



What Is Hoarding Disorder?

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The Hoarding Project



Who We Are



- 501(c)(3) public charity
- Mission: To promote an effective, ethical, and sustainable response to hoarding in communities, through education, prevention, and collaborative approaches to treatment.



+ FAQ: What is hoarding disorder?



Quick answer: With the DSM5 hoarding disorder is a diagnosis, the common definition has 4 parts:

1. **Excessive acquisition** of stuff*
2. **Difficulty discarding** possessions
3. Living spaces that can't be used for their intended purposes because of **clutter**
4. Causing significant **distress** or **impairment** (Frost & Hartl, 1996)

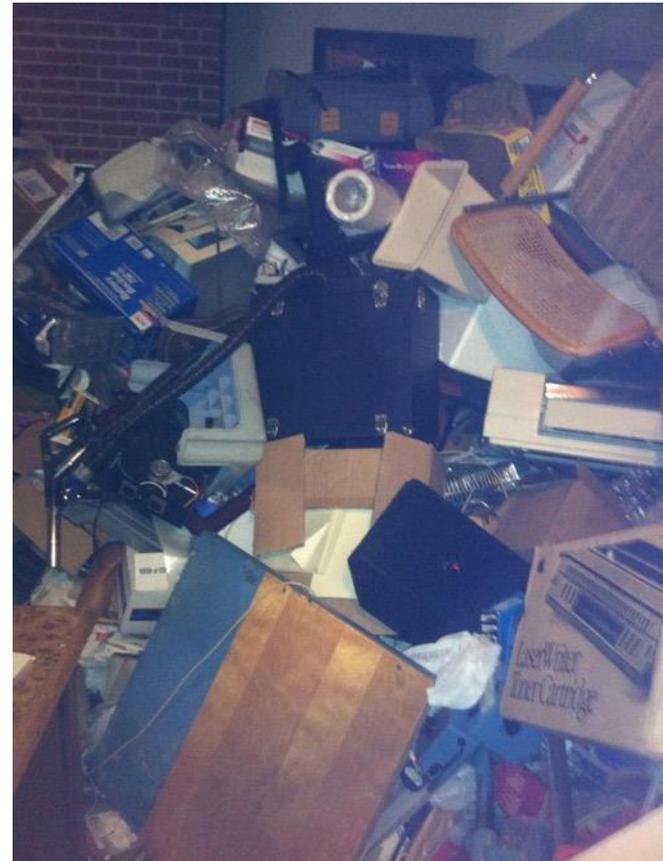
*Not universal in all people who hoard



FAQ's: How many people hoard and are some people more likely to hoard than others?

Quick answer: Research shows that

- About **2-5%** of the population hoard, which is about **15 million** people in the U.S., on the high end (Iervolino et al., 2009; Samuels et al., 2008)
- **Older people** hoard more than younger people
- People with **lower income** hoard more than people with higher income (Samuels, et al. 2008)
- No gender differences in prevalence rates (Timpano, et al., 2011)



+ FAQ: What's the difference between clutter, collecting, and hoarding?

Clutter: possessions are disorganized and may be accumulated around living areas

- No major difficulty with excessive acquisition AND no major difficulty discarding items
- Can carry on normal activities in home

Collecting: new possessions = part of larger set of items

- Display does not impede active living areas in home

Hoarding:

possessions become unorganized piles of clutter

- Prevent rooms from being used for normal activities
- Motivation to display items: lost





Are there other mental health issues related to hoarding?



