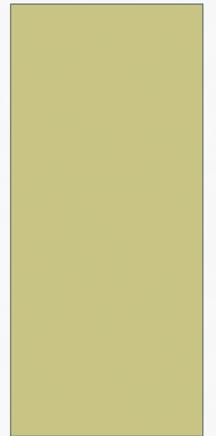


HOARDING DISORDER

A PROFESSIONALS GUIDE

DEVELOPED BY THE ALLEGHENY COUNTY HOARDING TASK FORCE



WHO WE ARE

The Allegheny County Hoarding Task Force is a collective group of individuals working to accomplish the mission of the Task Force.

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 that community services are better able to respond to individuals with hoarding disorder.

TOPICS COVERED

- Background and definitions
- Debunking the myths
- Common characteristics
- Diagnosis and assessment
- Stages of hoarding
- Risk and Emotional factors
- Interacting and engaging
- Therapy and remediation
- Roadblocks and barriers to treatment
- Dangers
- Universal precautions and personal protective equipment
- Human safety
- Policy and research

BACKGROUND AND DEFINITIONS

BACKGROUND AND 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.

BACKGROUND AND DEFINITIONS

- History of Hoarding Disorder
 - Prior to May of 2015 there was no way to diagnose 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 Americans with Disabilities Act (ADA).

BACKGROUND AND 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.

BACKGROUND AND DEFINITIONS

- ***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 collection's 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 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.

DEBUNKING THE MYTHS

DEBUNKING THE MYTHS

Stereotype

- Hoarded homes are filthy
- All hoarded homes have bugs and vermin
- People who hoard are poor
- People who hoard are lazy
- People who hoard have agoraphobia and/or anti-social personality disorder
- People who hoard are overweight
- People who hoard are uneducated

Reality

- Many hoarded homes are organized and clean
- Many hoarded homes do not have any infestation
- Hoarding affects people of all socio-economic status and backgrounds
- Individuals who suffer from hoarding disorder often struggle with depression. This makes doing everyday tasks very difficult
- A lot of people who hoard have a community and family who love them
- Individuals who suffer from hoarding disorder come in all shapes and sizes
- Most individuals who hoard not only have an education but often have had a well paying job either in the past or present

COMMON CHARACTERISTICS

COMMON CHARACTERISTICS

- Individuals that hoard are often:
 - Visual learners
 - Highly educated
 - Creative
 - Passionate
 - Have strong environmental concerns
 - Enjoy giving to others
 - Social
 - Enjoy reading literature
 - Strive for knowledge

DIAGNOSIS AND ASSESSMENT

DIAGNOSTIC AND STATISTICAL MANUAL

- The following is direct diagnostic criteria from the Diagnostic and Statistical Manual 5th edition.
- (DSM – 5), published in 2015. The DSM provides standardized diagnostic criteria of psychological disorders

DIAGNOSTIC AND STATISTICAL MANUAL

- Persistent difficulty discarding or parting with possessions, regardless of their actual value.
- This difficulty is due to both a perceived need to save the items and distress at the thought of discarding them.
- 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).

DIAGNOSTIC AND STATISTICAL MANUAL

- 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).
 - The hoarding is not attributable to another medical condition.
 - 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.)

DIAGNOSTIC AND STATISTICAL MANUAL

- Specifiers
 - With excessive acquisition
 - With good or fair insight
 - With poor insight
 - With absent insight/delusional belief

(Diagnostic and Statistical Manual 5, 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:
 - Psychiatric functioning
 - Social functioning
 - Occupational functioning
 - Safety and sanitation of the home
 - Activities of Daily Living (ADL).

ASSESSMENT

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

- How does the client interact 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?

ASSESSMENT

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

- How does the client describe 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?

ASSESSMENT

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

- How does the client react to the idea of item removal?
 - Is the client strongly resistant to reducing or discarding items?
 - Is the client open to 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?

