="text-align: right;">(Source: Mayo Clinic)</p>
Hantavirus	<p>If a home/property houses rodents, surfaces may be contaminated and result in transfer to humans. The Centers for Disease Control and Prevention (CDC) indicates cleaning an infected house exposes individuals to infected surfaces and cause illness.</p> <p style="text-align: right;">(Source; CDC)</p>
Botulism	<p>Botulism is a bacterial toxin produced by <i>clostridium botulinum</i>, which attacks the nervous system causing paralysis and can be life threatening if untreated.</p> <p>The botulinum toxin may be present in improperly canned or damage canned items. Expired or damaged canned items should be discarded.</p> <p>Botulism can be treated by botulinum anti-toxin and supportive care.</p> <p>Proper cleaning and hygiene will reduce the possibility of infection.</p> <p style="text-align: right;">(Source: CDC)</p>

10(b) - Animal/vermin Danger

Animals and vermin may be present in hoarding situation. it is important to understand animal hoarding is different from attracting animals and vermin. Animal hoarding is distinctly acquiring animals

Item	Description
Rodents	<p>Merriam-Webster defines a rodent as a relatively small gnawing mammal (such as a mouse, squirrel, or beaver) that have in both jaws a single pair of incisors with a chisel-shaped edge.</p> <p>Mice, rats, squirrels are examples of rodents that can possibly be present in a hoarded home.</p> <p>Rodents may carry disease causing pathogens in addition to causing damage from gnawing and chewing on objects, which may also create a fire hazard if chewing on electricity cords.</p> <p style="text-align: right;"><i>(Merriam-Webster, 2016)</i></p>
Vermin and pests	<p>Vermin is defined as a small, common, harmful or objectionable animal (as lice or fleas) that are difficult to control</p> <p>Birds, insects, lice and ticks are examples of vermin and pests.</p> <p style="text-align: right;"><i>(Merriam-Webster, 2016)</i></p>
Other non-domesticated animals	<p>Raccoons, bats, feral cats and dogs may inhabit a severely hoarded property and potentially carry disease, including rabies. These domesticated animals may cause additional property damage and create unsanitary conditions.</p>
Domesticated animals	<p>Cats and dogs are the most common domesticated animals. These animals may reside in a home and are often dependent on humans for survival and wellbeing.</p> <p>In a severely hoarded home domesticated animals may become trapped under debris or unable to access fresh food and water, a result the animals will run away or die.</p>

10(c) - Chemical/particulate Danger

Chemicals and particulates may be present in hoarded homes. It is important to understand that chemicals and particulates may pose a health and safety risk to individuals in a hoarding situation. Chemicals may be hoarded and improperly labeled and stored. Empty chemical containers may contain residual product, so containers should not be used for any other future purpose. Mixing chemicals is potentially dangerous and should never be done.

Particulates

Item	Description
Asbestos	Asbestos is a fibrous material that was used for insulation and construction. Disturbance of asbestos can result in the release and inhalation of fine, undetectable particles into the air. Asbestos exposure has been linked to a form of lung cancer.
Dust and other allergens	Allergens and dust are common irritants that are likely to be present in hoarded home.

Cleaning and Household Supplies

Cleaning supplies	Hoarding homes may contain many cleaning supplies. It is important to not use these cleaning supplies if they are not in their original packaging or there is any doubt the contents have been altered.
Paints, stains and varnishes including lead based products	When handling paints, varnishes, stains or other household products that may contain lead, it is important to act according to strict safety standards. Removal may require professional assistance. <i>(NYS Dept. of Health, 2010)</i>

10(d) - Structural Dangers

Structural Danger	Description
Fire hazards	<p>Accumulation of flammable and combustibile materials in excess poses a fire hazard. Evacuation and rescue during a fire or other emergency may be compromised as a result of the level of hoarding.</p> <p>Some hazards include:</p> <ul style="list-style-type: none"> • Multiple extension cords • Overloaded outlets • Blocked heating vents • Improper use and maintenance of appliances • Damage to electrical system • Occupant smoking without precaution
Unstable surfaces	<p>Depending on the extent of a hoarding situation, walking paths may be cluttered with debris, creating tripping hazards and affect balance.</p>
Inaccessible egress	<p>Many hoarded properties are at an increased fire risk. In the event of a fire or need to evacuate, exits may not be easily accessible or usable.</p> <p>Individuals with mobility impairments may be in particular danger when an emergency exit is needed.</p>
Risk of collapse/entrapment	<p>Depending on the level of hoarding, piles of clutter may collapse/cave in and/or shift, especially when disturbed by humans and animals.</p> <p>Depending on the damage to the property, excessive items may create sagging floors and ceilings.</p>
Damaged utilities	<p>Gas lines and/or electrical sources may be damaged, leading to shock and fire hazards.</p> <p>Water and sewage pipes may be damaged, especially in older properties with brittle lead piping.</p>