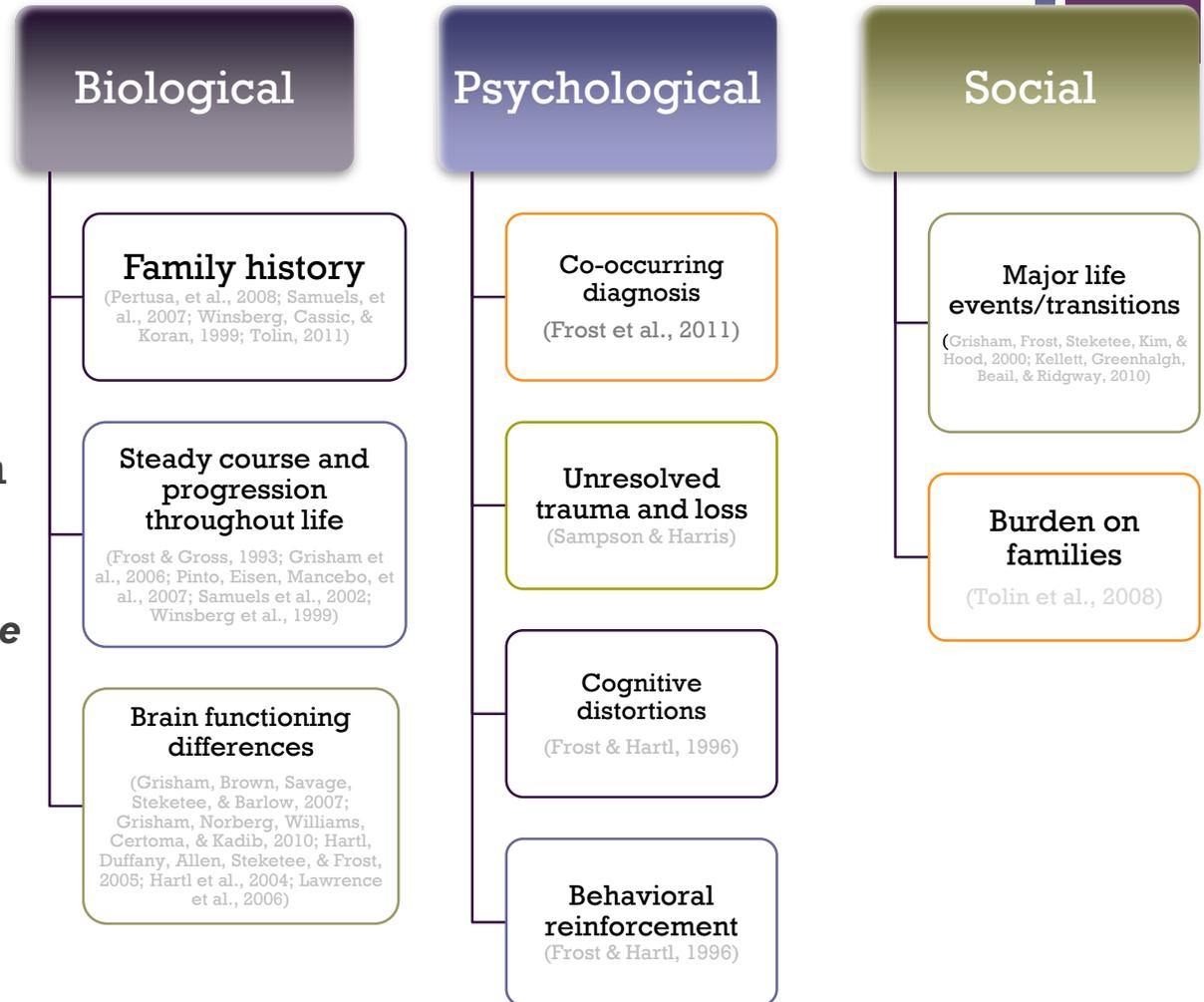
- Yes, hoarding disorder must be considered a co-occurring disorder and is associated with another mental health diagnosis 92% of the time (Frost et al., 2011)
 - 57% major depressive disorder
 - 29% social phobia
 - 28% generalized anxiety disorder (Frost et al., 2006)
 - 30-40%: OCD (e.g. Samuels et al., 2007)
 - 31%: Organic Brain Illness
 - 30%: Personality Disorders (Mataix-Cols, et al., 2000)
 - 20%: ADHD (e.g. Sheppard et al., 2010)
 - Dementia (Hwang et al., 1999)
 - Eating Disorders (Frankenburg, 1984)
 - Substance abuse (Samuels et al., 2008)



The BIOPSYCHOSOCIAL Model of Hoarding Disorder states that:

Hoarding behavior arises from a variety of external and internal variables that are **biological**, **psychological**, and **social** in nature.

We can't talk about one of these pieces without talking about the others!





What is the link between Hoarding and the Brain?



