Hoarding Support Program

90 minute hoarding training
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Dleinweber@jfcsp Philly.org
Learning Objectives

- What is Hoarding Disorder
- Current Research, Trends in treatment, treatment modalities, and recommendations
- How to apply treatment modalities, sorting sessions, assessment tools in practice
- Group work, Buried In Treasures
- Developing a sustainable program, task force, volunteers in hoarding programs
- Building resources for intervention
What do you think of when you see or hear of someone hoarding?

won’t change  dirty  doesn’t try

not trying  disgusting

lazy  sick
Consequences of Stigma

• Waste of money, time
• Burn out
• Lost relationships
• Anger, mistrust, guilt
• Shame, embarrassment
• Recidivism

• Trauma
A little experiment
A little experiment

• Choose one item you have near you that you value, but is not the most important/cherished item you own.

• Throw that item away….don’t think about it just throw it away, it has no value. Its trash.

• Ponder how that felt...

• Share your feelings, thoughts, what item did you throw away? On a scale of 1-10 how important was that item to you? On the same scale, how did it feel for someone to tell you it was “trash” or “did not have value”?
Hoarding Disorder

Hoarding Disorder Definition

*American Psychiatric Association DSM-V*

1. Difficulty discarding
2. Accumulation of Stuff that Prevents Normal Use of Space
3. Distress or Impairment
4. Not some other medical condition
5. Not some other mental health condition
 Estimates are that hoarding behaviors affect between 2 - 6% of the population.

 The 5% rate is 2x the rate of OCD & 4x the rate of bipolar and schizophrenia.

 In Philadelphia, this is between **23,600-59,000** adults.

 Hoarding behaviors usually start in adolescence and often become more problematic with age.
Co-Occurring Disorders

- Depression
- Social phobia
- OCD
- Personality Disorders, OCPD
- Generalized Anxiety Disorder (GAD)
- Schizophrenia
- ADHD
- Acquisition-Related Impulse Control Disorders

- Eating Disorders
- Brain Injury
- Traumatic Life Events (not PTSD)
- Alcohol Dependence
- Prader-Willi Syndrome
- Developmental Disabilities
- Dementia
- Organic Mental Disorders

75% of individuals with Hoarding Disorder have a co-occurring disorder
Hoarding Risk Factors

- Age
- Race/Ethnicity
- Gender
- Income
- Other contributing factors
- “Universal Phenomenon”

IMPORTANT: there is not a “typical” description of a person who hoards. Hoarders are from all backgrounds, ages, socioeconomic status, gender, ethnicity & race.
Why Hoarding Disorder

PHTF recognizes the impact of hoarding on the individual and the community.

**For the individual:**
- Conflict with loved ones over clutter
- Risk of death, injury or serious health condition
- Overwhelmed and exhausted by clutter
- Unable to prepare or store food
- Unable to have friends and family visit
- Risk of citation, eviction, utility shutoff
- Unable to return home after hospitalization
- Financial problems due to cost of acquiring and storing belongings
- Mental health problems, especially depression
- Shame, embarrassment, defensiveness

**For the community:**
- Landlords & neighbors: Disrepair, maintenance hazards, infestations, citations
- Code enforcement: Structural damage, blocked exits, citations and condemnation
- Emergency Responders: Fire hazards, Lack of access for medical personnel
- Health Department: Infestations, health hazards
- Senior Services: Removal of older adults, delayed discharge from hospitals
- Child Protective Services: Removal of children
- Animal Protective Services: Removal of animals
Origin of the Program

• JFCS Older Adults Care Management team identified Hoarding Disorder as an ongoing concern impacting the aging population from aging in place.
• JFCS Care Managers often assisted with clean out services, extermination services, and referrals to other resources.
• JFCS identified this as a need to be addressed and understood the complexity of Hoarding Disorder.
• In 2014, JFCS sought out funding to develop a program....and the rest is history.
HOARDING MAY IMPEDE FIRST RESPONDERS

COVERED HEATING VENTS MAY CAUSE FIRES

BIological fluids may contain pathogens

UNTREATED MOISTURE MAY WEAKEN FLOORBOARDS

CLUTTER MAY BLOCK EXITS IN CASE OF EMERGENCY

HEAVY LOADS MAY LEAD TO COLLAPSE
Questions
Current Research In Hoarding Disorder

• Indecisiveness is often evident during sorting/discarding sessions
  • Memory problems are often identified as a reason to save

• Lack of global insight
  • May be less aware of their emotional experience than others

• Current treatment options not as robust as other psychiatric disorders
  • CBT combined with skills training to personalize treatment
  • One size for all treatment does may not be as beneficial with HD, focus on which treatments work and which treatments work for who
    • Emotional sensitivity, executive functioning, persistence should be factored in

• Many communities still approach HD not from a MH perspective, highlighting the need for more evidenced based treatment
  • CBT combined with skills training to personalize treatment
  • One size for all treatment does may not be as beneficial with HD, focus on which treatments work and which treatments work for who
    • Emotional sensitivity, executive functioning, persistence should be factored in

Significant need for more research
Types of Intervention

Intervention can focus on:

1. Primarily the Home
   - Cleanout

2. The Person and the Home
   - Safety Day
   - Harm Reduction through Adaptive Skill-Building
   - Reducing Acquisition
   - Exposure Therapy
   - Support Groups

3. Primarily the Person
   - Cognitive Behavioral Therapy
   - Psychotherapy
   - Medications
Types of Treatment

- Cognitive Behavioral Therapy
- Motivational Interviewing
- Skills Training
- Medication
Cleanouts and Safety Days

• **Major Cleanout:** removal of all clutter from the home, often when the individual is temporarily absent. Not recommended.
  - Emotional flooding, Trauma, Distrust, Frustration, Impaired Relationships, Money, Sometimes necessary

• **Safety Day:** removal of enough clutter to make conditions safe in the home (harm reduction).
  - Extensive planning
  - Client-directed
  - Only when necessary
Example – Downward Arrow

• https://www.youtube.com/watch?v=DJSTzTdXwWc
Support Groups

- Buried In Treasures
- Finder’s Keepers, peer led group
- Art Therapy
- Mindfulness
- Drop-In Support Groups
- Clutterer’s Anonymous
- Support for loved ones
Motivational Interviewing

• Person-centered
• Highlights disconnect between discomfort with discarding and how problematic hoarding has become

Aims to achieve two things:
• Increase behavior change
• Increase confidence in self
## Psychotherapy & Medications

<table>
<thead>
<tr>
<th>Psychotherapy:</th>
<th>Medication:</th>
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<tbody>
<tr>
<td>• Most common is CBT</td>
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<td>• Typically provided in office</td>
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<td>• SSRI typical use, common treatment in OCD</td>
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<tr>
<td>• Not enough research for effective use</td>
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</table>
Questions
What does the JFCS Hoarding Intervention Programs do?

Hoarding Intervention Programs focus on the person, not the STUFF.

We provide in-home support, our approach is hands on, and intensive.

Assessment, treatment planning, and evaluation.

Overall goal to support older adults age in place, program dependent.

Buried In Treasures Support Groups

Training & Education
Engagement

ACES

• Action Words
• Curious Questioning
• Empathetic Statements
• Statements of Concern

• Use these to build rapport and trust which are imperative.
Engaging Individuals: Dos and don’ts

• **DO** utilize the same language and descriptors the client uses to describe their items or clutter, such as “collections”, “things”. These are items of value to the individual and we want to validate their feelings and beliefs.

• **DO** consider safety first rather than discarding items.

• **DO** identify strengths rather than barriers and utilize positive, encouraging language.

• **DON’T** use language that can be perceived as judgmental or negatively defines their possessions. (“trash”, “junk”, “mess”, etc.). Be cautious of your non-verbal cues!

• **DON’T** engage in a power struggle regarding objects and be aware of suggestions to discard perceptibly valuable items, even well intended suggestions may have a negative impact.

• **DON’T** touch personal possessions with permission.
Every hoarding intervention team combines support & enforcement including:
- The person who is hoarding.
- Friends, family and peers who struggle with hoarding
- Professional organizer or case manager
- Counselor or therapist
- Legal Aid
- Landlord or Code Enforcer
## Assessment

<table>
<thead>
<tr>
<th>Clutter Image Rating (CIR)</th>
<th>a 4 or higher would indicate the need for support</th>
<th>Quarterly</th>
</tr>
</thead>
<tbody>
<tr>
<td>Activities of Daily Living-Hoarding (ADL-H)</td>
<td>a 1.5 or higher score would indicate the need for support</td>
<td>Quarterly</td>
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<tr>
<td>Home Environment Index (HEI)</td>
<td>assesses for squalor in the home. This tool alone would not indicate hoarding, but does assess for sanitary concerns in a hoarded home.</td>
<td>Quarterly</td>
</tr>
<tr>
<td>HOMES Multi-disciplinary Hoarding Risk Assessment Tool</td>
<td>to determine the level and/or type of services needed upon initial assessment</td>
<td>Initial, Discharge</td>
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<tr>
<td>Hoarding Initial Assessment Tool</td>
<td>developed by JFCS as a bio-psycho-social tool to understand symptomology and attachment to hoarded items. This tool helps to develop the individualized treatment plan</td>
<td>Initial</td>
</tr>
<tr>
<td>PHTF Initial Benchmarks for a Safe and Healthy Home</td>
<td>Developed by the PHTF as a tool to guide the process, not an evaluative tool for assessment.</td>
<td>As needed by member or provider</td>
</tr>
</tbody>
</table>
Assessment Tools

- Clutter Image Rating
- Home Environment Index
- Activity of Daily Living-Hoarding
Example Assessment Tool: CIR
ADL-Hoarding

