



Opening '24 Doors Together

Accessible Housing:

A Human Right

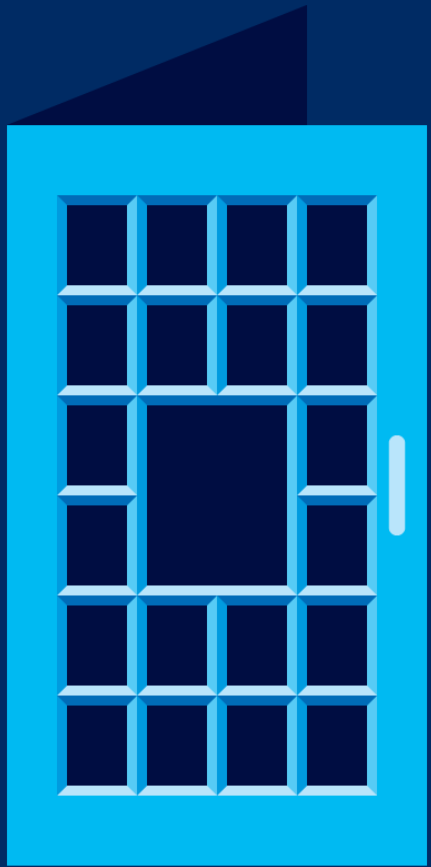
Inglis Self-Determination Housing of PA Statewide Housing Conference

Presented By



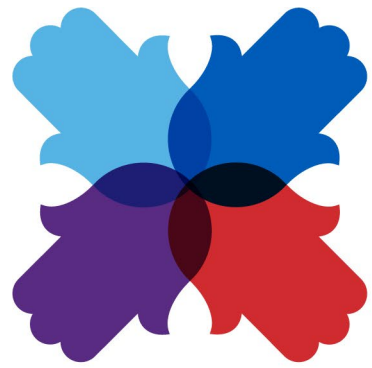
In Partnership With





Hoarding Disorder: Sustainable Solutions

JFCS Hoarding Support Program



JFCS

Do
Good,
Well.

Hoarding Support Program

Dara Leinweber, Hoarding Program Coordinator

Gabe Halperin-Goldstein, Hoarding Care Manager

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



Stigma

What do you think of when you see or hear of
someone hoarding?

won't change

dirty

doesn't try

not trying

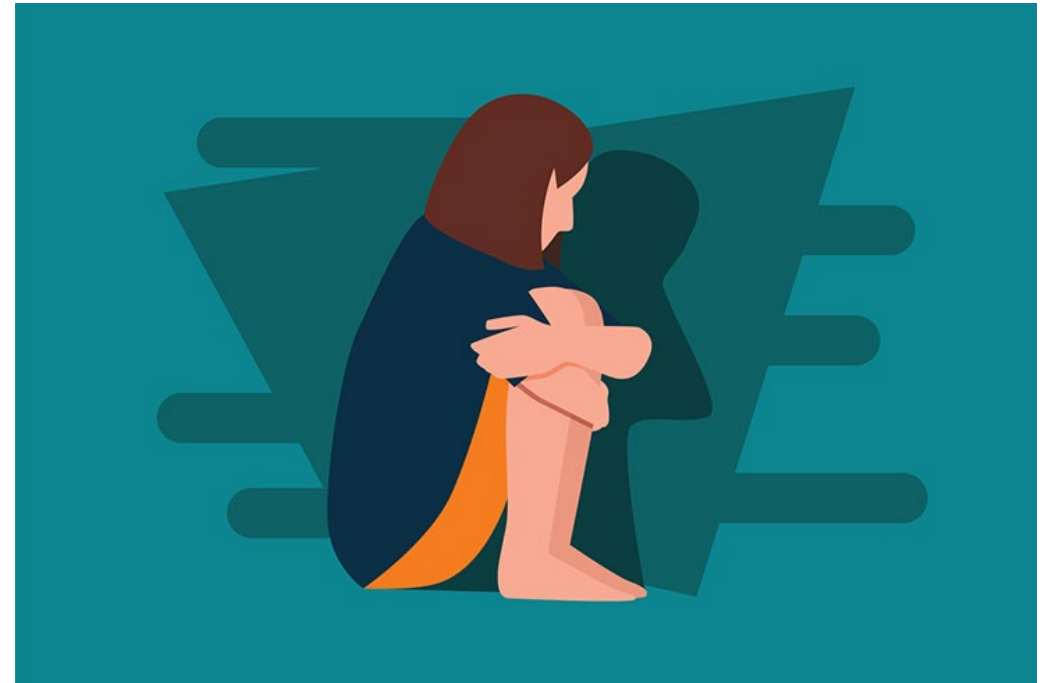
disgusting

lazy

sick

Consequences of Stigma

- Waste of money, time
- Burn out
- Lost relationships
- Anger, mistrust, guilt
- Shame, embarrassment
- Recidivism
- **Trauma**



