

# **Hoarding: A Collaborative Approach**

**JUNE 15TH, 2022**

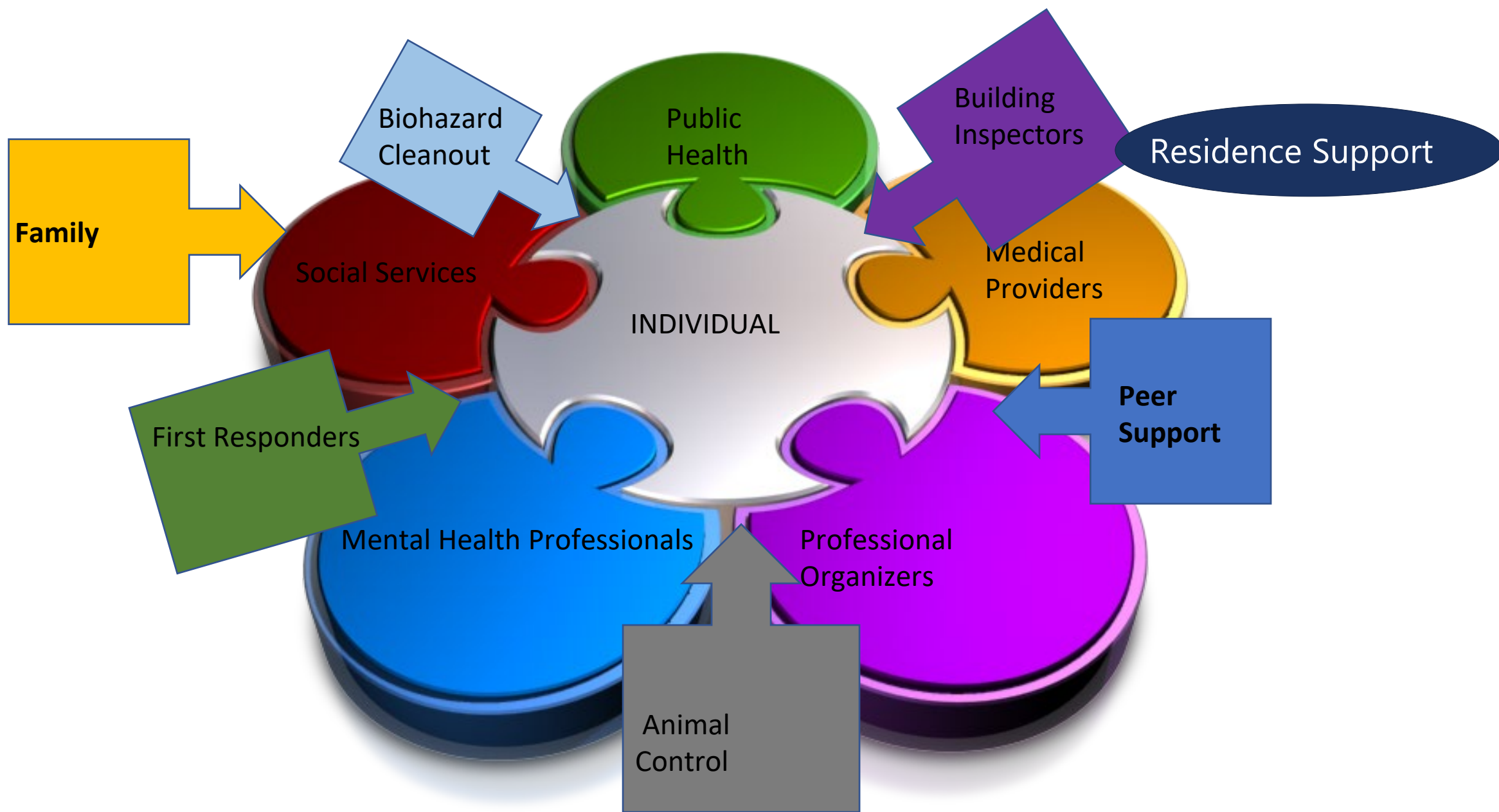
**MN World Elder Abuse Awareness Day Conference**

# **Presenters**

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Incoming President of the Minnesota Hoarding Task Force**

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Founding Member Minnesota Hoarding Task Force**

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Supervising Environmentalist  
Hennepin County Public Health Department**



# Learning Objectives

## **Occupational Therapist Perspective:**

- Define hoarding & describe common co-occurring conditions & risk factors.
- Associated positive personality traits
- Describe the addictive cycles of acquisition & avoidance

## **Professional Organizer Perspective:**

Become familiar with...