### Activities of Daily Living for Hoarding (ADL-H)

<table>
<thead>
<tr>
<th>Activity</th>
<th>Can do it easily</th>
<th>Can do it with a little difficulty</th>
<th>Can do it with moderate difficulty</th>
<th>Can do it with great difficulty</th>
<th>Unable to do</th>
<th>Not Applicable</th>
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<tbody>
<tr>
<td>1. Prepare food</td>
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<td>2. Use refrigerator</td>
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<td>3. Use microwave</td>
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<td>4. Use kitchen sink</td>
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<td>5. Put on clothes</td>
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<td>6. Move around inside the house</td>
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<td>7. Do laundry quickly</td>
<td>☐</td>
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<td>8. Use sink</td>
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<td>9. Use bathroom sink</td>
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<tr>
<td>10. Use bathroom sink quickly</td>
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<td>11. Answer door quickly</td>
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<td>12. Fix in small pieces</td>
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<td>☐</td>
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<td>13. Sleep in bed</td>
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<td>14. Do laundry</td>
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<td>15. Find important things in the home, etc.</td>
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<td>Home Environment Index</td>
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<td>Choose and handling poor sometimes lead to sanitation problems. Please circle the best-fit for the option closest to the home. Is what norms are the following situations present in the home?</td>
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<td>1. Food burned?</td>
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<td>1. Some risk of fire (for example, loose flammable material)</td>
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<td>2. Moderate risk of fire (for example, damaged materials near heat sources)</td>
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<td>3. High risk of fire (for example, flammable materials near heat sources, chimney, etc.)</td>
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<td>2. Mold or moisture?</td>
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<td>1. Steam</td>
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<td>2. Some moisture or moisture in kitchen</td>
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<td>3. Long-term exposure to moisture (for example, chemical hazards, etc.)</td>
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<td>3. Dirty or clogged sink?</td>
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<tr>
<td>1. Sink dirty and clean</td>
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<td>2. Sink full of water, possibly clogged</td>
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<td>3. Sink clogged or overflowing that has overflowed into room, etc.</td>
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<td>4. Standing water in sink, tub, other containers, basements, etc?</td>
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<td>1. No standing water</td>
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<td>2. Some water in kitchen</td>
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<td>3. Water in several places, especially in the kitchen</td>
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<tr>
<td>3. Water in numerous places, especially in the kitchen</td>
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<td>5. Human/animal waste?</td>
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<td>1. No human waste, animal waste, or waste visible</td>
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<td>2. Human waste or vomit, no animal waste or waste inside egg or less</td>
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<td>3. Some animal or human waste or no waste (for example, in unhatched eggs)</td>
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<td>4. Animal or human waste or vomit on floor or other surface</td>
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<td>6. Mildew or mold?</td>
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<td>1. No mildew or mold detectable</td>
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<td>2. Small amount of mildew or mold in limited areas and expected places (for example, on edge of shower curtain or refrigerator)</td>
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<td>3. Considerable, noticeable mildew or mold</td>
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<td>4. Visible significant mold or mildew on most surfaces</td>
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<td>5. Food containers?</td>
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<td>1. All food washed and put away</td>
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<tr>
<td>2. A few unwashed dishes</td>
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<tr>
<td>3. Many unwashed dishes</td>
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<td>4. Almost all dishes are unwashed</td>
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</table>
Questions
Mission

The Philadelphia Hoarding Task Force is a coalition that seeks to improve outcomes for people who hoard and reduce the catastrophic consequences related to hoarding for residents of the City of Philadelphia.

Balancing the rights of the individual with the health and safety needs of the community, the task force works to provide individuals and organizations in the region with the tools they need to successfully overcome this challenging issue.
Philadelphia Hoarding Task Force

• Ways PHTF can support implementation of Hoarding Support Services

Training Statewide

Pilot Hoarding Program

Ongoing Consultation & Support
PATHWAYS TO A HEALTHY & SAFE HOME

Initial Benchmarks

- Clear 3 feet wide pathways throughout the home including hallways and stairs.
- Reduce all piles to no more than 4 feet above the floor.
- Reduce all piles near windows to below window all height and keep windows accessible so they can be opened.
- Keep all doors clear of belongings, so that they can be opened freely.
- Keep the stove and oven clear of clutter, so that the oven door can open completely. Keep paper and other flammable materials at least 1 foot away from the stovetop.
- Keep belongings at least 1 foot away from heaters, heating equipment, hot water heaters and electrical panels.
- Regularly remove rotten food, food containers and garbage from the home.
- Keep outlets, surge protectors and extension cords clear of clutter. Do not run extension cords across piles or pathways.

Once you've got these covered, you're well on your way to a healthy and safe home! Remember, if your home also has structural, electrical, plumbing or infestation issues, then there will be some additional steps to take to ensure a healthy and safe home.
Where to access services

HOARDING SUPPORT PROGRAM

"IT'S BEEN A LONG HAUL. MY POSSESSIONS – OLD MAIL, BOOKS, CASES OF SODA, MULTIPLE BOTTLES OF PEROXIDE, THOUSANDS OF CD'S, AND SO, SO MUCH ELSE – THREATENED TO DROWN ME. JFCS PROVIDED GUIDANCE AND HANDS-ON ASSISTANCE OVER A LONG PERIOD TO MAKE THAT SEA RECEDE AND ORDER BE FOUND. TODAY THAT JOURNEY CONTINUES."

JFCS CLIENT

Courtney Owen, LCSW  |  Director, Individual & Family Services
Pronouns: she/her/hers
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