A little experiment

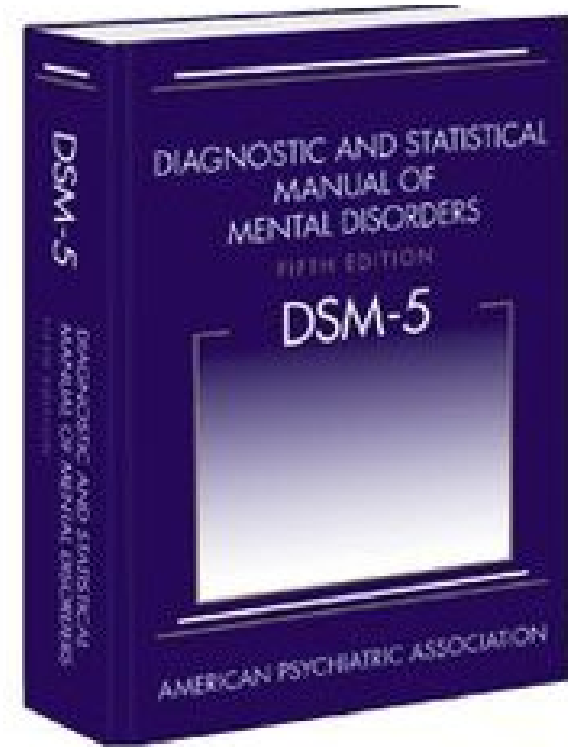
- Choose one item you have near you that you value, but is not the most important/cherished item you own.
- Throw that item away....don't think about it just throw it away, it has no value. Its trash.
- Ponder how that felt...
- Share your feelings, thoughts, what item did you throw away? On a scale 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



DSM-5
2013

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Hoarding Prevalence

- 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.



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PREHISTORIC HOARDER



COVERED HEATING VENTS
MAY CAUSE FIRES

HOARDING MAY IMPEDE
FIRST RESPONDERS

BIOLOGICAL FLUIDS MAY
CONTAIN PATHOGENS

HEAVY LOADS MAY
LEAD TO COLLAPSE

UNTREATED MOISTURE MAY
WEAKEN FLOORBOARDS

CLUTTER MAY BLOCK EXITS
IN CASE OF EMERGENCY

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

Psychotherapy:

- Most common is CBT
- Typically provided in office

Medication:

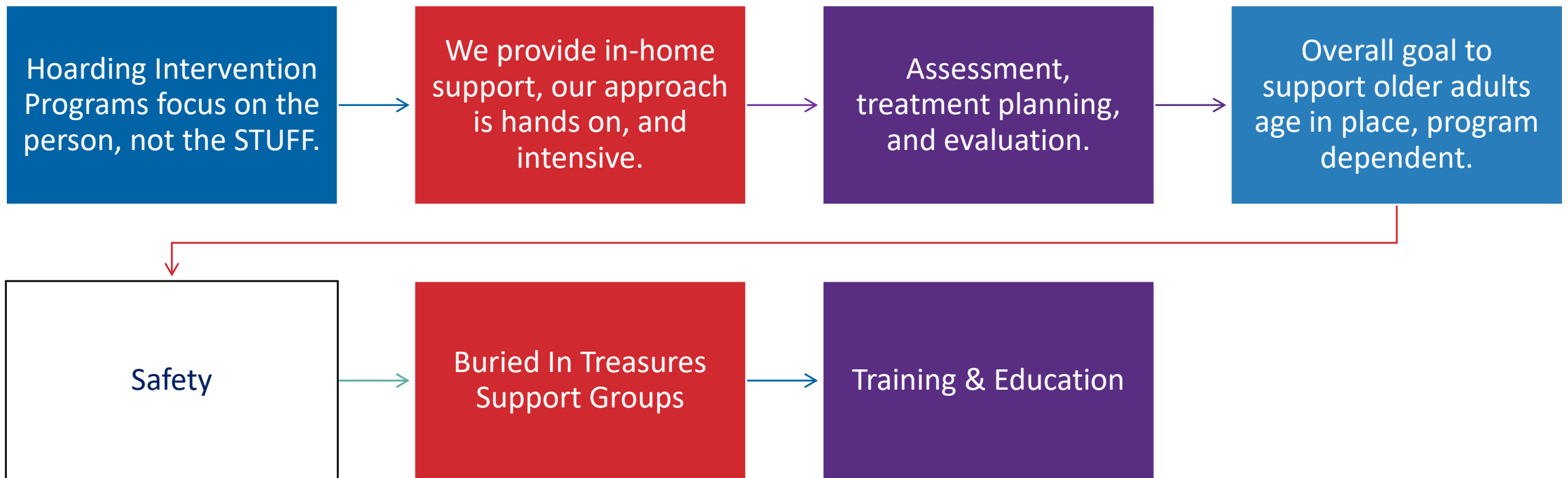
- SSRI typical use, common treatment in OCD
- Not enough research for effective use