ASSESSMENT

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

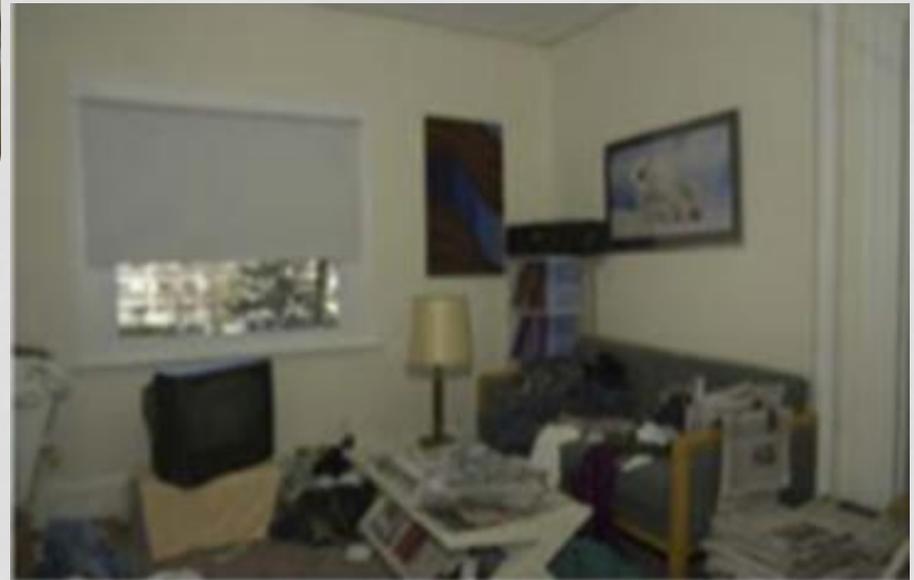
- Is the client's home dangerous and how does the client respond if the home is dangerous?
 - Is there a high risk of injury to the client due to the items and the way they are stored?
 - Is there a high risk of fire?
 - Are emergency personnel able to enter the home with ease?
 - When an area of concern is discussed, does the client accept that there might be a hazard or do they justify the situation?

STAGES OF HOARDING

STAGE 1

- All doors and stairways are accessible
- All amenities are accessible and working
- Functioning bathroom and clean clothes
- All family members and pets are healthy, clean, and well nourished
- Maintains finances
- Invites friends over
- Not generally viewed as a hoarder
- Feelings of anxiety about their clutter, with minimal effects

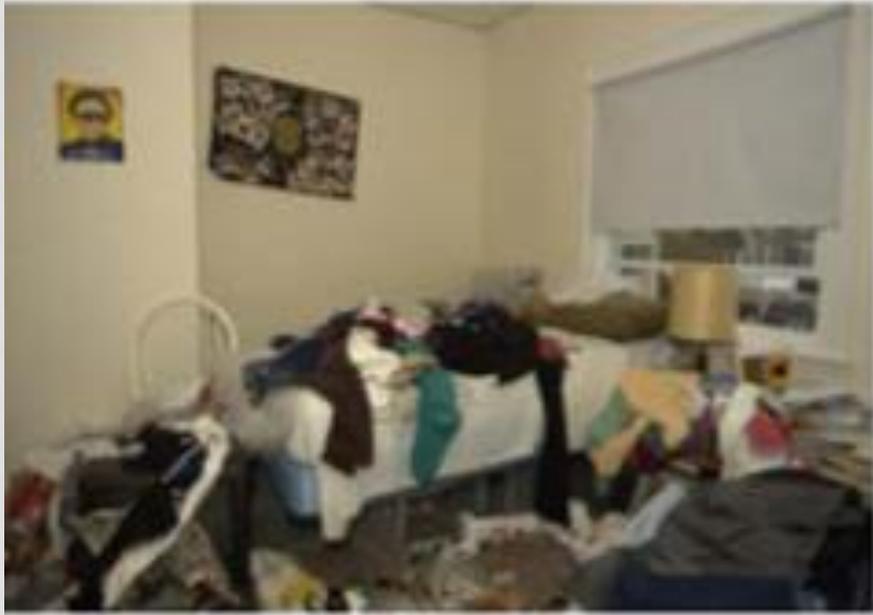
STAGE 1



STAGE 2

- 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)
- Pet odors becoming noticeable
- Shift in focus from life to clutter
- Diminished social and family interaction
- Reduction in the number of guests they have over because of embarrassment
- Mild anxiety and depression
- Shifting from embarrassment to justification

STAGE 2



STAGE 3

- 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
- Consumes reheated, precooked, or fast food because the kitchen is only borderline functional
- Decrease in physical activity
- Family has attempted to intervene numerous times and is faced with rejection and withdrawal
- Work place problems
- Growing financial concern

STAGE 3



STAGE 4

- 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;
- No access to fresh foods nor a safe/workable food preparation area.
- 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,
- Bathes in the sink or not at all
- Struggles to get to work on time or no longer working
- Significantly behind on bills and other serious financial troubles
- Utilities may be shut off
- Pets may have run away or died in the house
- Individuals may have shut everyone out of their lives
- Focuses mostly on the past or an unrealistic future