...strategies for one-on-one interaction

...a basic structure for hands-on work

## **Legal and Code Enforcement:**





# PROFESSIONAL REHABILITATION CONSULTANTS

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Our mission is to empower individuals living with mental illnesses or other chronic conditions to live a full, satisfying life through participating in meaningful daily activities.

# Hoarding Disorder & the DSM-5

- **Persistent difficulty discarding or parting with possessions, regardless of their actual value**
- **Difficulty is due to a perceived need to save the items and to distress associated with parting with them**
- **Accumulated possessions congest, block and clutter active living areas and substantially compromise the intended use of the rooms (if spaces are clear, it is due to the intervention of others)**
- **The hoarding behavior causes clinically significant distress or impairment in social, occupational, or other important areas of function**
- **The hoarding behavior is not caused by medical condition or a symptom of a mental health disorder**

**SPECIFIERS: with excessive acquisition, with good or fair insight, with poor insight, with absent insight/delusional beliefs**

# Differentiation of HD

- **Collecting:** Frequently organized, displayed, has limitations such as size, manufacturer, often valuable. Care is taken to preserve the items. (IOCD Foundation, 2021)
- **Clutter:** Unrelated items, usually disorganized, and often in storage areas. With HD, the clutter is due to excess acquiring and is likely in the living areas of the home and limits participation in daily activities, (IOCD Foundation, 2021)
- **Diogenes Syndrome (Squalor):** unsanitary conditions in the home. “It is most often found in elderly persons who have additional mental challenges, such as dementia. Squalor can sometimes occur as the result of HD, and sometimes occurs without HD. In HD, squalor occurs when the items saved include spoiled food and/or when animals are present. In many cases, squalor results from the neglect of normal cleaning activities.” (IOCD Foundation, 2021)

# **But what /S it?**

- **Mal-adaptive coping strategy with addictive components.**
- **Person with HD get's a HIGH when they find a treasure.**
  - **Feels like problem solving**
- **Person experiences a high level of RELIEF when the avoid discarding or sorting.**
  - **I will get to that when \_\_\_\_\_ happens**
- **Other Mal-adaptive coping strategies include:**
  - **Alcohol, gambling, eating disorders, gaming, self harm, ... you get the picture.**
- **A very lonely disease. Hoarding is an effective way to keep people away when boundaries are too porous. But it works too well.**