Questions ⁽¹⁾



What does the JFCS Hoarding Intervention Programs do?



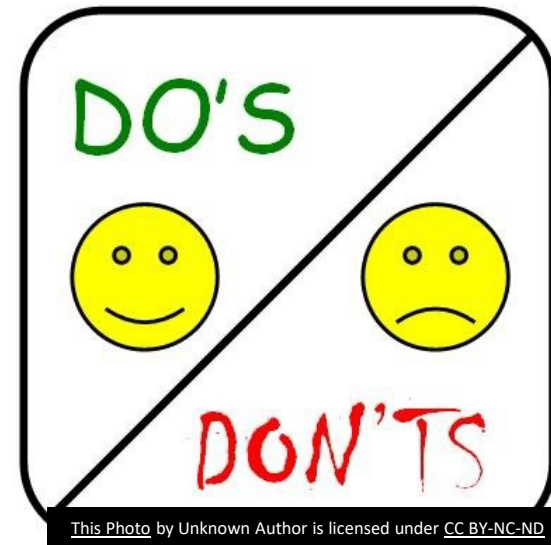
Engagement

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 perceivably valuable items, even well intended suggestions may have a negative impact.
- **DON'T** touch personal possessions with permission.



Team-Building

- 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

Support

Enforcement



Assessment

Name of Assessment tool	Use	Frequency
Clutter Image Rating (CIR)	a 4 or higher would indicate the need for support	Quarterly
Activities of Daily Living- Hoarding (ADL-H)	a 1.5 or higher score would indicate the need for support	Quarterly
Home Environment Index (HEI)	assesses for squalor in the home. This tool alone would not indicate hoarding, but does assess for sanitary concerns in a hoarded home.	Quarterly
HOMES Multi-disciplinary Hoarding Risk Assessment Tool	to determine the level and/or type of services needed upon initial assessment	Initial, Discharge
Hoarding Initial Assessment Tool	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	Initial
PHTF Initial Benchmarks for a Safe and Healthy Home	Developed by the PHTF as a tool to guide the process, not an evaluative tool for assessment.	As needed by member or provider

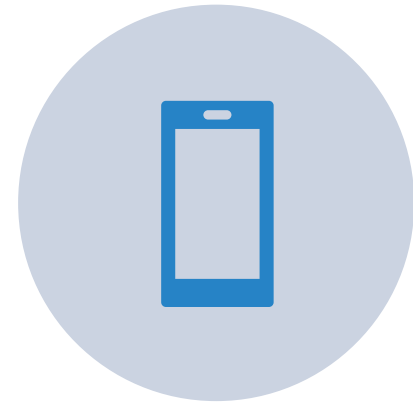
Assessment Tools



CLUTTER IMAGE
RATING



HOME ENVIRONMENT
INDEX



ACTIVITY OF DAILY
LIVING-HOARDING

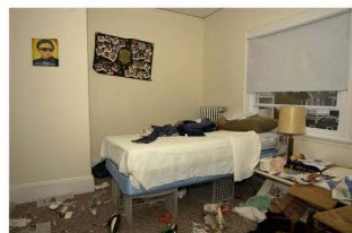
Example Assessment Tool: CIR

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



8



9

ADL-Hoarding

Activities of Daily Living in Hoarding

Sometimes clutter in the home can prevent you from doing ordinary activities. For each of the following activities, please circle the number that best represents the degree of difficulty you experience in doing this activity because of the clutter or hoarding problem. If you have difficulty with the activity for other reasons (for example, unable to bend or move quickly due to physical problems), do not include this in your rating. Instead, rate only how much difficulty you would have due to hoarding. If the activity is not relevant to your situation (for example, you don't have laundry facilities or animals), check the Not Applicable (N/A) box.