- **Brain functioning differences – Occipital and frontal lobes** (Saxena et al, 2004)
 - Abnormalities in areas associated with: executive functioning, impulse control, and processing of reward value

- **Maladaptive Cognitive Processes** (Grisham, Brown, Savage, Steketee, & Barlow, 2007; Grisham, Norberg, Williams, Certoma, & Kadib, 2010; Hartl, Duffany, Allen, Steketee, & Frost, 2005; Hartl et al., 2004; Lawrence et al., 2006)
 - **Information processing difficulties**
 - Over-reliance on visual vs. categorical memory cues
 - Attention: Churning; “Clutter blindness” = failure to recognize extent of clutter in the home (Steketee & Frost, 2014, p.2-3)
 - Over- or undercategorization



FAQ: What are the Safety & Health risks associated with hoarding?

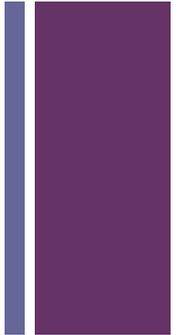
Safety

- Fire hazard
- Blocked exits
- Risk of falls/items falling
- Lack of routine home maintenance
- Structural damage to building from increased weight and volume of clutter
- Risk of eviction and homelessness

Health

- Impaired functioning
 - Poor hygiene and grooming, nutrition
 - Inattention to medical needs
 - Inadequate financial management
 - Difficulty cleaning around clutter
 - Sleeping on floor instead of bed
- Mental Health
- Increased Health Problems
 - Molds, bacteria, dust, dirt
 - Asthma, allergies, headaches
 - Rodent/insect infestation
 - Animal/human feces/remains (hanta virus, tapeworm, psittacosis, cat scratch disease)

+ Mandated Reporting



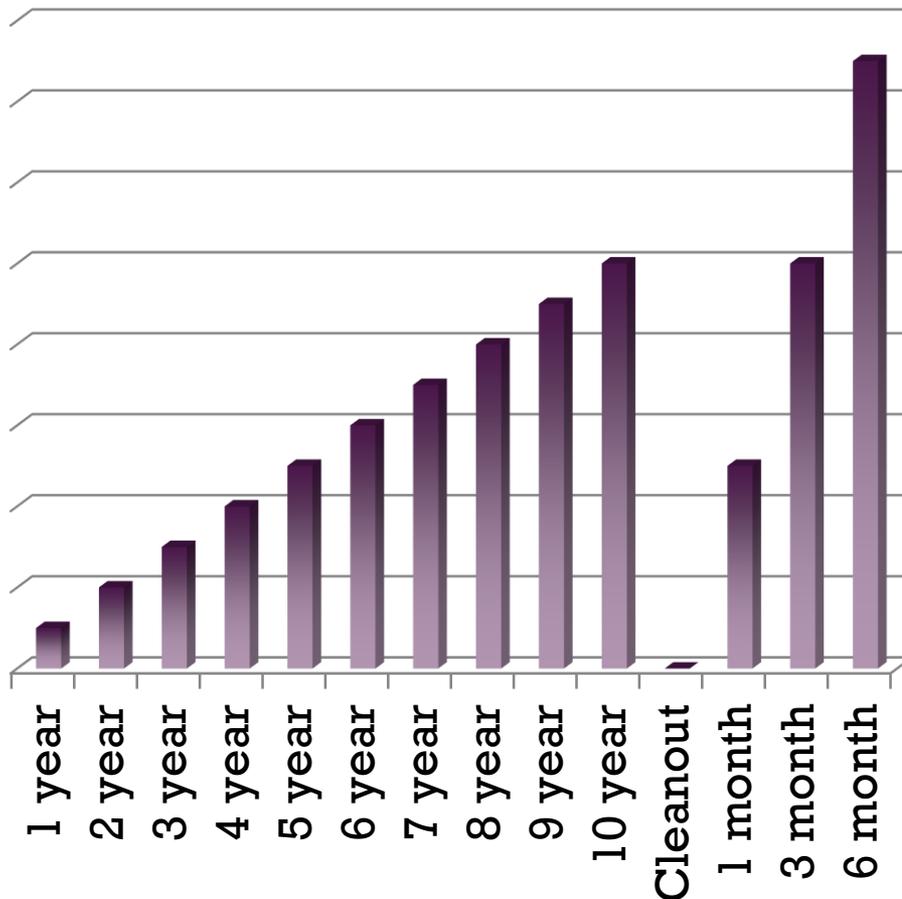
Quick answer: If there is a threat of endangerment to the health and safety of:

- A child/minor
- Older adult (over 60 with a cognitive, physical, or functional impairment)
- Person with disability or dependency

you must report (if you are a mandated reporter)