Section 11 – Universal Precautions and Personal Protective Equipment

Precautions and Personal Protective Equipment (PPE) Introduction

Precautions should be taken and Personal Protective Equipment (PPE) should be used as appropriate to reduce the risk of infection and contact with hazards in a hoarding situation. The type of interaction, hoarding severity and hoarded content will inform the precaution and equipment that should be used. The following precautions and PPE are available to use in a hoarding situation.

Information in this section is gathered through web-based research. Information in this section is used or general knowledge and each situation is unique and this documents is not a comprehensive manual that addresses safety. It is designed to provide a general overview.

Precautions

Precautions are measures taken to reduce the likelihood of coming in contact with, acquiring and transmitting disease or hazardous material to self or others. Standard precautions should be taken when entering a hoarded property. Proper judgement should be used regarding the level of precaution needed.

The following are some examples of precautions that could be taken in a hoarding situation.

- Wash hands thoroughly
- Ventilate work area as much as possible
- Bring a change of clothes
- Change clothes before returning to personal residence
- Have a First Aid kit on hand
- Use PPE

Personal Protective Equipment

Personal Protective Equipment, (PPE) is used to protect an individual from possible hazards by creating a barrier between the environment and person. PPE reduces, but does not eliminate environmental dangers. The level of equipment used will vary, depending on the specific situation.

Some important PPE items are listed below:

- Durable work gloves
- Shoe covers
- Goggles/face shield
- Respirator/mask (two strap, N – 95)
- Protective gown
- Closed toed shoes.
- Hand sanitizer
- Face shield

Section 12 – Human Safety in a Hoarding Situation

Family Safety

Family may either live with the person that hoards or in another location. Family members who live in a hoarded home are subject to the dangers and may be frustrated with the family member who hoards and the environment.

Caregiver and Professional Safety

Caregivers and professionals that enter the home are subject to a variety of health and safety concerns. The following are important steps to consider to safeguard yourself:

- Take only essential items with you.
- Place personal belongings into a plastic bag, seal it, and leave it near the door, to be picked up when exiting.
- Consider bringing a change of clothes in more severe circumstances.
- Avoid wearing loose fitting clothing, open-toed shoes, or shoes with deep treads that could hold pests or unsanitary debris. Consider using protective equipment (gloves, boots, gown, mask) in more concerning environments while weighing the impact this may have on the therapeutic alliance.
- Avoid sitting, particularly on soft-covered furniture.
- Do not lift, carry, or walk into areas you do not feel comfortable accessing.
- Be aware of your exits and paths. Avoid areas where piles can easily topple.

(Source: Chater, Shaw, & McKay, 2013)

Hoarding Client Safety

It is important to consider the safety of the client who hoards. The client's level of insight will influence the mitigating safety factors the client is willing to take.

Hoarding clients should have

- Two accessible exits in every rooms.
 - Primary exit – doorway
 - Secondary exit – doorway/window
- Smoke AND carbon monoxide detector with batteries replaced every 6 months and replaced following manufacturer recommendations or when needed.
- Emergency response system, when indicated
- Working and accessible landline/cellular telephone.
- Area to store and prepare foods safely
- Working bathroom
- Working utilities

Community Safety

Hoarding in apartments and closely constructed homes create dangers for the community in addition to the individual that hoards. Community safety is effected because the consequences and risks of hoarding are often not easily confined.

Some examples of hoarding community dangers include:

- Water damage
- Odors
- Fire
- Infestation of bugs, fleas, and other animal and pests that may travel outside the apartment/home.

First Responders Safety Issues

When responding to an emergency, first responders are faced with increased safety risks in hoarded properties. Hoarded homes may not have direct paths and egress that prevent emergency responders from successfully carry out their duties. Hoarding situations create a substantial risk to both occupants and responders.

