

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

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: General community members who are seeking more information about hoarding disorder.

Purpose: Examine multiple components of hoarding, including hoarding disorder basic definitions, , stages of hoarding, risk factors, interaction, resource and support.

Sincerely,

The Allegheny County Hoarding Task Force

What is Hoarding?

Hoarding Definition

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.

What the definition means

People with hoarding disorder get a lot of stuff and have a hard time getting rid of stuff they don't need or have too much of.

Defining Collecting and Squalor

- **Collecting** – A person who collects items of a specified type, professionally or as a hobby. These items may be displayed and carefully stored and well maintained.
- **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.

What is the difference between collecting and 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 a hard time getting rid of all kinds of items of little or no value, with items scattered randomly that intrudes on living spaces.

Hoarding and Squalor

- Squalor and hoarding differ in that hoarding is the unrestrained acquiring of items and failure to discard unneeded items. Squalor is the unsanitary conditions that may come from a hoarding situation.

Debunking the Myths of Hoarding

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.

Individuals who hoard are often

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

Stages of Hoarding

Hoarding disorder is chronic and progressive, meaning hoarding is likely to increase over time. The Hoarding Clutter Image Rating Scale is used to determine the extent of clutter. For more information about this scale please click on the link below. The clutter image rating scale uses 9 stages, however in the descriptions below a 1 to 5 scale is used, with stage 1 being least advanced and stage 5 most advanced.

Clutter Image Rating Scale Link:

http://www.hoardingconnectioncc.org/Hoarding_cir.pdf

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
- Maintained finances
- Invites friends' over
- Not generally viewed as a hoarder
- Feelings of anxiety about their clutter, with minimal effects

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)
- Noticeable pet odors
- Shift in focus from life to clutter
- Diminished social and family interaction
- Reduction in the number of guests they have over because of embarrassment
- Anxiety and depression
- Shifting from embarrassment to justification

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
- 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

Stage 4



- 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
- 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
- Pets may have run away or died
- Individuals may have shut everyone out of their lives
- Individual is focused mostly on the past or an unrealistic future

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

- Isolated to their house, unless it is to move into their car or a homeless shelter

What are common characteristics of People with Hoarding Disorder?

Age

Hoarding gets worse with age. People 54 years of age and older are three times more likely to hoard. Hoarding likely started long before, but not bad enough for others to pay attention until they were older

Family History

Research has shown a link between hoarding disorder and brain activity in certain regions of the brains. They also discovered that families with two or more relatives who hoard also are more likely to hoard

Dementia

Unfortunately, as our population ages, there is more people with dementia.

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

Depression and Anxiety

Many individuals with hoarding disorder also suffer from depression and anxiety. One study found that 50% of individuals with a hoarding disorder also have a depressive disorder as well.

Isolation and Feeling Alone

People with hoarding disorder may often feel alone. Their past experiences 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 over human contact.

Decision making

Research indicates that some Individuals that have hoarding disorder may have a hard time deciding and take a long time to decide about whether to keep an item or throw it away.

Trauma and Stress

Sometimes individuals that have suffered trauma turn their affections towards items and the joy that they bring serves as a substitute in for healthy interpersonal relationships. When having faced things like housing insecurity or economic hardship, it makes sense to the individual to save everything under the idea that there is or may come a time where they will need it and be unable to afford to purchase a similar item.

How do people with Hoarding disorder improve their situation?

Treatment of 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. Discarding possessions without the individual's involvement, participation and consent will be counterproductive, causing trauma, stress and distrust of the individual.

Therapy

Between 60 and 80 percent of people improve after treatment, with an average decrease in symptoms of about 30 percent. (Frost)

At this point most treatment takes place in an office setting. These sessions will include homework assignments for the client to complete on their own. These homework assignments are pivotal to the decrease in symptoms.

Community Human Services offer a support group that meets once a month on the first Wednesday of every month from 10:30am - 12:00pm. This group can be attended by anyone and is held at 2525 Liberty Ave. Pittsburgh PA, 15222. If individuals are unable to attend in person they may call in on our conference line 412.246.1665 Access Number: 456

Clutterers Anonymous (<https://clutterersanonymous.org/>) offers several different forms of support for individuals who suffer from hoarding disorder. They have the option of both phone meetings and face to face meetings. They also have phone activity lines. A phone activity session is a moderator-led gathering of two or more clutterers who come together on a CLA conference call line on a designated day and time. Clutterers actively declutter, set goals, make commitments, announce victories, give and receive support.