- Building codes differ from city to city and county to county, but general safety concerns include:
 - **Health**
 - Ex: cannot use bathtub/shower/toilet; cannot prepare food/use refrigerator/sink; presence of feces or urine; insects/rodents; mold
 - **Obstacles**
 - Ex: Cannot move freely/safely; inability for EMT to enter/gain access; unstable piles/avalanche risk; egresses/exits, vents blocked/unusable
 - **Structure**
 - Flammable items by heat source; Storage of hazardous waste/material; Caving walls; Electrical wires/cords exposed; No heat/electricity; No running water/plumbing problems

+ FAQ: Can't I just clean out a hoarded home?



Quick answer: Not if you can avoid it.

- It can do more harm than good.
 - Can be traumatizing
 - Emotional Flooding
 - Even threats can be unhelpful
 - Can ruin relationships and trust

“In all three instances of going in and cleaning these places up, within weeks of relocating the individual back into a clean environment, the individual passed away...it was such a dramatic change for them because we didn't realize the impact of the sociological change.” (Brace, 2007)

- It's not sustainable
- BUT sometimes it's necessary



FAQ: So if I can't clean out a home that is hoarded, what am I supposed to do? What if there is no time to do therapy?



Quick answer: **Safety** comes first. Although it would be ideal to address underlying issues first, we can't always do that.

Rule of thumb:

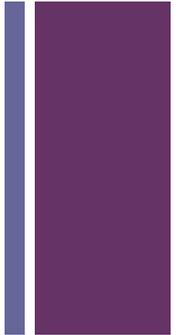
1. **Safety** first.
2. **Skills** second.
 - Emotional regulation (self-soothing)
 - Self-awareness/mindfulness
 - Organization, categorization, etc
3. **Therapy and everything else** can follow.
 - Grief, loss, and trauma
 - Hoarding work: acquisition/discarding





+ Screening and
Assessment Tools

+ Screening: ASK!



- First and foremost, ASK!
- Make sure to incorporate some form of question that can help indicate a problem at home with clutter, excessive acquisition, or difficulty discarding.
- Examples:
 - Are any areas of your home difficult to walk through because of clutter?
 - Are you unable to use any parts of your home for their intended purposes? For example, cooking, using furniture, washing dishes, sleeping in bed, etc?
 - Do you find the act of throwing away or donating things very upsetting?
 - Do you have strong urges to buy or collect free things for which you have no immediate use?
 - Have you ever been in an argument with a loved one because of the clutter in your home?



+ ICD Clutter-Hoarding Scale (CHS)

- Assessment of home's interior, except where outside structure affects overall safety of interior
- Guideline tool by professional organizers and related professionals
- 5 categories: Structure and Zoning; Animals and Pests; Household Functions; Health & Safety; Personal Protective Equipment (PPE)

Available for free download: www.challengingdisorganization.org



“Levels” of Hoarding (ICD Clutter—Hoarding Scale)



INSTITUTE FOR
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DISORGANIZATION

