

## The Impact of Hoarding Disorder on Individuals, Families and Communities

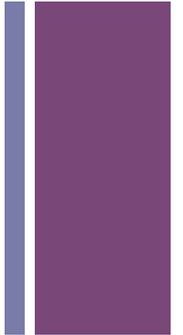
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The Hoarding Project –

[www.thehoardingproject.org](http://www.thehoardingproject.org)

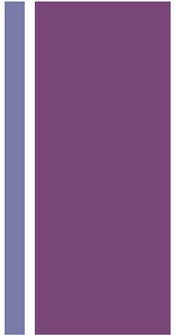
NAPSA Conference, October 3, 2013

# + Objectives



- Background on Hoarding
- Safety/health issues involved with hoarding
  - Are there any precautions *we* should take for our safety?
- Measurement/Assessment Tools
- What to do when we encounter a homeowner with a hoarding situation:
  - How to talk with them re: hoarding concerns
  - How to offer resources
- Further Considerations

# + History and Background





# Background on Hoarding

# + FAQ: What is hoarding disorder?



**Quick answer:** A new diagnosis with the DSM5, 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



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



## Quick Answer:

- **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

# + FAQ's: How many people hoard?

**Quick answer:** More than you think but we're really not sure yet!

- Estimates range greatly- up to 15 million in the U.S.
- Studies haven't been big enough to give accurate estimates yet



## ■ Prevalence

- 2-5% of the population (Iervolino et al., 2009; Samuels et al., 2008)

On the high end,

That means that over

**342 million** people **on the planet**

meet criteria for moderate to severe compulsive hoarding behavior.

That's approximately

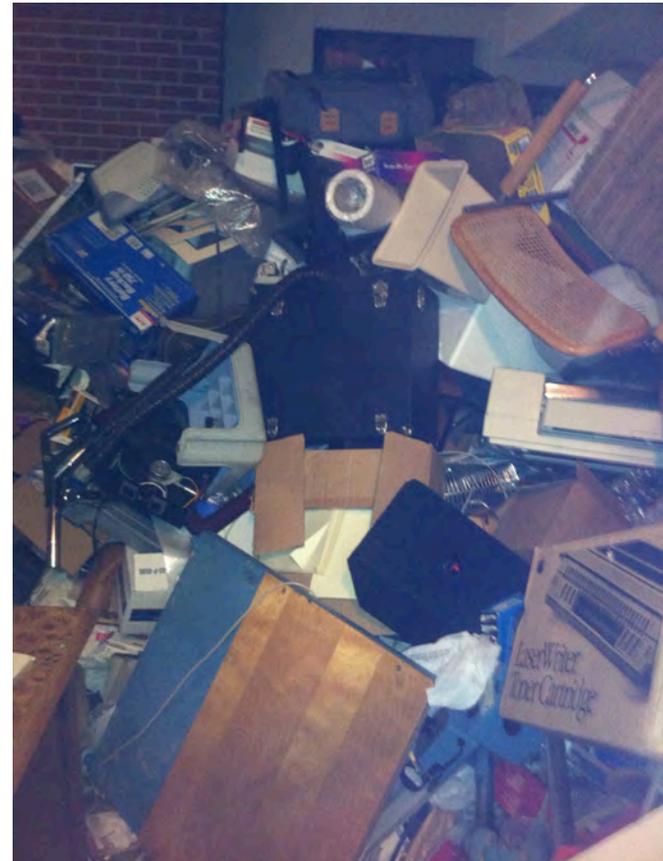
**15.7 million** people in the **United States.**



## FAQ's: Are some people more likely to hoard than others?

**Quick answer:** Research shows that

- **Men** hoard more than **women**
- **Older people** hoard more than **younger people**
- People with **lower income** (Samuels, et al. 2008) hoard more than people with **higher income**



# + FAQ: What causes hoarding?

- Quick answer: lots of things can contribute to hoarding-like biological, psychological, and social factors.

