Objectives

- Recognize effective diagnosis and treatment strategies of hoarding disorder.
- Describe alternative options to treatment other than a forced cleanout.
- Apply evidence-based treatment strategies to address issues of safety in hoarding disorder.
- Discuss development of collaborative networks in your area to form a community response to hoarding disorder.
Who We Are

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

Background on Hoarding Disorder
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

How many people hoard and are some people more likely to hoard than others?

Research projects 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 (Samuels, et al. 2008)
- People with lower income hoard more than people with higher income (Samuels, et al. 2008)
- Gender differences?
+ 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:** existing and new possessions that are 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)
- 87% major depressive disorder
- 29% social phobia
- 28% generalized anxiety disorder (Frost et al., 2006)
- 30-40%: OCD (e.g. Samsma et al., 2007)
- 31%: Organic Brain Illness
- 30%: Personality Disorders (Mataix-Cols, et al., 2000)
- 28%: ADHD (e.g. Sheppard et al., 2010)
- Dementia (Iubreng et al., 1999)
- Eating Disorders (Frankenburg, 1984)
- Substance abuse (Samsma et al., 2008)
Hoarding and Older Adults

- Symptoms severity increased with each decade of life (Ayers et al., 2010)
- 25% of elderly community-dwelling day care residents and 15% of nursing home residents displayed hoarding symptoms (Marx & Cohen-Manfield, 2003)
- Increased dysfunction in several domains of executive functioning
  - Mental control, working memory, inhibition, and set shifting (Ayers et al., 2013)
- Major consequences for older adults:
  - Increased risk of falls, fire hazards, food contamination, social isolation, and medication mismanagement (e.g. Ayers et al., 2010; Frost & Gross, 1993; Kim, Steketee, & Frost, 2001)
  - Increased risk of medical conditions (e.g. Ayers et al., 2013; Timpano et al., 2011; Tolin et al., 2008)

What causes hoarding?

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!
Is there a family link to hoarding, and when does is start?

- **Family history** (Pertusa, et al., 2008; Samuels, et al., 2007)
  - More likely to have 1st degree relatives with hoarding (12%) or with hoarding symptoms (49%) (Winsberg, Cassic, & Koran, 1999)
- **Social learning** (Folin, 2011)
- **Genetic link** (Iervolino et al., 2009; Lochner et al., 2005; Samuels, Shugert et al., 2007)
- **Course and progression:** behaviors begin during childhood or adolescence (Frost & Gross, 1993; Grisham et al., 2006; Pinto, Eisen, Mancoho, et al., 2007; Samuels et al., 2002; Winsberg et al., 1999)

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
What are the Psychological Factors that contribute to hoarding?

- Mental health/emotional distress (Frost & Hartl, 1996)
  - Co-morbid mental health conditions
  - Unresolved trauma and loss (Sampson & Harris)

- 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

What are the Social Factors that contribute to hoarding?

- Major life events/transitions (Grisham, Frost, Steketee, Kim, & Hood, 2000; Kellett, Greenhalgh, Beail, & Ridgway, 2010)

- Higher frequency of lifetime traumatic events (Cromer et al., 2007; Hartl et al., 2005)

- Up to 55% report experiencing a stressful event at onset of symptoms (Grisham et al., 2006)

- Burden on families

- Positive interpersonal relationships can serve as a protective factor against hoarding severity (Sampson & Harris, 2012)

- Social stigma

- Culture
What’s up with animal hoarding? Is it the same thing as object hoarding?

- There are some similarities between the two, but they differ in several ways.
- Research on animal hoarding is about 20 years behind object hoarding
  - Each situation is different
  - Presence of squalor does not mean animals are being hoarded

What are the Safety & Health risks associated with hoarding?

