



# ENGAGING PEOPLE WHO HOARD

## A HARM REDUCTION APPROACH

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# OVERVIEW

- Hoarding behavior and hoarding disorder
- Definition of hoarding disorder and factors that influence harm potential
- Late-life hoarding and risk
- Help-refusal and harm potential
- Definition, rationale, and principles of harm reduction applied to hoarding clients who refuse help
- Strategies to engage hoarding clients who refuse help

# HOARDING DISORDER (DSM-5)

- Difficulty discarding or parting with objects
- Difficulty discarding due to urges to save
- Symptoms result in accumulation of possessions that clutter living areas
- Distress or interference resulting from behaviors
- Not better accounted for by medical conditions or other mental health conditions.



# HOARDING DISORDER OR NOT

- Organized collections of items
- Cluttered environment does not cause distress or interfere with activities of daily living
- Temporary situations resolved in six months



# HOARDING BEHAVIOR OR HOARDING DISORDER

- Hoarding behavior may be present in other medical or mental health conditions
- Dementia, head trauma, Prader-Willi syndrome, obsessive-compulsive disorder, eating disorders, autism spectrum disorder
- Careful assessment essential in helping clients who hoard

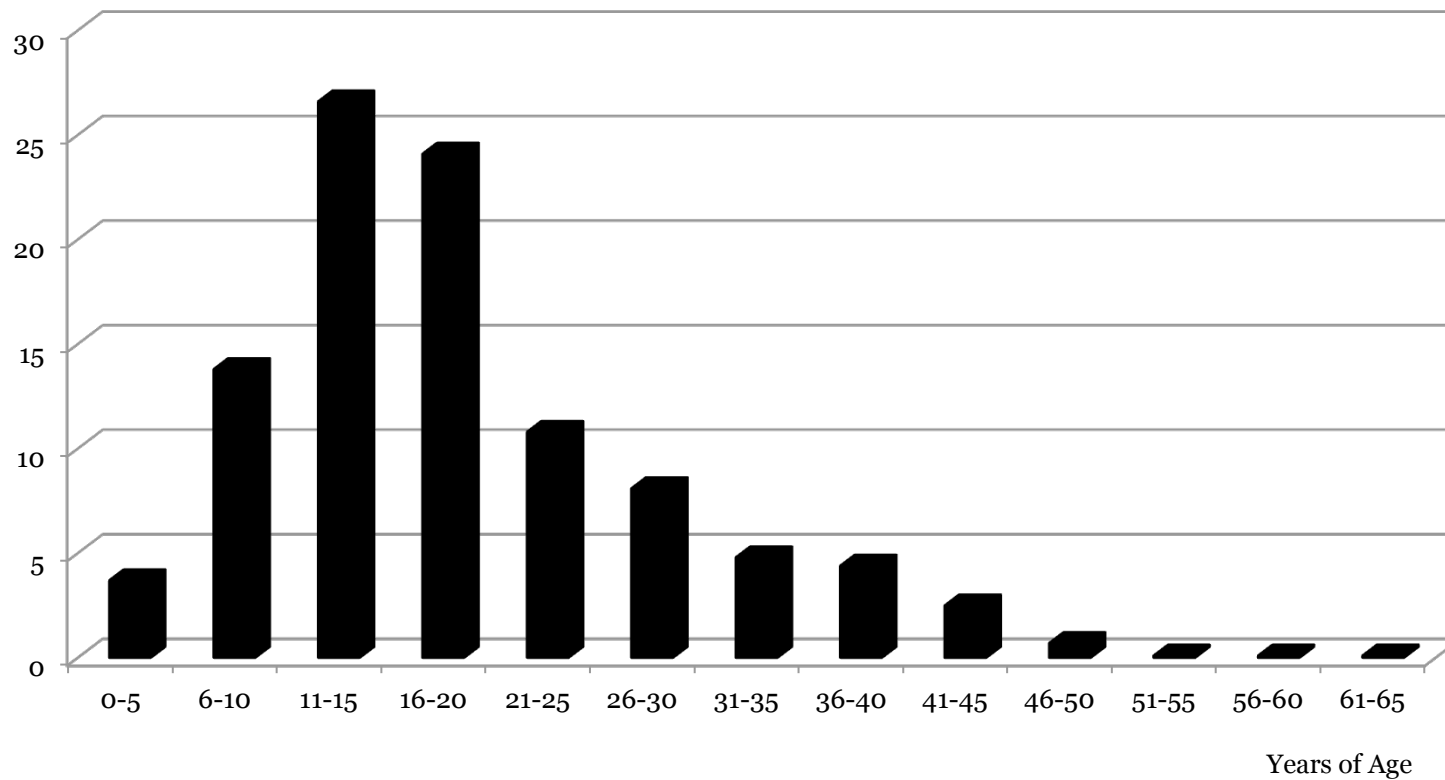


# CLINICALLY SIGNIFICANT HOARDING

- Appears to be increasing nationally (Steketee, Frost, & Kim, 2001)
- 2-5% general population
- Complex problem with multiple contributing causes and wide range of presentations, often undetected for many years



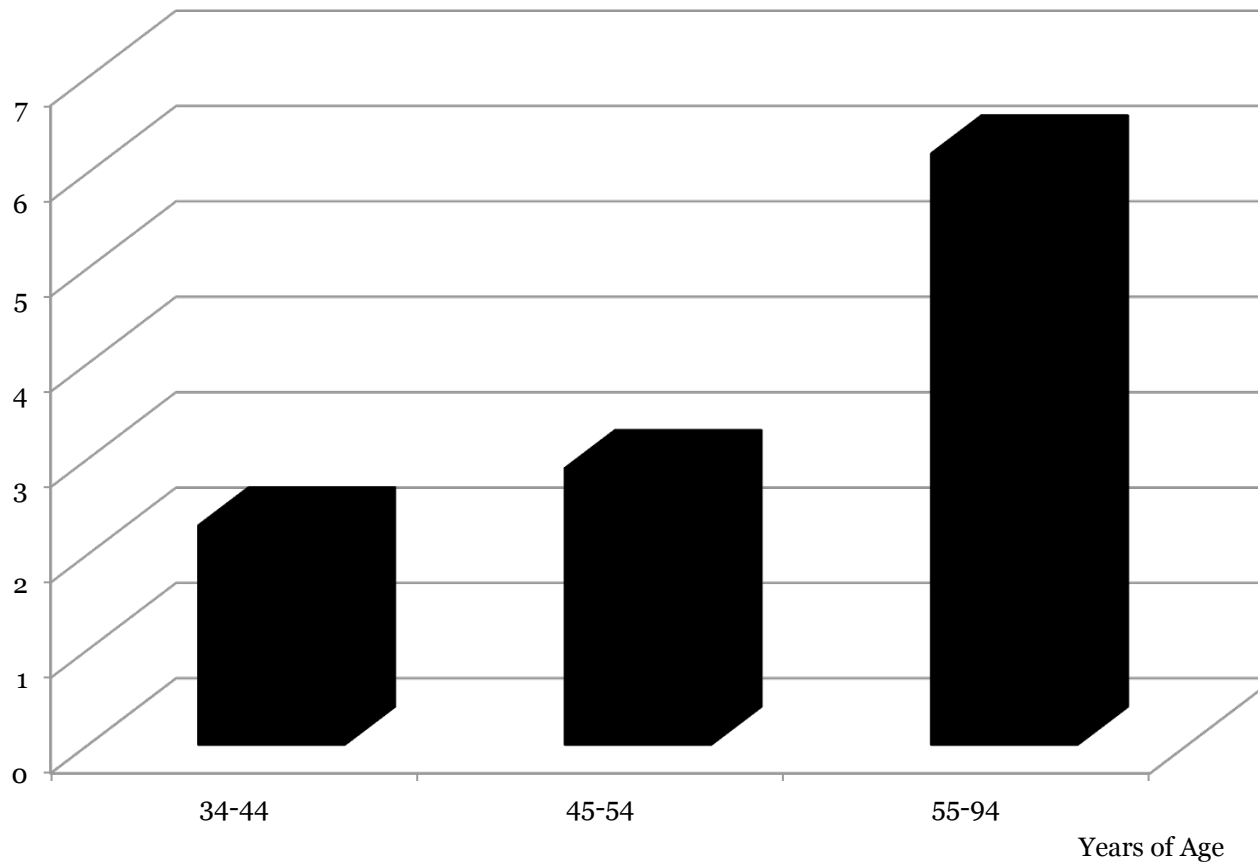
# AGE OF ONSET OF HOARDING



Tolin, Meunier, Frost, & Steketee (2011)



# PREVALENCE OF HOARDING BY AGE



Samuels et al. (2008)