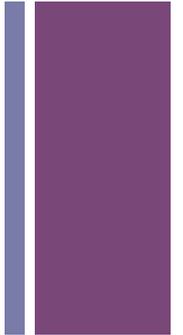
The **BIOPSYCHOSOCIAL**  
Model of Compulsive  
Hoarding  
states that:

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





# FAQ's: What are the Biological Factors that contribute to hoarding?

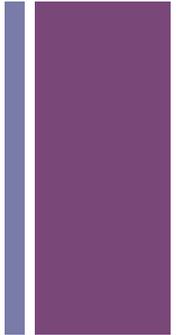


- Family history/genetic link
- Brain functioning differences
  - Occipital and frontal lobes (Saxena et al., 2004).
    - These are the parts of the brain that are responsible for visual things and executive functioning (see below)
- Information-processing (cognitive) deficits (Grisham, Brown, Savage, Steketee, & Barlow, 2007; Grisham, Norberg, Williams, Certoma, & Kadib, 2010; Hartl, Duffany, Allen, Steketee, & Frost, 2005; Hartl et al., 2004; Lawrence et al., 2006; Tolin & Villavicencio, 2010; Tolin, Villavicencio, Umbach, & Kurtz, 2010; Wincze, Steketee, & Frost, 2007)
  - Attention
  - Memory
  - Categorization
  - Complex thinking
  - Decision-making

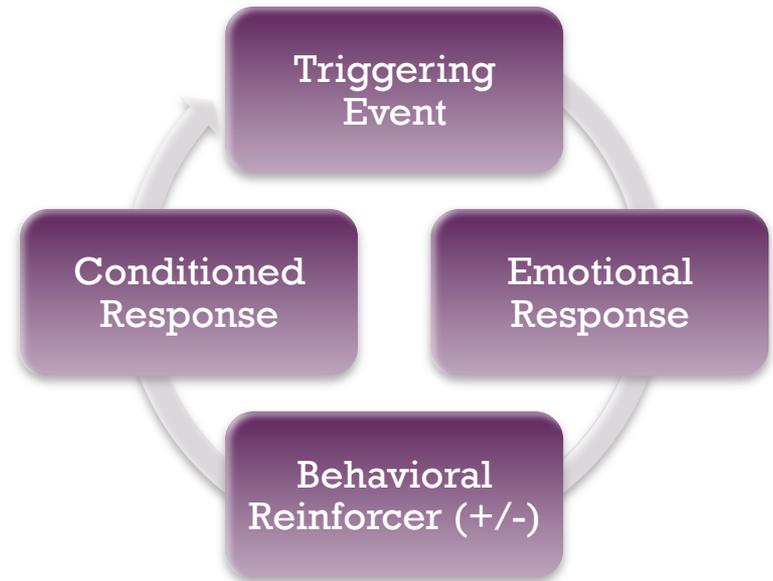




# FAQ's: What are the Psychological Factors that contribute to hoarding?

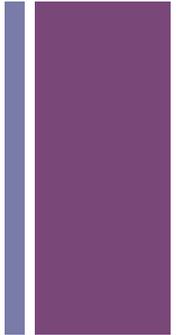


- Mental health/emotional distress
  - Unresolved trauma and loss
- People who hoard have specific beliefs about and attachment to their possessions (Frost & Hartl, 1996)
  - Feelings toward object
  - Memory-related concerns
  - Desire for control
  - Responsibility and waste
  - Aesthetics
- Hoarding behaviors can be reinforced over time (Frost & Hartl, 1996)
  - Acquiring things makes us feel good, so we want to do more of it
  - Getting rid of things makes us anxious, so we want to do less of it