Activities affected by clutter or hoarding problem	Can do it easily	Can do it with a little difficulty	Can do it with moderate difficulty	Can do it with great difficulty	Unable to do	N/A
1. Prepare food	1	2	3	4	5	6
2. Use refrigerator	1	2	3	4	5	6
3. Use stove	1	2	3	4	5	6
4. Use kitchen sink	1	2	3	4	5	6
5. Eat at table	1	2	3	4	5	6
6. Move around inside the house	1	2	3	4	5	6
7. Exit home quickly	1	2	3	4	5	6
8. Use toilet	1	2	3	4	5	6
9. Use bath/shower	1	2	3	4	5	6
10. Use bathroom sink	1	2	3	4	5	6
11. Answer door quickly	1	2	3	4	5	6
12. Sit in sofa/chair	1	2	3	4	5	6
13. Sleep in bed	1	2	3	4	5	6
14. Do laundry	1	2	3	4	5	6
15. Find important things (such as bills, tax forms, etc.)	1	2	3	4	5	6

HEI

Home Environment Index

Date: _____

Clutter and hoarding problems can sometimes lead to sanitation problems. Please select the answer that best fits the current situation in the home.

To what extent are the following situations present in the home?

1. Fire hazard
 - ☐ 0 = No fire hazard
 - ☐ 1 = Some risk of fire (for example, lots of flammable material)
 - ☐ 2 = Moderate risk of fire (for example, flammable materials near heat source)
 - ☐ 3 = High of fire (for example, flammable materials near heat source; electrical hazards, etc.)
2. Moldy or rotten food
 - ☐ 0 = None
 - ☐ 1 = A few pieces of moldy or rotten food in kitchen
 - ☐ 2 = Some moldy or rotten food throughout kitchen
 - ☐ 3 = Large quantity of moldy or rotten food in kitchen and elsewhere
3. Dirty or clogged sink
 - ☐ 0 = Sink empty and clean
 - ☐ 1 = A few dirty dishes with water in sink
 - ☐ 2 = Sink full of water, possibly clogged
 - ☐ 3 = Sink clogged with evidence that it has overflowed onto counters, etc.
4. Standing water (in sink, tub, other container, basement, etc.)
 - ☐ 0 = No standing water
 - ☐ 1 = Some water in sink/tub
 - ☐ 2 = Water in several places, especially if dirty
 - ☐ 3 = Water in numerous places, especially if dirty
5. Human/animal waste/vomit
 - ☐ 0 = No human waste, animal waste, or vomit visible
 - ☐ 1 = No human waste or vomit; no animal waste or vomit outside cage or box
 - ☐ 2 = Some animal or human waste or vomit visible (for example, in unflushed toilet)
 - ☐ 3 = Animal or human waste or vomit on floors or other surfaces
6. Mildew or mold
 - ☐ 0 = No mildew or mold detectable
 - ☐ 1 = Small amount of mildew or mold in limited amounts and expected places (for example, on edge of shower curtain or refrigerator seal)
 - ☐ 2 = Considerable, noticeable mildew or mold
 - ☐ 3 = Widespread mildew or mold on most surfaces
7. Dirty food containers
 - ☐ 0 = All dishes washed and put away
 - ☐ 1 = A few unwashed dishes
 - ☐ 2 = Many unwashed dishes
 - ☐ 3 = Almost all dishes are unwashed