# PREVALENCE OF LATE LIFE HOARDING

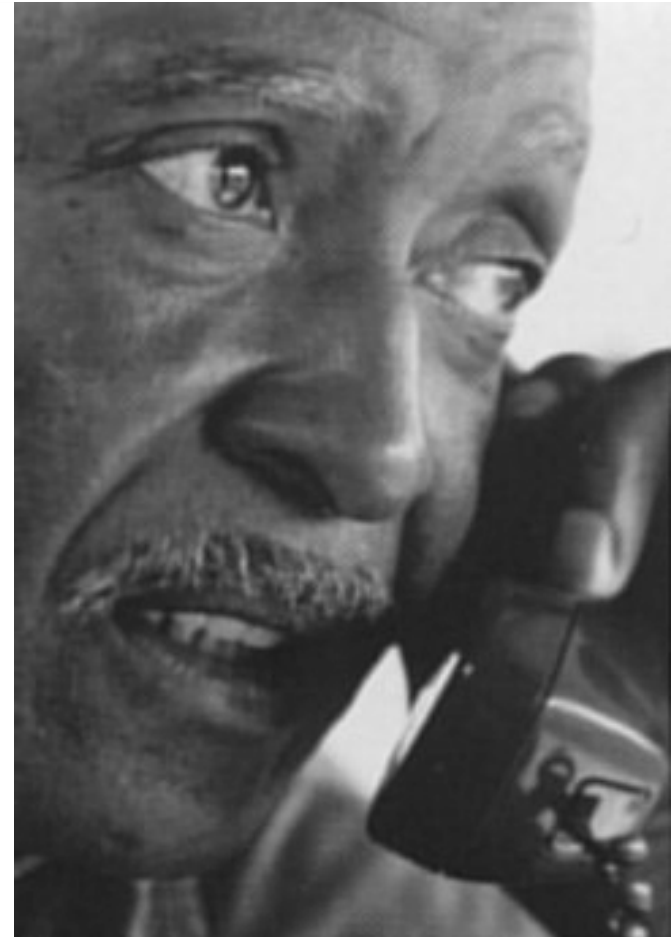
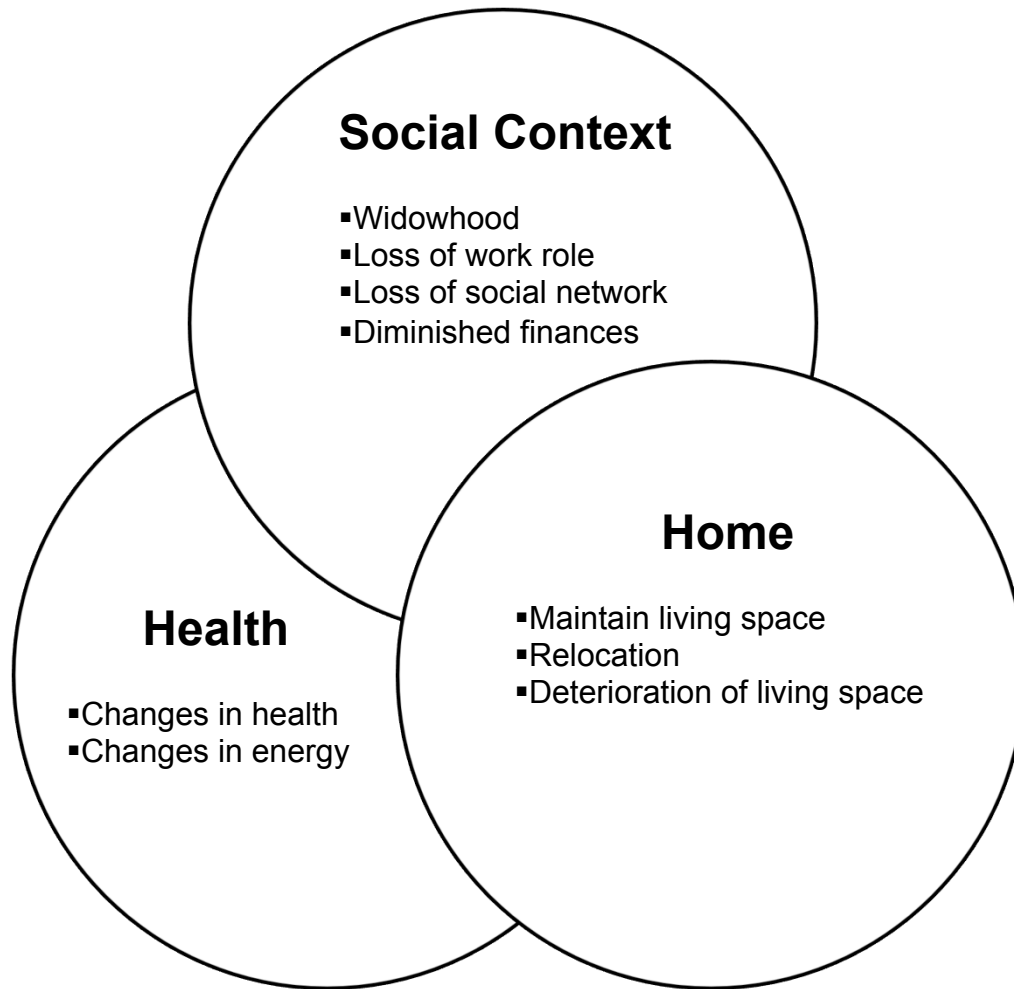
- > 40% of hoarding complaints to local health departments involved elder service agencies (Frost, Steketee, & Williams, 2000)
- Lifelong hoarding versus late-onset hoarding triggered by life changes (e.g., moving from larger to smaller residence, loss)