CLUTTER — HOARDING SCALE (CHS) QUICK REFERENCE GUIDE

	Structure and Zoning	Animals and Pests	Household Functions	Health and Safety	Personal Protective Equipment (PPE)
LEVEL I	All doors, stairs and windows accessible; plumbing, electric and HVAC operational; fire and CO2 detectors installed and functional	Normal animal control (behavior/sanitation); approved number of animals; no evidence of rodents or insects	No excessive clutter; all rooms properly used; appliances functional; good housekeeping and maintenance	Safe, sanitary; no odors; medication control OK	OPTIONAL
LEVEL II	1 major exit blocked; 1 major appliance or HVAC device not working for longer than one season; some plumbing or electrical systems not fully functional; fire or CO2 detectors non-existent or non-functional	Evidence of inappropriate animal control; visible or odorous pet waste; visible pet fur/hair/feathers; light to medium evidence of common household pests/insects	Clutter beginning to obstruct living areas; slight congestion of exits, entrances, hallways and stairs; some household appliances not functional; inconsistent housekeeping and maintenance	Diminished appropriate sanitation; odors from dirty dishes, food prep, laundry, toilets; mildew present; medication control questionable	LIGHT PPE Medical or work gloves; caps (baseball or poly bouffant); first aid kit; insect repellent; hand sanitizer
LEVEL III	Outside clutter of items normally stored indoors; HVAC devices not working for longer than one season; fire or CO2 detectors non-existent or non-functional; one part of home has light structural damage (occurring within past six mos.)	Animal population exceeds local regulations; inappropriate animal control; inadequate sanitation; audible evidence of pests; medium level of spiders; light insect infestation such as bed bugs, lice, fleas, roaches, ants, silverfish, spiders, etc.	Clutter obstructing functions of key living areas; building up around exits, entrances, hallways and stairs; at least one room not being used for intended purpose; several appliances not functional; inappropriate usage of electric appliances and extension cords; substandard housekeeping and maintenance; hazardous substances in small quantities	Limited evidence of maintaining sanitation (heavily soiled food prep areas, dirty dishes, mildew); odors obvious and irritating; garbage cans not in use or overflowing; dirt, dust and debris; dirty laundry throughout house; Rx and OTC medications hazardous control (re children, pets, mentally impaired)	MEDIUM PPE Face masks or N95 respirator masks; eye protection; gloves; disposable coveralls; poly caps; work shoes/boots; first aid kit; hand sanitizer; insect repellent
LEVEL IV	Excessive outdoor clutter of items normally stored indoors; HVAC devices not working for longer than one year; CO2 detectors non-existent or non-functional; structural damage to home lasting longer than six months; water damaged floors, damaged walls and foundations, broken windows, doors or plumbing; odor or evidence of sewer backup	Animal population exceeds local ordinances; poor animal sanitation; destructive behavior; excessive spiders and webs; bats, squirrels, rodents in attic or basement (audible and visible); medium insect infestation	Diminished use and accessibility to key living areas; several rooms cluttered to extent they cannot be used for intended purposes; clutter inhibits access to doorways, hallways and stairs; inappropriate storage of hazardous/combustible materials; appliances used inappropriately; improper use of electric space heaters, fans or extension cords	Rotting food, organic contamination; expired, leaking cans or bottles, buckled sides and tops; dishes and utensils unusable; no linens on beds; sleeping on mattress; chair or floor; infestation of bedding and/or furniture; medications Rx and OTC medications easily accessible to anybody	FULL PPE Face masks or N95 respirator masks; safety goggles; medical or industrial grade latex or nitrile gloves; heavy duty work gloves; disposable coveralls; caps; work shoes/boots; first aid kit; hand sanitizer; insect repellent; headlamp or flashlight
LEVEL V	Extreme indoor/outdoor clutter; foliage overgrowth; abandoned machinery; ventilation inadequate or nonexistent; HVAC systems not working; water damaged floors, walls and foundation; broken windows, doors or plumbing; unreliable electrical, water and/or septic systems; odor or sewer backup; irreparable damage to exterior and interior structure	Animals at risk and dangerous to people due to behavior, health and numbers; pervasive spiders, cockroaches, mice, rats, squirrels, raccoons, bats, snakes, etc.; heavy infestation of insects such as bed bugs, lice, fleas, cockroaches, ants, silverfish, etc.	Key living spaces not usable; all rooms not used for intended purposes; entrances, hallways and stairs blocked; toilets, sinks and tubs not functioning; hazardous conditions obscured by clutter; appliances unusable; hazardous and primitive use of kerosene, lanterns, candles, fireplace/woodstove as primary source of heat and/or light	Human urine and excrement present; rotting food; organic contamination; cans or jars expired, leaking or buckled; dishes and utensils buried or nonexistent; beds inaccessible or unusable due to clutter or infestation; pervasive mold and/or mildew; moisture or standing water; Rx and OTC medications easily accessible to anybody; presence of expired Rx	FULL PPE REQUIRED N95 respirator mask or mask with organic filter(s); safety goggles; medical or industrial grade latex or nitrile gloves; heavy duty work gloves; disposable coveralls; poly caps; work shoes/boots; first aid kit hand sanitizer; insect repellent; headlamp or flashlight

Uniform Inspection Checklist- Quick Reference

The inspector must be able to view, reach, and test all items on the inspection checklist.