Questions ⁽²⁾

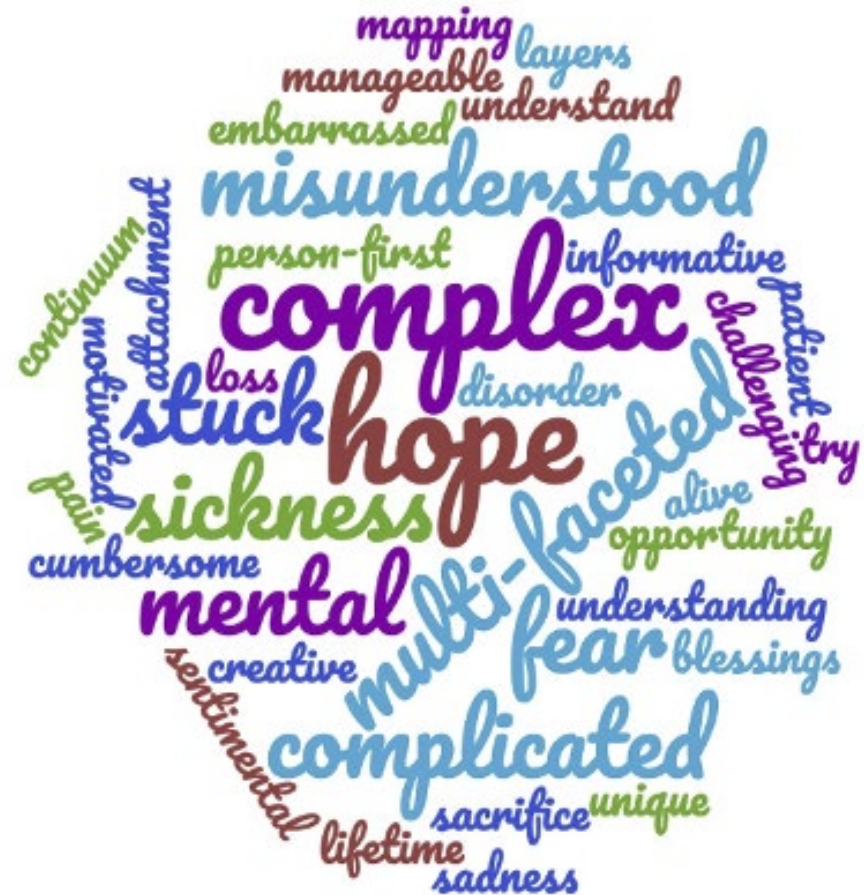


Philadelphia Hoarding Task Force (PHTF)

Mission

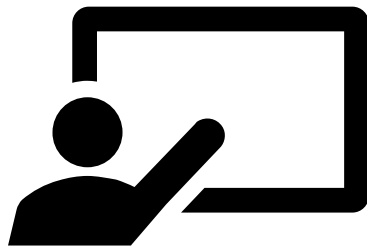
The Philadelphia Hoarding Task Force is a coalition that seeks to improve outcomes for people who hoard and reduce the catastrophic consequences related to hoarding for residents of the city of Philadelphia.

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.

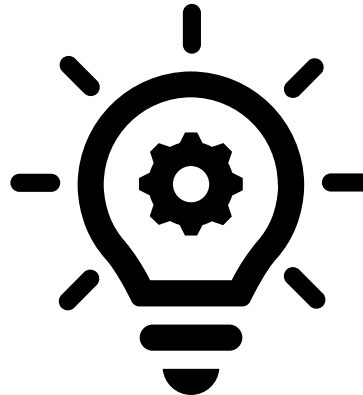


Philadelphia Hoarding Task Force

- Ways PHTF can support implementation of Hoarding Support Services



**Training
Statewide**



**Pilot
Hoarding
Program**



**Ongoing
Consultation
& Support**









PHTF PATHWAYS TO A HEALTHY HOME

PHILADELPHIA
HOARDING
TASK FORCE

PATHWAYS TO A HEALTHY & SAFE HOME

Initial Benchmarks

Start with these 8 goals to reduce risk and improve safety in your home.

- ☐  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 sill 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 all 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 rotting 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 ME GUIDANCE AND HANDS-ON ASSISTANCE OVER A LONG PERIOD TO MAKE THAT SEA RECEDE AND ORDER BE FOUND. TODAY THAT JOURNEY CONTINUES.”

- JFCS CLIENT

Gabe Halperin-Goldstein, LSW | *Hoarding Care Manager*

Pronouns: he/him/his

Jewish Family and Children’s Services of Greater Philadelphia

(c) 267.398.2940 | (f) 215-402-1007

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Dara Leinweber | *Program Coordinator*

Pronouns: she/her/hers

Jewish Family and Children’s Services of Greater Philadelphia

(c) 215.356.3083 | dleinweber@jfcsp Philly.org

www.jfcsp Philly.org | Care Navigation: 866-532-7669

Thank you for attending this session! Please take a moment to fill out this survey
(Also available in your program book)



Accessible Housing:

A Human Right