<table>
<thead>
<tr>
<th>Safety</th>
<th>Health</th>
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<tbody>
<tr>
<td>Fire hazard</td>
<td>Impaired functioning</td>
</tr>
<tr>
<td>Blocked exits</td>
<td>Poor hygiene and grooming, nutrition</td>
</tr>
<tr>
<td>Risk of falls/items falling</td>
<td>Inattention to medical needs</td>
</tr>
<tr>
<td>Lack of routine home maintenance</td>
<td>Inadequate financial management</td>
</tr>
<tr>
<td>Structural damage to building from increased weight and volume of clutter</td>
<td>Difficulty cleaning around clutter</td>
</tr>
<tr>
<td>Risk of eviction and homelessness</td>
<td>Sleeping on floor instead of bed</td>
</tr>
</tbody>
</table>

- 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)
Emotional/Psychological Impact of Hoarding Clean-outs on Clients

Clean-outs 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

Diagnosis and Assessment of Hoarding Disorder
300.03 Hoarding Disorder

a. “persistent difficulty discarding or parting with possessions, regardless of their actual value”

b. Difficulty due to a perceived need to save items and to distress associated with discarding them

c. Difficulty discarding possessions results in 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, authorities)

d. Hoarding causes clinically significant distress or impairment in social, occupational, or other important areas of functioning (including maintaining a safe environment for self and others)

e. Not due to medical condition (e.g. brain injury, cerebrovascular disease)

f. Not due to another mental health condition (e.g. OCD, major depressive disorder, schizophrenia, neurocognitive disorders, autism)

Specify if:

a. With excessive acquisition

b. Insight (good, poor, delusional)

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?
Structured Interview for Hoarding Disorder
(Pertusa et al., 2013)

- Diagnostic tool
- Interview structured to help guide a clinician's diagnosis through the 6 criteria of hoarding disorder and its 2 specifiers
Hoarding Assessment Tool (Steketee & Frost, 2007)

- Done in addition to the physical observation of home
- Better understand:
  - causes of problem
  - features that might affect intervention
  - Avenues/impediments to change
- Conducted as a conversation
- Ideally conducted by a mental health professional, but other professionals with good skills in dealing with sensitive issues can also do this

- May require multiple visits to office and/or home
  - Home is ideal
- Topics addressed:
  - Onset and duration of hoarding problem
  - Home environment and contents
  - Home dwellers’ thoughts and feelings about possessions
  - Current acquiring
  - Reasons for saving
  - Strategies for organization
  - Role of family, friends, community members
  - Immediate long-term threats to health or safety
  - Problems resulted from hoarding
  - Previous intervention attempts
  - Personal goals and values with regard to current and future use of home
+ **Hoarding Rating Scale (HRS)**  
(Tolin, Frost, Steketee, 2010)

- 8-item scale, self-report measure
- 2-3 minutes
- Assesses severity of main features of hoarding
  - Clutter
  - Difficulty discarding
  - Acquisition
  - Distress
  - Functional impairment
- 0 (no problem) to 8 (extreme problem)
- Hoarding disorder: score at least a 4 or above on clutter and difficulty discarding, as well as on either distress OR functional impairment
- Mild but significant hoarding: 16
- Moderate: Avg. 24
- Severe: Above 30

### Examples

1. Because of clutter or number of possessions, how difficult is it for you to use the rooms in your house?
2. To what extent do you have difficulty discarding (or recycling, selling, or giving away) ordinary things that other people would get rid of?

+ **Cognitive Assessments**

- **The Montreal Cognitive Assessment**  
  - [www.mocatest.org](http://www.mocatest.org)

The MoCA is a cognitive screening test designed to assist Health Professionals for detection of mild cognitive impairment.