# MORE ABOUT LATE LIFE HOARDING

- No association between hoarding and material deprivation (Frost & Gross, 1993)
- Older clients may accurately assess extent of clutter but underestimate its harmfulness (Steketee et al. 2012)
- Hoarding prevalence higher among men than women (Iverolino et al., 2009)
- Unmarried older adults exhibit more severe clutter and greater impairment (Steketee et al., 2012)
- Late onset hoarding (>50 years) may result from undetected cerebrovascular events (Anderson, Domasio, & Domasio, 2010)
- Most late life hoarding clients are female, unmarried, and live alone (Steketee et al., 2012)
- Less acquiring in late life hoarding due to reduced mobility and means to acquire (Steketee et al., 2012)

# AGE-RELATED RISK FACTORS FOR PEOPLE WHO HOARD



# RISKS FOR OLDER ADULTS WHO HOARD

- Interference with Activities of Daily Living
- Increased isolation
- Increased conflict with others, loss of family support system
- Increased risk of eviction
- Increased risk of injury
- Increased difficulty managing chronic health conditions
- Increased risk of medication mismanagement
- Increase risk of food-related illnesses



# HOARDING DISORDER AND RISK OF EVICTION

(Rodriguez et al., 2012)

- 23% individuals seeking help for housing problems, including eviction met criteria for hoarding disorder
- 5 to 10 times higher than prevalence of hoarding disorder in the general population
- 32% currently threatened with imminent eviction
- 44% had history of previous legal eviction proceedings
- 20% evicted from home one or more times
- 48% currently seeking mental health treatment

# WHY THEY REFUSE HELP

- Fear of discovery
- Different solutions to the problem
- Hopelessness and depression
- Shame and humiliation
- Resentment, distrust, and defensiveness
- Poor insight



# FEAR OF DISCOVERY



- If the situation is private, your loved one may fear discovery and possible eviction
- Your loved one may fear loss of possessions
- Family members are afraid too, they fear discovery and possible eviction of their loved one, but also they fear for their loved one's safety and health



# DIFFERENT SOLUTIONS



- May admit a problem but wants to solve it in a different way (e.g., relocate rather than discard possessions; conditions necessary to discard)

# HOPELESSNESS AND DEPRESSION

- Believe real change is unattainable because problem returns
- Prior treatment did not help
- Individual exhausted from past treatment efforts (Linehan, et al., 2000)
- Ruminating about change but never doing it because of depression (Velasquez, et al., 1999)



# SHAME AND HUMILIATION

- Client may feel deeply ashamed of the condition of the home
- Client may have experience repeated shaming experiences from family members, neighbors, and the society at large (stigmatization)