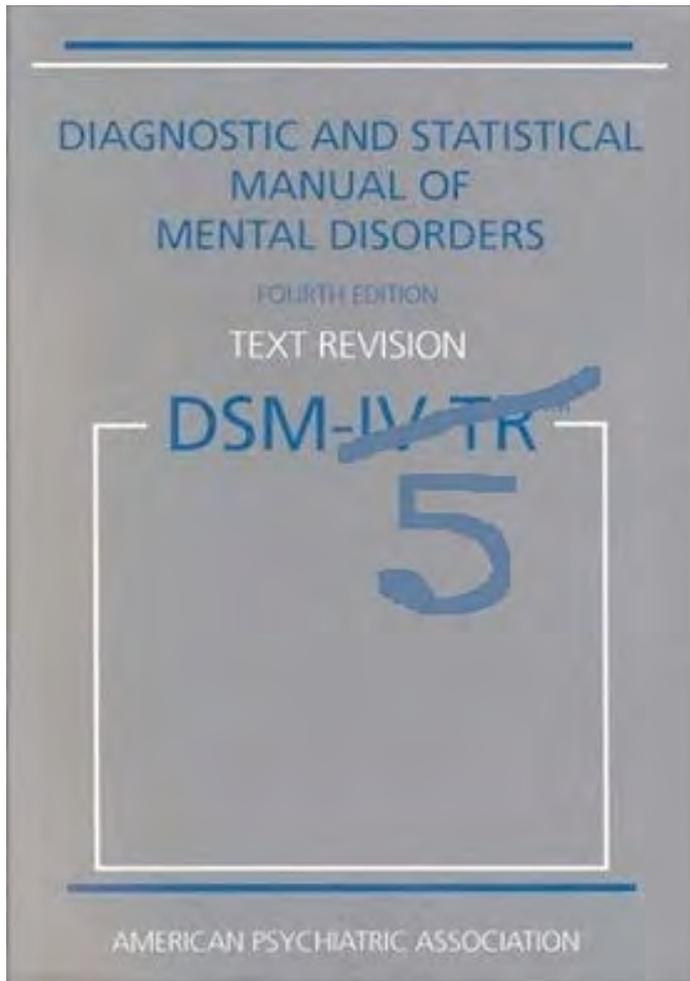
# FAQ's: What are the Social Factors that contribute to hoarding?



- Interpersonal relationships
  - The better family connections (in past and present), the less hoarding (Sampson & Harris)
- Social support
  - The more support experienced from family, the less hoarding (Sampson & Harris)
- Major life events/transitions
  - Unresolved trauma and loss contributes to hoarding (Sampson & Harris)
- Social stigma
  - “Hoarding is weird”
  - Stigma can contribute to depression, anxiety, etc.
- Culture
  - Western, consumer cultures = hoarding is present
  - Not sure about other, non-consumer-driven cultures
  - Consider context (e.g. refugee families, etc)



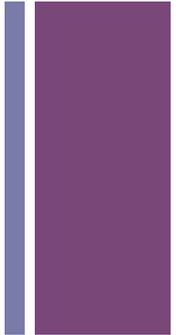
# + FAQ: Is hoarding really just OCD?



- **Quick answer:** Not necessarily
  - Only about 30-40% of people who hoard actually show other symptoms of OCD
  - It's also associated with lots of other mental health issues:
    - Depression- <53%
    - Anxiety- <24%
    - ADHD- <20%
    - Impulsivity-
    - Personality Disorders- <29%
    - Organic Brain Illness- <31%



# FAQ: Hoarding must be some sort of coping mechanism, right?



**Quick answer:** It depends.

## Trauma has been related to hoarding in the research

- **Traumatic life events** (Cromer, Schmidt, & Murphy, 2007; Hartl, Duggany, Allen, Steketee, and Frost, 2005)
  - 76%: endorsed a history of a traumatic life event (Breslau et al., 1998)
  - 55%: stressful life event around onset of hoarding (Grisham, et al., 2006)
  - Relational traumas