Fire Responders

Entering a hoarded home that is on fire is extremely dangerous for fire personnel. Hoarded homes may contain many flammable items creating an explosion risk. The fire may also weaken piled of hoarding items, creating cave ins and entrapment risks. Individuals that are trapped in a hoarded home that is consumed by fire are less likely to be rescued. Hoarding situations reduce the ability of fire personal to control the fire and preserve further property damage. Hoarding may increase the speed which fire spreads because the abundance of combustibile material to serve as a fuel source.

Medical Responders:

When responding to an emergency, medical responders may not be able to identify the individual's location nor access it, due to having to remove and navigate debris. Additionally, removing an individual experiencing a medical emergency may be delayed or quite difficult -especially when heavy medical equipment such as a stretcher, oxygen and/or other emergency equipment is involved

Section 13 – Community Approach and Legal Support

Introduction

Research and policy about hoarding disorder are currently limited and in their infancy. Recently there has been a greater awareness of hoarding because of popular television shows, and the addition of the diagnosis to the DSM – 5.

Communities have grappled with issues around hoarding and hoarding disorder. To address hoarding disorder, many communities have developed Task Forces to engage a multidisciplinary approach

Community Approaches

Across the United States, community hoarding task forces have formed to address hoarding related issues but oftentimes have limited available resources. These task forces are often the first step to organizing a collective group of individuals from a variety of professions with a diversity of experience to discuss this multifaceted disorder and how their community should approach hoarding.

Some notable task forces have developed, including the San Francisco Task Force on Compulsive Hoarding, which released a report titled *Beyond Overwhelmed* in 2009.

San Francisco Task Force on Compulsive Hoarding

The San Francisco Task Force on Compulsive Hoarding launched in the summer of 2007, convening representatives from major city departments, non-profit housing and service providers, and others to strategize on how to facilitate collaboration among service systems that is needed to implement multi-disciplinary strategies on compulsive hoarding.

- Identify gaps and barriers in service
- Assess current services and needs
- Identify best practices to improve coordination of services and eviction prevention to reduce eviction and improve quality of life for compulsive hoarders
- Raise awareness among the public and policy makers
- Facilitate information exchange among various service providers to improve service linkages and coordination
- Make policy recommendations
- Conduct PR campaign about compulsive hoarding issues
- Create and present final report in 2009

Objectives:

Identify what is needed to reduce evictions and improve the quality of life for compulsive hoarders in San Francisco and facilitate information exchange among various service providers so as to improve service linkages and coordination. Develop a mechanism for continually coordinating available services, identifying ways to use existing resources to prevent eviction for compulsive hoarders, and identifying gaps in services and needs

Philadelphia Hoarding Task Force

The Philadelphia Hoarding Task Force is a coalition that seeks to improve outcomes for people who hoard and reduce the catastrophic consequences related to hoarding for residents of the City of Philadelphia

Balancing the rights of the individual with the health and safety needs of the community, the task force works to provide individuals and organizations in the region with the tools they need to successfully overcome this challenging issue.

- The Philadelphia Task Force has worked to look at community resources and list them on their website.
- Coordinate community education and training resources about hoarding
- Provide an overview of laws and rules applicable to people with hoarding disorder.

Legal Support

- Individuals diagnosed with hoarding disorder are protected under the Americans with Disabilities Act (ADA).
 - Individuals with a hoarding disorder diagnosis are entitled to reasonable accommodation.
 - Contact your local legal aid organization or ADA coordinator for additional information.
 - Your local ADA coordinator can advise you of your rights and responsibilities under the ADA law

Children, Youth and Family and Adult Protective Services

If the safety of children, older/vulnerable adults is suspected or in question, contact the appropriate protective service agency.

Protective Service Contact Numbers

- **Children Protective Services** 1-800-932-0313
 - <http://www.county.allegheny.pa.us/Human-Services/Programs-Services/Children-Families/Child-Protection.aspx>
- **Older Adults Protective Service** 1-800-344-4319
 - <http://www.alleghenycounty.us/Human-Services/About/Contact/Older-Adult-Abuse.aspx>

Section 14 – Call to Action and Conclusion

Call to Action and Conclusion

There is a void in academic literature and research on hoarding disorders. Insurance will only pay for treatments that are “evidence based”, meaning they have been well researched treatments and proven to work. With little research on the topic of hoarding comes minimal approved treatments. This also affects the availability of funding for those struggling with this disorder. Hoarding disorder research needs to be made a priority. As community members, we can advocate for more funding to be directed to hoarding disorder research and programs that assist those struggling with hoarding. Raising awareness and destigmatizing this disorder helps create an environment where those who once struggled silently can confidently reach out for help

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