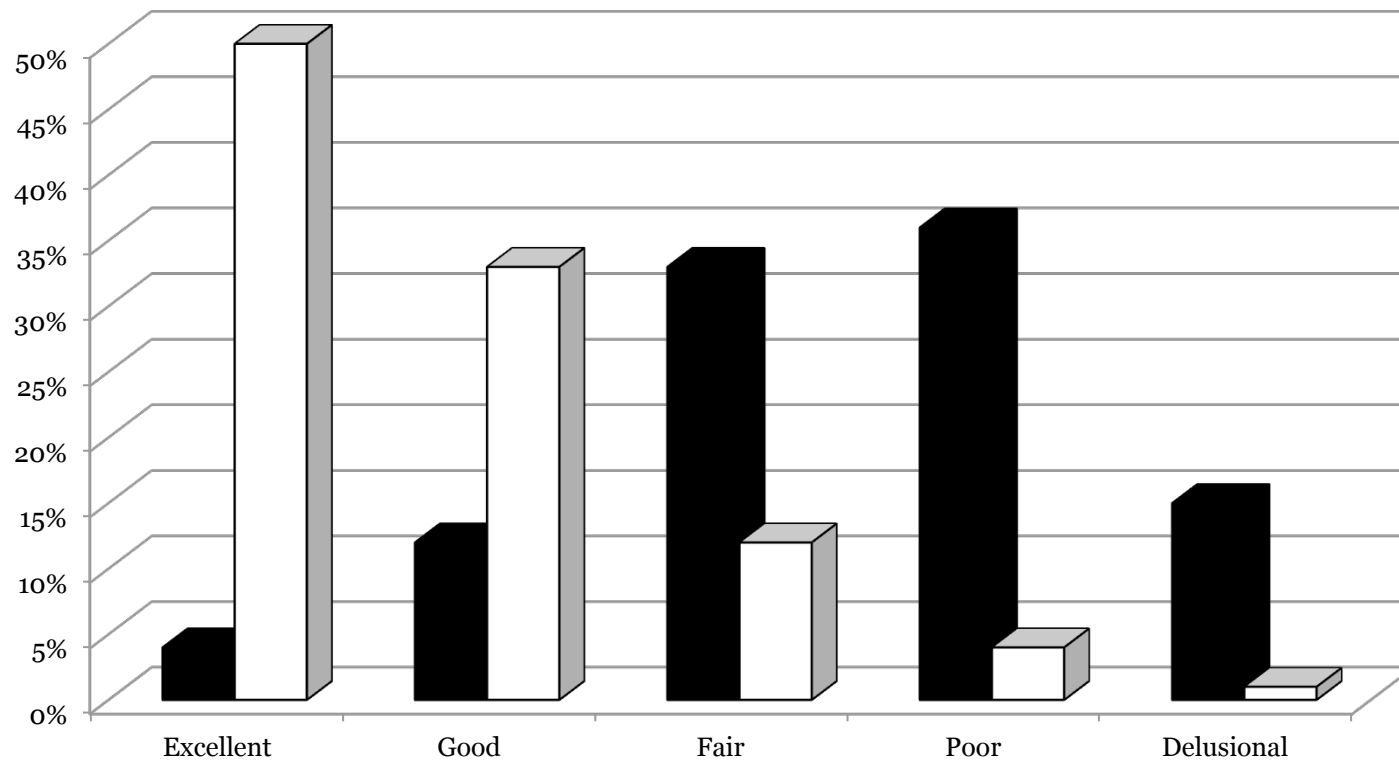
# RESENTMENT, DISTRUST, AND DEFENSIVENESS