STAGE 4



STAGE 5

- 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

STAGE 5



RISK FACTORS

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
- 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.
- Like other individuals that hoard, individuals with dementia
 - Forget to discard things
 - Believe 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

- 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 to 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 or Obsessive-Compulsive Personality Disorder, 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

- People with hoarding disorder may feel socially isolated.
- Their past experiences may have caused them to distrust people and they find interacting with people often causes 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.
- They 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

- Most Individuals who struggle with hoarding have a history of trauma.
- As a means of coping with the past, individuals seek comfort in possessions.
- These possessions serve multiple purposes depending on the trauma.
 - Possessions may create a physical barrier between them and the persons or world that harmed them.
 - Turn their affections towards items and the joy that they bring serves as a substitute for healthy interpersonal relationships.

EMOTIONAL FACTORS

PRESERVATION OF A PERFECT PAST

- The individual is in such a dark place that they are hanging on to the past
- Individuals with hoarding disorder may feel there is no end in sight to their situation
- They might create a fantasy past, if their past was not pleasant and will fully believe this imagined past
- If they had a traumatic past, they may hold onto one positive memory and believe that was the norm

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

FAKE FUTURE, AVOIDING REALITY, AND BOUNDARIES

- Stuff can be an escape
 - May submerge themselves with the items that make them feel the best, such as clothing or craft supplies, when their lives feel unmanageable
 - May spend time trying to clean or organize and get lost in the process rather than coping with an unpleasant experience
 - May experience blurred lines between a need and want

INTERACTING AND ENGAGING

INTERACTION AND ENGAGEMENT

- Make sure individual that hoards feels in control
- Set obtainable and realistic goals
- Be patient and maintain trust
- Late-Stage hoarding disorder clients will be in denial, so...
 - Remain positive and supportive
- Focus on love and concern
- Offer to help and assist in clean up

LEVEL OF INSIGHT

- 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.

(Sources: Miller and Rollnick & DSM 5)

- **No Insight**

- No awareness; denial and justification of one's hoarding situation.
- Believes hoarding behavior and situation is not problematic.

- **Poor Insight**

- Some awareness of one's situation, causes and consequences.
- Mostly believes hoarding behaviors are not problematic.

- **Good Insight**

- 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.

THERAPY, ENGAGEMENT,
AND REMEDIATION

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

MOTIVATIONAL INTERVIEWING

- 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

(Source: Miller & Rollnick)

COGNITIVE BEHAVIORAL THERAPY

- 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)
 - 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 of CBT, which requires the patient to actively work on improving their situation in small doses.

(Source: NAMI, 2016)

EXPOSURE RESPONSE PREVENTION

- 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.

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. Individuals that have the opportunity to interact with others will learn more about themselves. Through interaction in a support group, individuals can better learn 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)

ROAD BLOCKS AND BARRIERS

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; however, 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.
- Some individuals may be unable to see how their hoarding is negatively affecting their life and relationships.
- Some clients 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 the 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

- Some individuals that hoard are ashamed and embarrassed and hide their situation from others.
 - Individuals may receive support in other domains of their life, but keep their hoarding hidden.
- Lack of support related to hoarding 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.

DANGERS

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.

TOXOPLASMOSIS GONDII

- Illness from *toxoplasma gondii* parasite, which may cause flu-like symptoms and is found in the following areas:
 - Cat feces
 - Contaminated water
 - Contaminated surfaces (knives, counters)
 - Unwashed fruit/vegetables

HANTAVIRUS

- Hanta Virus Causes *Hantavirus Pulmonary Syndrome* and is transmitted from rodent urine and droppings and contaminated surfaces.
- 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.

BOTULISM

- Botulism is a bacterial toxin produced by *clostridium botulinum*, which attacks the nervous system causing paralysis and can be life threatening if untreated.
- The botulinum toxin may be present in improperly canned or damaged canned items.
 - Expired or damaged canned items should be discarded.
- Botulism can be treated by botulinum anti-toxin and supportive care.

ANIMALS AND VERMIN

- Animals and vermin may be present in hoarding situations.
- Animal hoarding is different from attracting animals and vermin. Animal hoarding is distinctly acquiring animals.

RODENTS

- Merriam-Webster defines a rodent as a relatively small gnawing mammal that has in both jaws a single pair of incisors with a chisel-shaped edge.
- Mice, rats, and squirrels are examples of rodents that can possibly be present in a hoarded home.
- 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 electrical cords.