# **Risk Factors to new Onset**

**Interpersonal Violence**

**Home Break-ins**

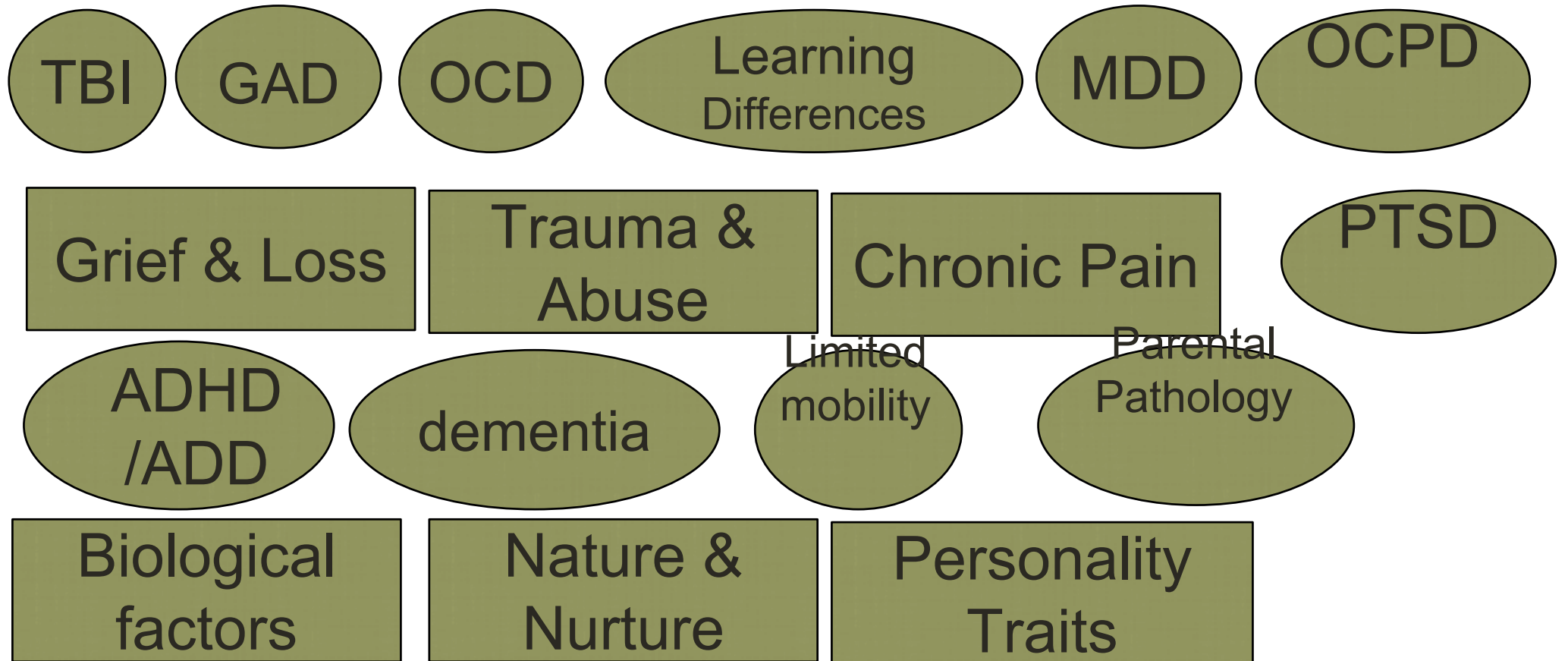
**Harsh Physical Discipline**

**Physical Abuse or Sexual Abuse**

**Relationship disruptions - *death of a parent, death of a child, divorce***

(Samuels, et al, 2008, Tolin, 2011)

# Co-Occurring Conditions/Risk Factors



# Associated Attributes

- High Sense of **Responsibility** (Donate, recycle, reuse, preserve, hold, repair, give to others, etc)\*
- Highly **Creative** (Many project ideas, alternative uses for many belongings, trouble executing)\*
- **Identity** found in objects (Occupation, Athletic Equipment, Fixer, Host, Books, Maker, Inventor, etc)\*
- Emotional Attachment through objects (sentimental, historical, familial, document )\*
- **Strong Visual and Spatial Memory** (belief that the item must be visible or it will be forgotten)
- Difficulty with Decision Making (thinking becomes overly creative)\*
- **Detailed Thinkers & Planners** (perhaps after events where control was lost\*)
- Unusually strong positive feelings associated with acquiring new objects\*
- **Curious** and have a variety of interests
- Expression of emotions through objects

# Statistics on Hoarding

- **Estimates are that 2-6% of all homes are hoarded, likely 19 million or MORE US homes.**
- **70% of people living with HD report symptoms started before age 20** (Cath, Nizar, Boomsma, Matthews, 2016)
- **Onset can develop in childhood and becomes more common with increased age. Hoarding symptoms baseline 2.6% then increase by 20% with each additional 5 years of age in older adults.** ((Cath, Nizar, Boomsma, Matthews, 2016)
- **Depression is not necessarily the cause of hoarding, but people with hoarding disorder often become depressed** (Tolin, Frost, Steketee, 2014)
- **People who are depressed often lack motivation and physical energy needed to resolve issues related to hoarding symptoms,** (Tolin, Frost, Steketee, 2014)
- **Gender statistics are mixed & most likely equal. More women than men seek help.**
- **Children as young as 4 have been found to express hoarding behavior.**