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Contact Information: Maizie McDonald MSW, LCSW email: mmcdonald@nshc.org phone no: 978-624-2207

Priority #1: Harm Reduction Targets: The following items must be UNOBSTRUCTED (completely clear of any items). *Inspector: Place an 'X' next to items to indicate that they are unobstructed.*

Egresses - means of exit
Minimum of 36" wide clear pathways throughout residence
Smoke detectors, CO detectors, & sprinkler heads (all that apply)
All doors: including entry & exit, closet, cabinet, pantry, etc. (inspector must be able to open & close doors fully & freely & be able to latch if applicable)
Minimum of 1 unobstructed window in living room & each bedroom for emergency exit
Toilets, stoves, ovens, refrigerator, washing machine/dryer, open flame heat sources, fireplaces, water home, a/c, heat thermostats, trash containers
Emergency pull cords - end of cord must be no more than 18" from the floor (if applicable)

Priority #2: General Inspection Targets: The following items must be ACCESSIBLE (easily able to be reached by the inspector). *Inspector: Place an 'X' next to items if they are accessible to you.*

Windows
Electrical panel(s) & electrical outlets
All heat sources
All plumbing fixtures & pipes, including plumbing under all sinks
Sinks, bathtubs, & showers

Priority #3: General Health and Safety Targets: *Inspectors: Place an 'X' next to item if the general health and safety guideline has been met.*

Sinks must function and show routine use & care
Kitchen area must have a clear & clean space sufficient for food preparation
Refrigerator & freezer clean, not overfilled, no expired or rotting food
No expired or decaying food or garbage (to attract vermin)
Stove, range w/ oven - interior, exterior, & top must be clean & free of debris
No evidence of infestation
Garbage & debris must be removed from residence on routine basis
No trip hazards, fall hazards, or avalanche risk
No extension cords under carpets or across floors or rooms of residence
No long-term storage of newspapers, magazines, papers, or flammable liquids to cause fires
No exposed or frayed electrical wiring
No excessive pet odor, pet hair, pet waste

**Any items that are not marked must be addressed as part of the Eviction Diversion Program.*

www.masshousing.com

Uniform Inspection Checklist

+ Clutter Image Rating

(CIR; Frost, Steketee, Tolin, & Renaud, 2008)

- Developed to overcome problems with over- and under-reporting
- 9 pictures for 3 main rooms
 - Kitchen
 - Living room
 - Bedroom
- 1 = no clutter to 9 = severe clutter
- Review room and select picture that looks most like room in the home
- Score of 4 or more: clinically significant clutter problem

Clutter Image Rating: Bedroom

Please select the photo that most accurately reflects the amount of clutter in your room.



1



2



3



4



5



6



7



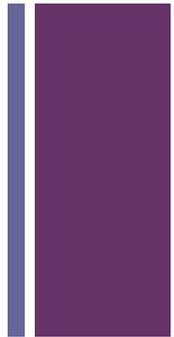
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9



HOMES[®] Multi-disciplinary Hoarding Risk Assessment



Health

- Cannot use bathtub/shower
- Cannot access toilet
- Garbage/Trash Overflow

- Cannot prepare food
- Cannot sleep in bed
- Cannot use stove/fridge/sink

- Presence of spoiled food
- Presence of feces/Urine (human or animal)
- Cannot locate medications or equipment

- Presence of insects/rodents
- Presence of mold or chronic dampness

Notes: _____

Obstacles

- Cannot move freely/safely in home
- Inability for EMT to enter/gain access

- Unstable piles/avalanche risk
- Egresses, exits or vents blocked or unusable

Notes: _____

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

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

Notes: _____

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

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

Notes: _____

Structure & Safety

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

Notes: _____

© Bratiotis, 2009

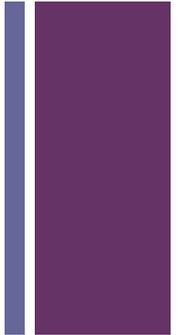
- Need for various services providers to have a common understanding of a range of problems associated with hoarding
- Checklist that can be used by anyone who encounters a hoarding situation, regardless of professional training



How to Talk about “It”



Discussing your Assessment of a Hoarding Situation



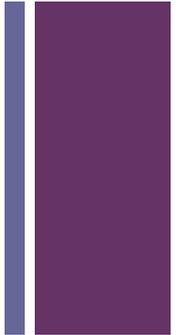
- Though it may be a tough conversation to have, remember that the anxiety you are feeling is about *you*, not the person who is hoarding
- Be direct.
 - Don't dance around the issue.
- Simply state the facts.
 - Begin with a general statement about your assessment, stating your organization's policy.