Clean up

The concept of a clean-up 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.

Road blocks and Barriers to Treatment and How You Can help

Sometimes events occur in our life that prevent us from achieving our goals as we originally planned. Below are some common barriers of people that hoard!

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.

Self – Recognition

Individuals with hoarding disorder will need to recognize they are hoarding. 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 benefit from the support of loved ones and mental health care providers.

Physical Ability

Some individuals with hoarding disorder may not have physical ability to clean up because of advanced age, fragility or physical disability. Individuals 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. With the way, the disorder is negatively portrayed in the media, an individual may be more comfortable hiding the illness and withdrawing from those around them, rather than becoming vulnerable to critics. Special care and sensitivity needs to be taken to engage an individual to accept services. By reducing the stigmatizing feeling and judgement, the amount of individual served may increase.

Transportation and Community Access

Access includes transportation and 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 a transportation are at a higher likelihood of social isolation.

In rural areas services are not always available and 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.

What is being done to help?

Hoarding has only recently entered the public awareness. Many communities have developed hoarding Task Forces, which are often groups of concerned citizens, professionals and sometimes individuals with hoarding disorder. Most Task Forces have little, if any funding to help individuals with hoarding disorder.

Task forces are often composed of community members from a diverse set of disciplines because addressing hoarding involves many community segments, which include behavioral health, public health, municipal code enforcement, advocates, family among others.

More research is also occurring about hoarding treatment and interventions along with the underlying causes.

What you can do to help

Someone with a hoarding disorder needs to be internally motivated to change their situations and this motivation cannot be forced upon someone with a hoarding disorder.

Simply cleaning out a hoarded home without treating the underlying situation will not solve the problem. Attempts to clean out is likely to cause distress, trauma, anger and overall is counterproductive to addressing the situation. Situations where a hoarded property is cleaned, will quickly return to a similar situation.

Support your loved one, be a cheer leader and recognize the small achievements that lead to big change.

The international OCD foundation identifies the following how to have a conversation about hoarding.

- Respect. Acknowledge that the person has a right to make their own decisions at their own pace.
- Have sympathy. Understand that everyone has some attachment to the things they own. Try to understand the importance of their items to them.
- Encourage. Come up with ideas to make their home safer, such as moving clutter from doorways and halls.
- Team up with them. Don't argue about whether to keep or discard an item; instead, find out what will help motivate the person to discard or organize
- Reflect. Help the person to recognize that hoarding interferes with the goals or values the person may hold. For example, by de-cluttering the home, a person may host social gatherings and have a richer social life.
- Ask. To develop trust, never throw anything away without asking permission.

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. Please see website for more information.

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>

Some hoarding based resources

Books and Literature	
Author	Title
Randy Frost	The Oxford Handbook of Hoarding and Acquiring
	Stuff: Compulsive Hoarding and the Meaning of Things
	Cognitive Approaches to Obsessions and Compulsions: Theory, Assessment and Treatment
	Buried in Treasures: Help for Compulsive Acquiring, Saving and Hoarding
Jerome Bubrick, Fugen Neziroglu, & Jose Yaryura-Tobias	Overcoming Compulsive Hoarding: Why You Save and How You Can Stop
Robin Zasio	The Hoarder in You: How to Live a Happier, Healthier, Uncluttered Life
Michael A. Tompkins & Tamara L. Hartl	Digging Out: Helping Your Loved One Manage Clutter, Hoarding, and Compulsive Acquiring
Fugen Neziroglu & Katharine Donnelly	Children of Hoarders: How to Minimize Conflict, Reduce the Clutter, and Improve Your Relationship

Online and National Resources	
Organization	Web Address
Children of Hoarders	http://childrenofhoarders.com/wordpress/
Institute for Challenging Disorganization	http://challengingdisorganization.org/
International OCD Foundation	https://iocdf.org/
National Association of Mental Illness (NAMI)	http://www.nami.org/
National Association of Professional Organizers (NAPO)	http://www.napo.net/

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