# ADLs Disrupted

- **Mal-adaptive coping strategy with addictive components**
- **Dressing – Bathing**
- **Eating/Feeding**
- **Sleeping**
- **Using the Bathroom**
- **Transferring (in and out of chairs, beds, tubs, toilets and cars)**



# IADLS Disrupted

- **Communication/Visiting**
- **Shopping/Duplicate purchases**
- **Preparing food**
- **Housekeeping/ Inability to create routines**
- **Laundry**
- **Managing medications**
- **Handling finances/Managing paperwork**



# Crisis vs Early Intervention

**Early intervention has the potential to reduce unnecessary pain and distress for individuals, families and communities.**

**Seeking help with early signs are less likely to disrupt housing.**



# **Predictive Behavior Associated with Crisis**

- **Refusal of help**
- **Isolation**
- **Denying access to the interior of dwelling**
- **Avoidance of the topic of personal possessions**
- **Excuses and justification for behavior (This is for my friend, If I don't buy the set- I can't have any of it, hiding purchases...)**

# Hoarding Related Consequences

- **Social Isolation (Ayers et al. 2010, Kim et al, 2001)**
- **Strained relationships (Tolin et al, 2008)**
  - **Family, Friends, landlords, neighbors**
- **Legal and financial problems**
  - **Credit card debt**
  - **High expenses (buying, storage fees)**
  - **Property damage - loss of investment/value of dwelling**

# Occupational Therapy & the Treatment of Hoarding Disorder

- Assess safety
- Navigate Buried in Treasures & other related resources.
- Support reframing for negative patterns of thought
- Teach & practice other coping strategies beyond acquiring & saving
- Teach & practice coping skills to tolerate anxiety, other symptoms & unpleasant emotions (Marval, 2019)
- Provide hands on and emotional support for remediation.



# Getting Ready to Assist

- **Get educated about HD & practice compassion**
- **Support safety, forgive, refocus (Tompkins, 2020)**
- **Meet as a team - understand the owner's goals & priorities (Tolin, Frost, Steketee, 2014)**
- **Don't take over decision making - let the person improve their decision-making skills (Tolin, Frost, Steketee, 2014)**
- **Listen: to directions, preferences, stories, & heartache**
- **Decrease accommodation & allow natural consequences (i.e.: paying for storage units, storing things in your home/office/car)**
- **Manage expectations & respect the person as they process major changes**
- **If dealing with a high volume of items, support ID'ing of categories that are cleared for recycling or donation (prepare to allow the person to double check your work)**
- **Record categories and locations to decrease anxiety about moving many objects. (Tolin, Frost, Steketee, 2014)**
- **Take breaks & plan rewards**
- **Respect your own limits**

## MN Hoarding Task Force

### All Volunteer Members & Board



- “Macro Work” (sorry, we are not a support group but can lead you to one).
- Expand & improve resources available to people impacted by hoarding including expansion of support groups, trained therapists, informed family and community members.
- Create a HUB for resources that serve Minnesotan’s impacted by hoarding
- Influence legislation, health care policies and societal attitudes in order to improve conditions for people who are impacted by hoarding
- Aim to reduce negative public attitudes and discrimination as it relates to people living with hoarding disorder through education and connection.  
[MNHTF.org](http://MNHTF.org)

# **System Improvement Needed**

- **Increase number of therapists and other mental health professionals who are trained to treat people with hoarding disorder**
- **Increase Screening for Hoarding Disorder.**
- **Improve Minnesota's resources dedicated to supporting people struggling with hoarding and related issues.**
- **Increase coordination of services by reducing the negative public attitudes and improve understanding of this and other Mal-adaptive coping strategies.**

# Support Peer-lead Support Groups

[Mutual-Support.org](https://Mutual-Support.org) offers facility guides for  
Buried in Treasures workshops

Clutterers Anonymous (CLA)

Spenders Anonymous

INFORMAL:

Facebook: ie: Tracy McCubbin

Other social media



# Web Resources

- The institute for Challenging Chronic Disorganization
- <https://www.challengingdisorganization.org/clutter-hoarding-scale->
- The Minnesota Hoarding Task Force     [MNHTF.org](https://mnhtf.org)
- IOCDF     <https://hoarding.iocdf.org/>
- Support

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Tompkins, M, (2020) *Helping people with hoarding disorder, alternatives to nagging, pleading and threatening*, Power Point presentation IOCD conference 2020.