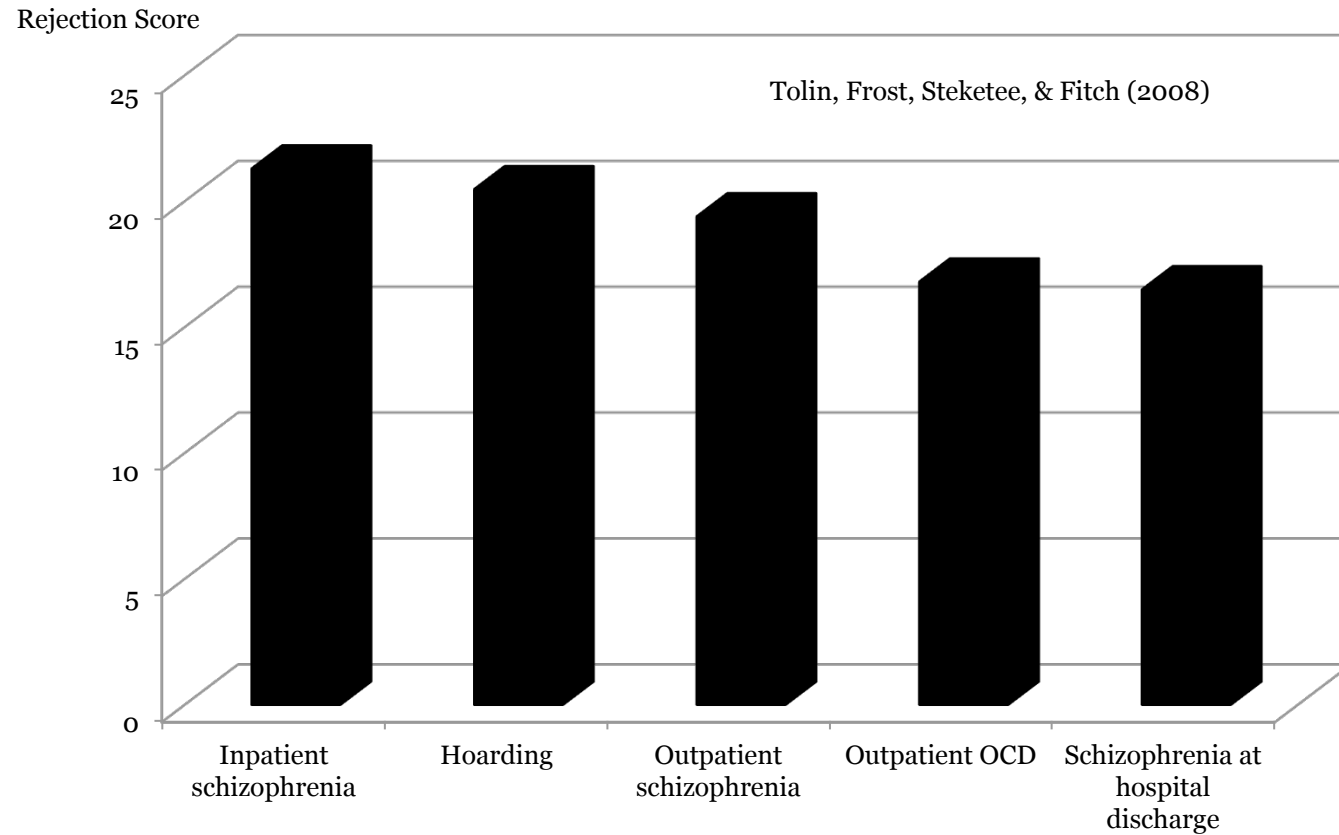
- Person who hoards may no longer ask for help because of past resentments, countless arguments, and much hurt with family members or others trying to help
- Eroded trust because of broken agreements about “helping”
- Past threats “I am going to call the landlord if you don’t let me help you get rid of some stuff”



# INSIGHT HOARDING VERSUS OCD

(TOLIN ET AL., 2010; FOA ET AL., 1995)





## INTERPERSONAL CONTEXT OF HOARDING

PEOPLE WHO HOARD EXPERIENCE CRITICISM AND REJECTION

# NATURE OF LOW INSIGHT

- **In schizophrenia**, unawareness of illness may result from significant and persistent neurocognitive deficits (deficits in abstract and flexible thinking and other executive functions) -- severity of impairments in executive function predict persistence of deficits in awareness (Marks et al., 2000; Lysaker, 1995)
- **In schizophrenia**, unawareness of illness may reflect a particular style of coping – people actively avoid recognizing the deficits associated with the illness or reappraise the deficits to minimize distress (Bassman et al., 2000)

## ROLE OF BOTH FACTORS ON INSIGHT IN SCHIZOPHRENIA (LYSAKER ET AL., 2002)

- Link between lack of insight and poor executive function
- Different coping strategies associated with different domains of insight
- People unaware of symptoms show greater preference for positive appraisals than those partially unaware or aware
- People unaware of the consequences of illness show greater preference for escape-avoidance as coping style than those partially unaware – may use positive reappraisal to interpret their symptoms but still not grasp the consequences of the illness