Assessments like this require a strict protocol and/or training in order to appropriately be used in session.
Assessments of Home Environment and Functioning

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)

<table>
<thead>
<tr>
<th>Leve</th>
<th>Structure and Features</th>
<th>Animals and Pets</th>
<th>Household Clutter</th>
<th>Health and Safety</th>
<th>Personal Protective Equipment</th>
</tr>
</thead>
<tbody>
<tr>
<td>L1</td>
<td>All items, waste, and dirt on floor, walls, and furniture, in areas of living areas, in presence of owner and children</td>
<td>None</td>
<td>Severe clutter</td>
<td>Severe clutter</td>
<td>No</td>
</tr>
<tr>
<td>L2</td>
<td>Room completely filled with clutter, items falling, and unable to move around</td>
<td>Some clutter</td>
<td>Moderate clutter</td>
<td>Moderate clutter</td>
<td>No</td>
</tr>
<tr>
<td>L3</td>
<td>Room or house is cluttered, items falling, and unable to move around</td>
<td>Moderate clutter</td>
<td>Moderate clutter</td>
<td>Moderate clutter</td>
<td>No</td>
</tr>
<tr>
<td>L4</td>
<td>Room or house is cluttered, items falling, and unable to move around</td>
<td>Severe clutter</td>
<td>Severe clutter</td>
<td>Severe clutter</td>
<td>No</td>
</tr>
</tbody>
</table>

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
Activities of Daily Living- Hoarding (ADL-H) Scales (Steketee & Frost, 2007)

- Extent to which ordinary activities can be accomplished in the context of hoarding problem
- Specific risks

Scoring: Average
- Sum scores (except NA’s) and divide by number of scored items
- Score in the 3 range: indicate substantial functioning impairment due to clutter

How much hoarding interferes with 16 ordinary activities
- Ex: bathing, dressing, preparing meals

7 questions: quality of living conditions
- Ex: presence of rotten food, insect infestation

6 questions: safety and health
- Ex: fire hazards and unsanitary conditions

2 subscales scored separately

HOMES® Multi-disciplinary Hoarding Risk Assessment

- Health
  - Current untreated illnesses
  - Current infection
  - Presence of spoiled food
  - Presence of insects or rodents
  - Presence of hazardous materials
  - Presence of explosive or flammable

- Obstacles
  - General need to go outside
  - Inability to maintain access
  - Presence of obstacles precluding entry

- Mental health
  - Note: this is not a clinical diagnosis; use only to identify risk factors
  - Does not seem to understand seriousness of problem
  - Defective or engrossed
  - Anxious, bright, or confused

- Endangerment
  - Evaluate threat based on other sections with attention to specific populations listed below
  - Immune to health consequences of problem
  - Responsible for protection of others
  - Presence of elderly or children

- Structure & Safety
  - Structural hazards
  - Electric or water hazards

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
Uniform Inspection Checklist: Quick Reference

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

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

- Exits - means of exit
- Minimum of 1/6" wide clear pathways throughout residence
- Smoke detectors, CO detectors, or sprinkler heads (all that apply)
- All doors, including entry & exit, closet, cabinet, pantry, etc. (inspector must be able to view & check door & door frame & bolt trim & catch of door)
- Minimum of 1 unobstructed window in living room & each bedroom for emergency exit
- Bathtubs, sinks, toilets, Murphy beds, existing heating/air conditioning, open floor/heat register, fireplace, gas lines, gas tanks, gas cylinders
- Emergency exit doors - exit of exit must be no more than 1/6" from the floor

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 & circuits, family
- All heat sources
- All plumbing fixtures & pipes, including plumbing water off stalls
- Doors, hitches, & shower

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

- Smoke free kitchen and show realistic size & measurements
- 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 (in upright oven)
- Stove, range & oven - interior, exterior, & top must be clean & free of debris
- No evidence of infestation
- Garbage & debris must be removed from residence as routine basis
- No drip hazards, fall hazards, or asbestos disk
- No evidence of excreta under carpet or area floor or means of residence
- No long term storage of newspapers, magazines, papers, or examine again to raise free
- No exposed or faulty electrical wiring
- No excessive pet odors, pet bed, pet waste

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

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Tufts Animal Care and Condition

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In Practice

Safe Animal Care and Certification: The turkeys are examined by a certified veterinarian, and any necessary care or treatment is provided.