# **Strategies for Working with People Who Experience Hoarding**

**Presented by Louise Kurzeka  
Everything's Together®**

Imagine

# Background

- Entered the organizing field in 1992
- Challenging clients begin to surface
- Needed to be more educated



# Keep in Mind what Hoarding Looks Like

- Excessive acquisition
- Great difficulty discarding
- Possessions are cluttered
- Distress is caused by the Issue



# One-on-One Interaction



- **Language is key - tone of voice**
- **Respect for possessions & nonjudgmental**
- **Be Direct and clear - Just the facts Ma'am**
- **Establish specific and manageable goals**
- **They always retain the power of choice**

# Safety First



Hazardous Locations- Identify and mediate combustibles and other issues as possible

# Safety First

## Blocked Exits

- Clearing walkways and doorways of clutter



# Safety First

- Pests

**Removing food sources  
that attract rodents and  
insects.**



# Easier to Discard Items

- Reading Material



- Excess Food



- Unused/Replaced Electronics



- Other



# Set a Staging Area – Consistent place to work



# Categorize, Contain, Label



# Assess Items One by One



# Assess Items One by One



# **One-on-One Work – Close the Session**

- **Review the progress**
- **Move items as close as possible to area of use**
- **Eliminate trash/recycle**
- **Have a plan for removing hazardous items**
- **Confirm next visit and area of focus**

# Communication Tools To Use

- Clutter Image Rating Scale - Google the name for free options
- ICD Clutter Hoarding Scale - [www.challengingdisorganization.org](http://www.challengingdisorganization.org)

## Clutter Image Rating Scale: Kitchen

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



1



2



3



4



5



6



7



8



9

# ICD: Clutter Hoarding Scale

	Structure and Zoning	Animals and Pests	Household Functions	Health and Safety	Personal Protective Equipment (PPE)
<b>LEVEL I</b>	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
<b>LEVEL II</b>	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
<b>LEVEL III</b>	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
<b>LEVEL IV</b>	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
<b>LEVEL V</b>	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

# Challenges Will Appear

- Staying in same location over time
- Co-morbid conditions add a twist
- Client impatient with progress
- Family impatient with progress
- Halt when “crisis” is averted
- May need to change out the person assisting



# Helpful Resources

- ICD Clutter Hoarding Scale: [www.challengingdisorganization.org](http://www.challengingdisorganization.org)
- Clutter Image Rating Scale: Google the name for free options
- Support Groups: <https://hoarding.iocdf.org/supportgroups/>
- Buried in Treasures: Help for Compulsive Acquiring, Saving, and Hoarding  
by David Tolin, Randy O. Frost and Gail Stekedee
- Stuff: Compulsive Hoarding and the Meaning of Things  
by Randy O. Frost and Gail Stekedee
- Compulsive Hoarding and Acquiring: Therapist's Guide  
by Gail Stekedee and Randy O. Frost

# Helpful Resources

- **Dirty Secret: A Daughter Comes Clean About Her Mother's Compulsive Hoarding** by Jessie Sholl
- **Don't Toss My Memories in the Trash** by Vickie Dellaquila
- **Overcoming Compulsive Hoarding: Why You Save & How You Can Stop**  
by Fugen Neziroglu, Jerome Bubrick and Jose Yaryura-Tobias
- **The Hoarding Handbook: A Guide for Human Service Professionals**  
by [Christiana Bratiotis](#), [Cristina Sorrentino-Schmalisch](#) and [Gail Steketee](#)
- **Digging Out: Helping Your Loved One Manage Clutter, Hoarding and Compulsive Acquiring** by Michael A. Tompkins and Tamara L. Hartl