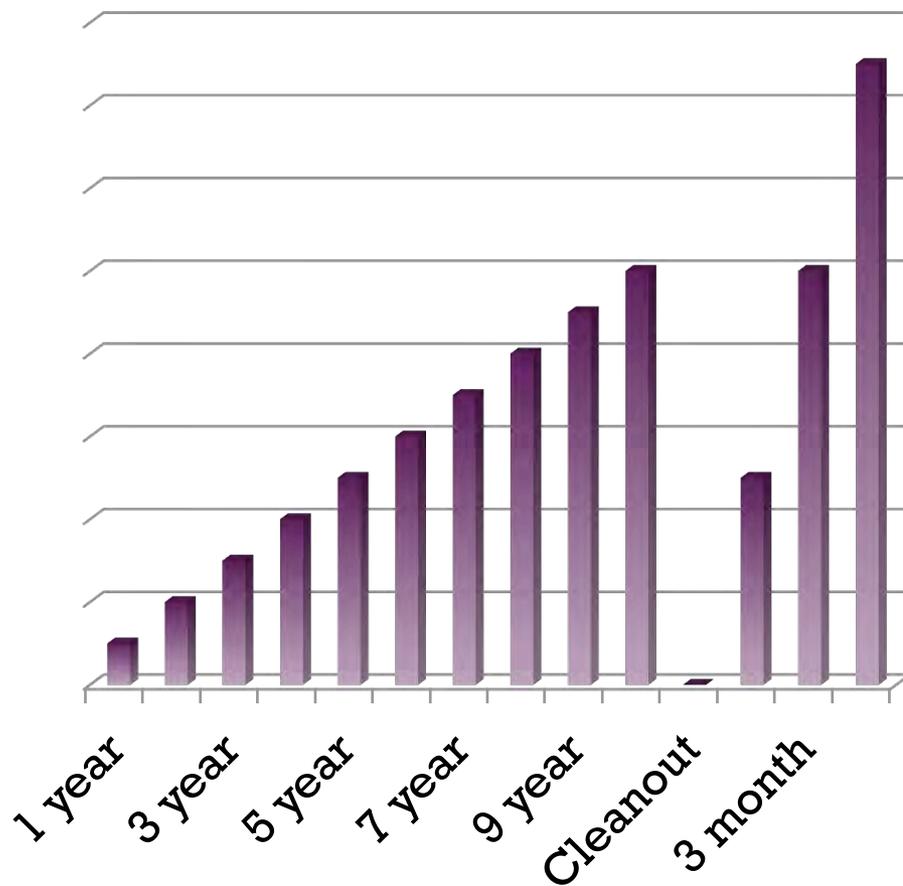
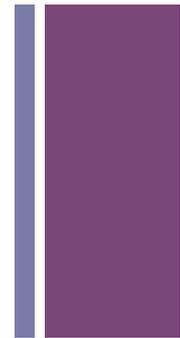
**But it can also be considered a reinforced behavior that occurs over time because of difficulties with:**

1. History/vulnerabilities
2. Information-processing deficits
3. Beliefs about possessions
4. Emotions
5. Reinforcement

Cognitive Behavioral Model of Compulsive Hoarding  
(Frost & Hartl, 1995)



# FAQ: Can't I just clean out my loved one's home?



**Quick answer:** Not if you can avoid it.

- It can do more harm than good.
  - Can be traumatizing
  - 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
  - Higher relapse rate among forced clean out
  - You'll just have to do it again later
- Sometimes it's necessary though
  - Involve the homeowner as much as possible for lasting change



# FAQ: Does therapy work come before, during, or after work on the hoarding problems?



**Quick answer:** It depends. Oftentimes, we can do them simultaneously when safety and coping skills are in place.

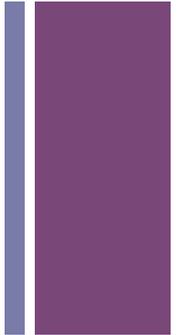
**Rule of thumb:**

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





# Why a theory of grief and loss for hoarding?

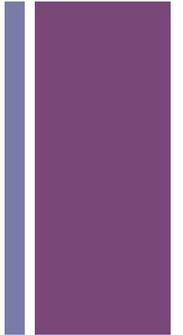


- **Presence of loss in stories**
  - Family members AND people who hoard
- **Current approaches for dealing with hoarding do not reflect an understanding of the role of grief and loss in hoarding behavior**
- **Behavioral treatment alone has not been effective**
  - Systemic approach
    - We are more than just our behaviors
- **Not “typical” losses**
  - Need a unique framework for working with unresolved losses





# Ambiguous Loss - What is it?

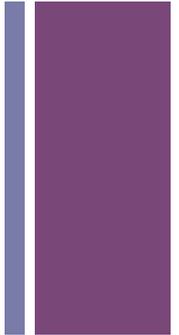


**Pauline Boss**

- University of Minnesota
  - Native American women
  - Wives of MIA/POW pilots in Vietnam war
  - Families living with dementia.
  