# RELEVANCE TO PEOPLE WHO HOARD

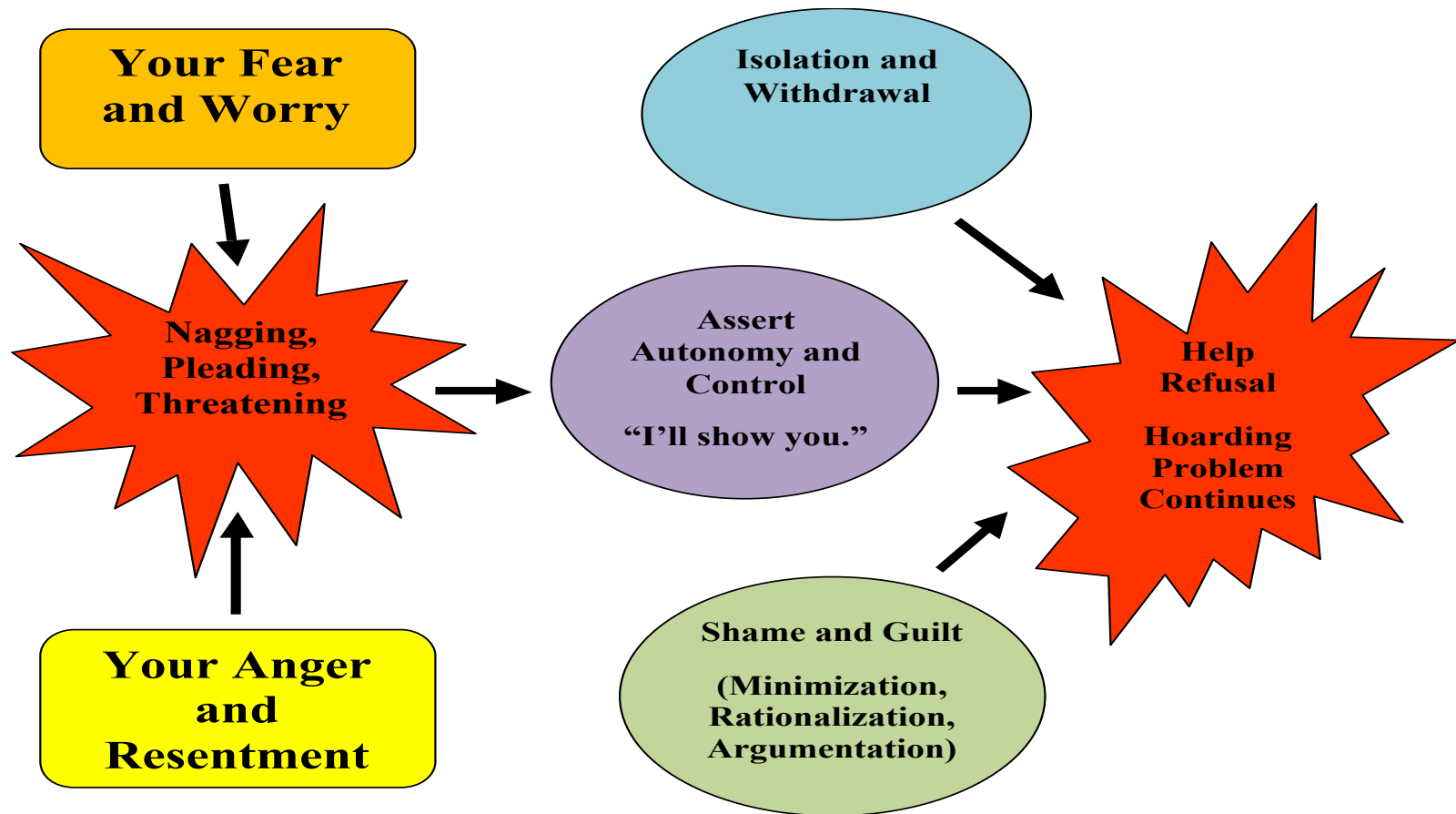
- People with partial unawareness may represent a more complex state influenced by neurocognitive and situational factors – such as familial attitudes or social conditions
- Partial unawareness of an illness – therefore – is not a lesser degree of unawareness
- Illness awareness may be on a continuum, from aware to unaware and those partially aware are not less unaware
- Even those with significant neurocognitive deficits may cope, to some degree, through positive reappraisal and escape-avoidance