- For example:

“Our organization’s policy requires that the homes to be repaired be in safe working conditions for our volunteers. After doing a home walk-through, I have several concerns about the amount of clutter and problems that may be resulting from that.”



Discussing your Assessment of a Hoarding Situation (cont.)

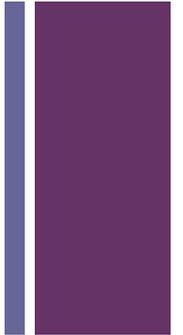


- State facts about what you have observed, leaving out “subjective” observations/assumptions.
 - NO: “You’re obviously not showering.”
 - YES: “I have some concerns about your ability to use your shower, due to the large amounts of items that I can see are stored in it.”

- Discuss the major areas of concern:
 - Health
 - Obstacles
 - Mental Health
 - Endangerment
 - Structure and Safety



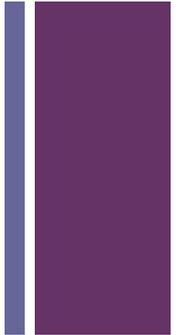
Discussing your Assessment of a Hoarding Situation (cont.)



- Being clear and having a quantifiable way to base your decision about housing repairs will help in several ways:
 - Can promote healthy change for the client, as you can offer resources to help them create a better living environment for themselves
 - Reduce the risk of discrimination suits (decisions are based in objective terms, rather than subjective)
 - Offers motivation for change
 - If you offer an option for repair down the road, if they make changes, then you are not “cutting off” resources to the client
- Make sure to make appropriate reports to departmental supervisors, if necessary



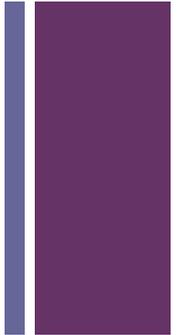
Motivational Interviewing (MI) Strategies for People who Hoard



- MI Areas useful for assessing and building motivation to change (Bratiotis, Schmalisch, & Steketee, 2012)
 - Client's perception of importance of addressing the problem
 - Client's confidence in ability to change
- Strategies (Frost & Steketee, 2007)
 - Ask for elaboration
 - Looking forward and looking backward
 - Affirming self-efficacy (that they want to do it themselves)
 - Evocative questions



Reviewing Session with Client



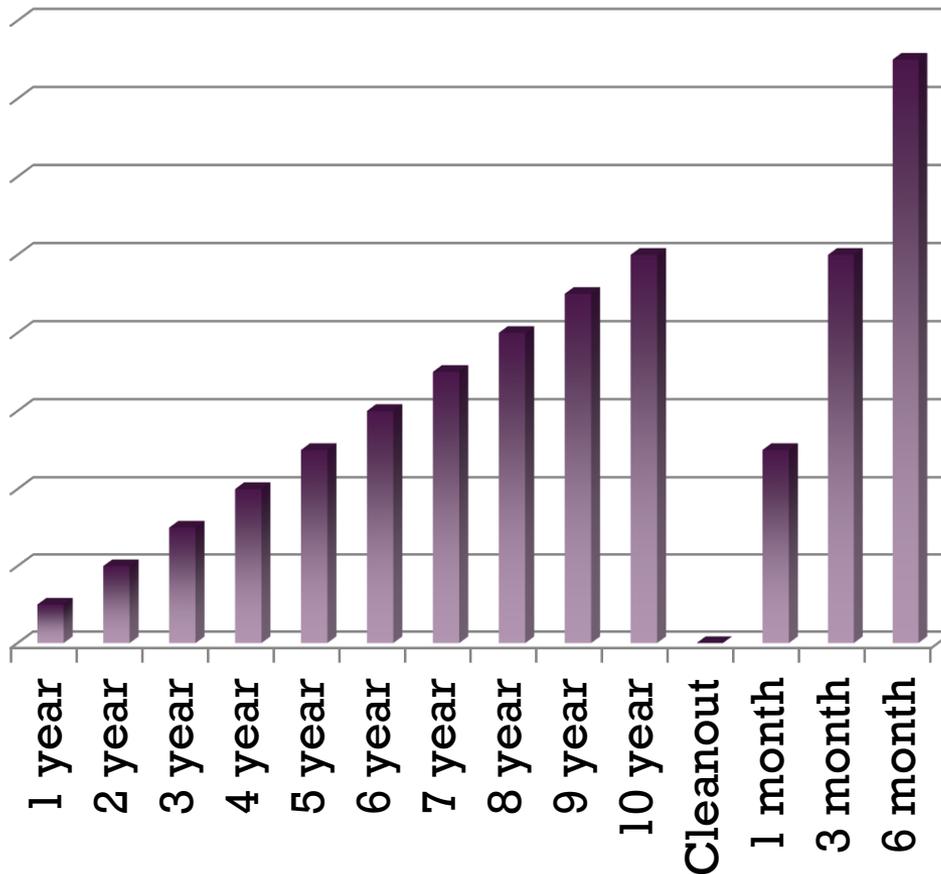
- Summarize your assessment with the client at the end of the home visit
- Address any imminent threats to safety immediately
- If safety is in place, you can proceed with therapy treatment as usual
- If safety factors are an issue, these must be prioritized before therapeutic work can begin