# **Legal and Environmental Health Perspective**

**Joseph W. Jurusik, R.E.H.S.**

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**Hennepin County Public Health Department**

# **Public Health Nuisances (PHN) - Types**

- **Private Nuisances – disputes between neighbors**
- **Public Nuisances – concerns of cities, such as noise, junk cars, tall grass, etc.**
- **Public Health Nuisances – concerns of a Board of Health, or other delegated Health programs with an ordinance**

# PHN - Definitions What are the powers of a Board of Health

- **Stat.145A, Subd. 8. Removal and abatement of public health nuisances.**

(a) If a threat to the public health such as a public health nuisance, source of filth, or cause of sickness is found on any property, the board of health or its agent shall order the owner or occupant of the property to remove or abate the threat within a time specified in the notice but not longer than ten calendar days.

# PHN - Definition

- MN Statutes, Chapter 145A states it is the *“act or failure to act”* that affects the public’s health
- Only a board of health can determine and order abatement of a PHN using 145A
- Non-board of health departments write orders based on their local ordinance
- Must be abated within 10 calendar days

# **PHN – Definition Continued**

- **Notices must be handed to the violator, sent by certified mail or posted on the property**
- **Depending on the condition the property may need to be posted “unfit for habitation” and entry (i.e. for clean up) may be restricted**
- **Police may need to monitor to ensure it is not occupied**
- **Clearance inspection is needed for re-occupancy**

# **PHN – Practical “Working” Definition**

- **Has the potential to make people sick.**
- **Provides harborage or attracts vermin.**
- **Can cause injury to those directly exposed.**

# Who is Involved?

- Police
- Child/Adult Protection
- Animal Control
- City Housing Officials
- HAZ MAT Team
- Drug Task Force
- Health Agencies (Social Services)
- Fire Department
- Septic Company's
- Cleaning Company's
- City Councils
- Medical Responders
- Media
- Utility Company's (Gas and Electric)

# **Hoarding: Environmentally Why is it a Problem?**

- **Service workers not able to safely perform their job**
- **Clear access for emergency personnel**
- **Fire Load**
- **Infestations and vermin can migrate to neighbors' property**
- **Child and vulnerable adult health and safety**

# Hoarding: Why Do People Do It?

- Collections
- New Items
- Perceive Value
- Want to Recycle
- Great Deal



# Hoarding

- Not able to use the room for the purpose intended.



# Hoarding: Issues - Feces



# Hoarding: Issues - Access

- Blocked Exits and Windows
- No Clear Paths to Doors and Windows



# Hoarding: Clean Up



# Hoarding: Clean Up (continued)

- Clean up in progress
- Sometimes it is a process



# Hoarding: Cleanup Goal

- Hopefully We Go ...

From This



To This



# Hoarding: Managing the Case and Clean-up

- Take a co-worker or go with the Police to every visit, **NEVER go alone!**
- Many need a search warrant
- Document with notes
- Label and date all evidence
- Document with photos

# **Hoarding: Managing the Case and Clean-up (continued)**

- **Ask everyone you deal with for a business card for your records, and give your card out**
- **Keep copies of everything (i.e., invoices)**
- **Keep a calendar to track dates and time involvement, in case costs need to be assessed back to the property taxes, or for court appearances**

# **Hoarding: Managing the Case and Clean-up (continued)**

- **Evaluate the risk of personal injury**
- **Personal Protective Equipment (PPE)**
  - Tyvek suit
  - Boots or shoe covers
  - Niton 95 (N95) mask
  - Head gear (hard hat)
  - Eye protection

# **Hoarding:**

## **What if it is not clean after 10 days?**

- **Time may be extended (sometimes issues are beyond the control of the property owner)**
- **The Health Agency may decide to clean the property and assess the property taxes**

# **Hoarding: Why is MHTF and Env. Health Collaboration Important?**

- **Chance to discuss with other professionals who work with hoarding issues.**
- **Learn other's perspective on hoarding**
- **Finding out what each person's goals are and how we can help each other**
- **Support**

# Questions For The Panel?