- A loss that is unclear, cannot be fixed, can be physical or psychological.
  
- No official verification of loss since final decisions have not been made.
  
- Complicates grief with no resolution due to relationship, not individual weakness.
  
- The interaction between ordinary and ambiguous losses.



# Two Types of Ambiguous Loss



## Type 1: Leaving without Goodbye

- Physical absence with psychological presence
- Catastrophic: disappearance, lost without a trace, missing in action
- Common: divorce, adoption, immigration

## Type 2: Goodbye without Leaving

- Psychological absence with physical presence
  - Catastrophic: dementia, depression, hoarding
  - Common: loss of a dream, loss of way of life
    - **For family members of people who hoard, this seems to be the type of loss experienced**



# Systemic Effects of Ambiguous Loss



- Stress: not because of weakness in the individual or family but because the situation of ambiguity is so difficult.
- “The ambiguity is the culprit.” (Boss, 3/17/12)
- Relationships are immobilized:
  - Decision-making is put off and confused.
  - Coping is blocked and grief is frozen.
  - Conflict is created within families.
  - Security/safety is questioned.

# + Ambiguous Loss: Effects on Individuals

Depression,  
anxiety, guilt, shame

Neglect or lack of  
self-care

Somatic Illnesses

Ineffective coping  
(gambling, hoarding)

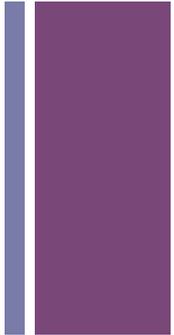
Abuse: substance and  
other

Distress and  
traumatization  
(the brain and dreaming)

PTSD



# + Ambiguous Loss + Hoarding



## Family Members

- Loss of relationships, future opportunities, sense of home *due to the hoarding behavior* (Sampson, in press)
- Understanding -> compassion -> support

## Person who Hoards

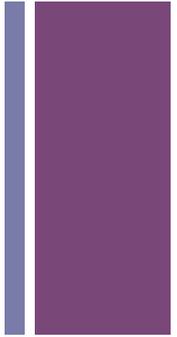
- Experiences of unresolved A.L. throughout life
  - Not necessarily related to hoarding
- Loss of relationships, etc *due to hoarding behavior*
- Understanding -> begin to work towards resolution -> increase in healthy coping

Need for integration of grief and loss theory into our understanding and work with compulsive hoarding





# FAQ: At what point is this reportable to the authorities?



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

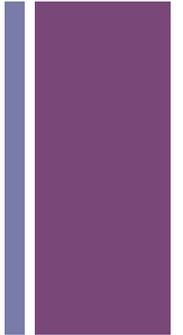
- **A child/minor**
- **Older adult (over 60 with a cognitive, physical, or functional impairment)**
- **Person with disability or dependency**
- **Animal**

**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: What's up with animal hoarding? Is it the same thing as object hoarding?



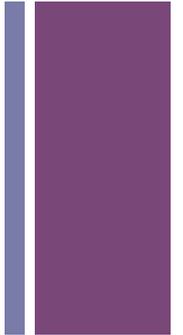
■ **Quick answer:** There are some similarities between the two, but they differ in several ways.

■ Research on animal hoarding is about 20 years behind object hoarding

- Similarities:
  - Acquisition, difficulty discarding, clutter, distress
  - Many people who hoard animals also hoard objects
  - Co-morbidities
- Differences:
  - Animal hoarding: squalor (100% of homes)
  - Gender and age differences
    - AH: More women; later age
  - Types of objects:
    - Objects: variety
    - Animals: one species
  - Lack of treatment for A.H.
  - MAJOR mental health concerns (a mental health professional *must* be involved)



# FAQ: 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

+ Further Consideration:

Safety Day  
Collaboration  
Hoarding Task Forces

Q&A  
Discussion