---

Animal Welfare: May 2016 15
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

Treatment and Strategies for Mental Health Professionals
Treatment Planning for Hoarding Disorder

- Combining strategies from across fields can help to most holistically treat this mental health and public safety issue
- Integrated treatment approach (modeled after treatment for co-occurring disorders)
  - Prioritize treatment goals for primary diagnoses
- CBT most Evidenced Based Practice
  - Integrated treatment for hoarding will include different types of interventions to support specific treatment goals
    - Examples:
      - Distress re: discarding items: Exposure treatments (CBT)
      - Organization skills: Executive skills building (ADHD treatment)
- Medication for Hoarding Disorder?

Common treatment goals for Hoarding Disorder

- Increase understanding of hoarding behavior.
- Create living space
- Increase appropriate use of space
- Organize possessions to make them more accessible
- Improve decision-making skills
- Reduce compulsive buying or acquiring and replace these behaviors with other pleasurable activities
- Evaluate beliefs about possessions
- Reduce clutter level in home environment
- Learn problem-solving skills
- Prevent future hoarding
Treatment Approaches and Therapies

- Motivational Interviewing
- Non-behavioral approaches:
  - Narrative Therapy
  - Ambiguous Loss Theory
- Behavioral approaches:
  - CBT – Exposure Therapy
  - DBT – mindfulness, anxiety management
- Safety Day – harm reduction approach

Other Interventions
Family Therapy

- Coaching
- Role-playing
- Communication
- Psychoeducation
- Support group involvement

Positive family relationships can help serve as a protective factor between psychological distress and hoarding severity (Sampson & Harris, 2013).

Support Groups

<table>
<thead>
<tr>
<th>People who Hoard</th>
<th>Family Members</th>
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<tbody>
<tr>
<td>Buried in Treasures</td>
<td>THP Manual</td>
</tr>
<tr>
<td>Peer-led options</td>
<td>Psychoeducation</td>
</tr>
<tr>
<td>Sense of belonging in a community</td>
<td>Communication</td>
</tr>
<tr>
<td>Non-judgment</td>
<td>Self-care</td>
</tr>
<tr>
<td>Processing</td>
<td>Stigma</td>
</tr>
<tr>
<td>Self-awareness</td>
<td>Trauma</td>
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Collaborative Approaches to Hoarding Disorder

Research indicates that individual treatment approaches have limited success. (Saxena, Brody, Maidment & Baxter 2007; Tolin, Frost & Steketee 2007)

Multidisciplinary approaches attend to the complex nature of hoarding. (Koenig, et al 2010)

Why work collaboratively?
- Ethical – right thing to do
- Effective – bio-psychosocial problems
- Resource-conserving - integrated care less expensive
- Clinician and professional-friendly – supportive in a situation which has small “successes”

Collaborative Work with Related Professionals

Identify stakeholders impacted by hoarding disorder.
- Housing
- Public health
- Mental health
- Protective services
- Aging services
- Legal
- Fire and police
- Medicine
- Animal control
- Organizers
- Cleaning companies
Hoarding Task Forces

- “A coordinated plan of intervention that maximizes resources across agencies is likely to achieve the best possible result with regard to reducing hoarding, benefiting the person who hoards and those affected by the problem, and long-term cost effectiveness.” (Bratiotis, Schmalish, & Steketee, 2011)

What is a Hoarding Task Force?

- An organized group of professionals working toward developing a practice of coordinated response from a variety of community fields

- To provide a “directed and managed response to hoarding cases that come to public attention” (IOCDF.org)

- Objectives:
  - Provide public education about hoarding
  - Give out service agency information
  - Provide support to individuals, families, and communities
What resources are available?

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
- International OCD Foundation
- Institute of Challenging Disorganization
- Children of Hoarders

Support Groups
- The Hoarding Project
- Children of Hoarders

Reading Resources
- Treatment for Hoarding Disorder Workbook (2014), Frost & Steketee.
- 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
- Loss, Trauma and Resilience (2006), Boss
- Motivational Interviewing: Preparing People for Change, 2nd ed. (2002), Miller & Rollinick
- Narrative Means to a Therapeutic End (1990), White & Epston
- Dirty Secret (2010), Jessie Sholl
- Coming Clean (2014), Kimberly Rae Miller