Clean Out Events



The Problem As We See It...



■ Cleanouts:

- Are not effective or sustainable
- They can be traumatizing
- They overlook the crisis/disaster nature of a cleanout event on a homeowner

■ BUT, sometimes they are *necessary* in order to preserve public safety

■ History

- UM Medical Reserve Corps & Psychological First Aid
- Hoarding clean-outs



Goals of “Safety Day”

- Bring client’s home to safety to reduce threat of eviction and comply with housing codes using a Harm Reduction Approach
 - Mitigate negative effects of stressful and potentially traumatic event
 - Only discard what is necessary to reach goals
- Keep client out of Diffuse Physiological Arousal (emotional flooding)
 - Use Psychological First Aid
 - Recognize and respond to symptoms of psychological crisis
 - Mitigate the traumatic effects

- Process and Application of Critical Incident Stress Management
 - *Adaptive, short-term psychological helping-process that focuses solely on an immediate and identifiable problem. It can include pre-incident preparedness to acute crisis management to post-crisis follow-up.*



- Additionally, need to understand the importance of preserving team members psychological well-being

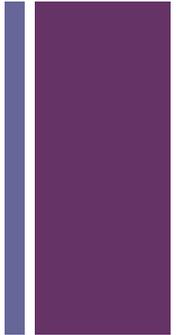


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Resources



What resources are available?



Quick answer: There are several different resources that are available to people who hoard, their families, and people who work with them.

Non-profit agencies:

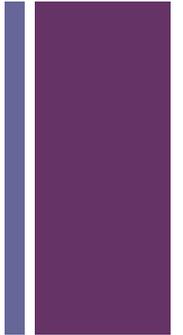
- The Hoarding Project (local)
- International OCD Foundation
- Mental Health Association of San Francisco
- Institute of Challenging Disorganization
- Children of Hoarders

Support Groups

- The Hoarding Project (local)
- Children of Hoarders
- Bay Area Resources
- Clutterers Anonymous



Important Local Resources, Info



The Hoarding Project

www.thehoardingproject.org

Local Task Forces

- King/Pierce: Monthly meetings
 - 3rd Wednesday morning of each month
 - Wataskforce@thehoardingproject.org

Support Groups

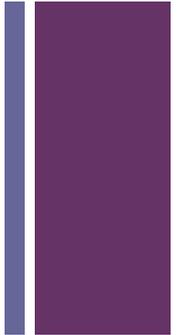
- Seattle: Greenwood Senior Center
 - 3rd Tuesday of each month
- Tacoma: TACID
 - Every Thursday



King/Pierce County
Hoarding Task Force



Reading Resources



- **Stuff: Compulsive Hoarding and the Meaning of Things (2010)**, Frost & Steketee
- **Buried in Treasures: Help for Compulsive Acquiring, Saving, and Hoarding (2007)** Tolin, Frost, & Steketee
- **Digging out: Helping Your Loved One Manage Clutter, Hoarding, and Compulsive Acquiring (2009)**, Tompkins & Hartl
- **The Hoarding Handbook: A Guide for Human Service Professionals (2011)**, Bratisotis, Sorrentino Schmalisch, & Steketee
- **Ambiguous Loss: Learning to Live with Unresolved Grief (2000)**, Boss
- **Motivational Interviewing: Preparing People for Change, 2nd ed. (2002)**, Miller & Rollnick



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The Hoarding Project

www.thehoardingproject.org

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