DOMESTIC AND NON-DOMESTIC ANIMALS

- Raccoons, bats, feral cats and dogs may inhabit a severely hoarded property and potentially carry disease, including rabies.
 - May cause additional property damage and create unsanitary conditions.
- 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.
 - In a severely hoarded home, domesticated animals may become trapped under debris or unable to access fresh food and water, and as a result, the animals will run away or die.

CHEMICALS AND PARTICULATES

- 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.

ASBESTOS, DUST, AND OTHER ALLERGENS

- 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.
- Allergens and dust are common irritants that are likely to be present in hoarded homes.

CLEANING AND HOUSEHOLD 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.
- 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.

STRUCTURAL DANGERS: FIRE

- Accumulation of flammable and combustible materials in excess poses a fire hazard.
- Evacuation and rescue during a fire or other emergency may be compromised.
- Some hazards include:
 - Multiple extension cords
 - Overloaded outlets
 - Blocked heating vents
 - Improper use and maintenance of appliances
 - Damage to electrical system
 - Occupant smoking without precaution

UNSTABLE SURFACES AND RISK OF COLLAPSE/ENTRAPMENT

- Walking paths may be cluttered with debris, creating tripping hazards and affecting balance.
- Piles of clutter may collapse/cave in and/or shift, especially when disturbed by humans and animals.
- Depending on the damage to the property, excessive items may create sagging floors and ceilings.

INACCESSIBLE EGRESS AND DAMAGED UTILITIES

- Many hoarded properties are at an increased fire risk. In the event of a fire or the need to evacuate, exits may not be easily accessible or usable.
- Individuals with mobility impairments may be in particular danger when an emergency exit is needed.
- Gas lines and/or electrical sources may be damaged, leading to shock and fire hazards.
- Water and sewage pipes may be damaged, especially in older properties with brittle lead piping.

UNIVERSAL PRECAUTIONS AND PERSONAL PROTECTIVE EQUIPMENT

PRECAUTIONS AND PPE

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

PRECAUTIONS

- 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
 - Respirator/mask (two strap, N – 95)
 - Protective gown
 - Closed toed shoes
 - Hand sanitizer
 - Face shield

SAFETY

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.

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 detectors 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 creates dangers for the community in addition to the individual that hoards. Community safety is affected, 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 animals and pests that may travel outside the apartment/home

FIRST RESPONDERS

- 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 carrying 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.
- Fire may also weaken piles of hoarded items, creating cave-ins and entrapment risks.
- Individuals that are trapped in a hoarded home consumed by fire are less likely to be rescued.
- Hoarding situations reduce the ability of fire personnel to control the fire and prevent further property damage.
- Hoarding may increase the speed with which fire spreads, because the abundance of combustible material serves 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.
- 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

POLICY AND RESEARCH

POLICY AND LEGAL SUPPORT

- Research and policies 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.
- There has been very limited policy movement on addressing hoarding disorder. Because hoarding is now listed in the DSM, therapy sessions are more likely to be eligible for insurance reimbursement.

HOARDING TASK FORCE

- 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*- and the Philadelphia Hoarding Task Force

HOARDING TASK FORCE

- Launched in the summer of 2007, The San Francisco Task Force on Compulsive Hoarding convened 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.
- The goals of the task force are:
 - 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 so as to improve service linkages and coordination
 - Make policy recommendations
 - Conduct PR campaign about compulsive hoarding issues
 - Create and present final report in 2009

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 accommodations.
- 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.

PROTECTIVE SERVICES

Some examples of situations that should be reported to protective services:

- Lack of water and/or heat
- Lack of a place to sleep
- Access to clean clothes
- Access to bathroom
- Children and elders can be removed if there's an infestation (i.e. bed bugs, fleas, roaches, large infestation of vermin)
- If the safety of children or older/vulnerable adults is suspected or in question, contact the appropriate protective services agency.

• Protective Service Contact Numbers

• **Child Protective Services**

1-800-932-0313

- <http://www.county.allegheny.pa.us/Human-Services/Programs-Services/Children-Families/Child-Protection.aspx>

• **Older Adult Protective Services**

1-800-344-4319

- <http://www.alleghenycounty.us/Human-Services/About/Contact/Older-Adult-Abuse.aspx>

CALL TO ACTION

- 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.

CONCLUSION

- 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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