# LOW INSIGHT MAY IN PART REFLECT ACTIVE COPING

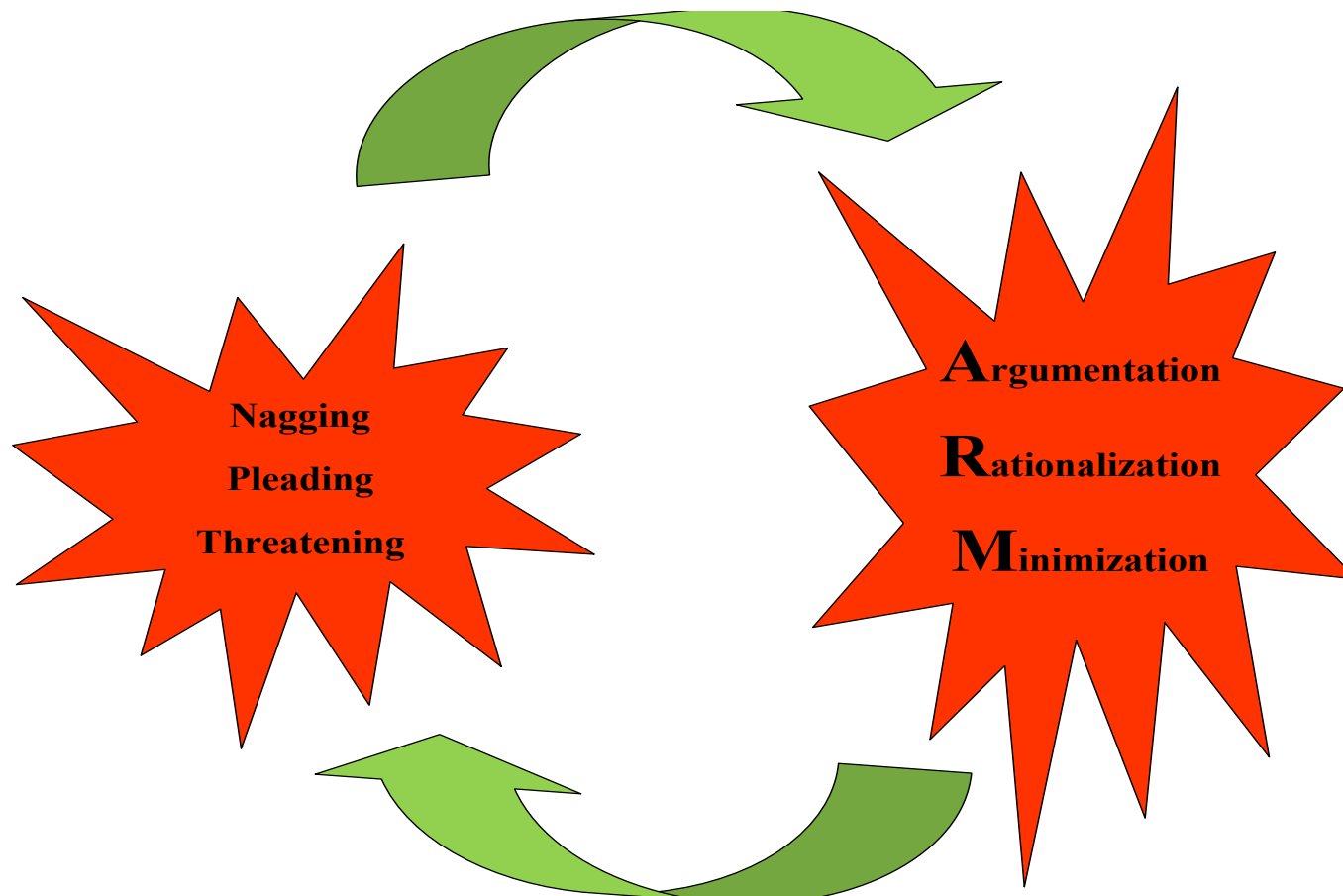


- Defensiveness (“Go away.”)
- Asserting self-determination (“I can do it myself.”)
- Rationalizations and minimizations (“It’s not that bad.”)
- Positive re-appraisals (“I’m not a hoarder, I’m a collector.”)

# DO NAGGING, PLEADING, AND THREATENING WORK?



# THEY ARM THEMSELVES



# ENGAGEMENT STRATEGIES



- Place problem outside person
- Use motivational interviewing to engage client throughout process
- Use appropriate pressure (e.g., modified cleanout and harm reduction as leverage)
- Work with family, friends, neighbors to decrease stigmatization
- Harm reduction

# PLACE PROBLEM OUTSIDE PERSON



- Avoid using you or your –  
“You have got to get rid of some stuff” Instead try, “I want to help you declutter your bed.”
- Refer to the stuff as the problem not the person –  
“This stuff makes it hard for me to have the relationship I want with you.”

# SELF-DETERMINATION, MOTIVATION AND ENGAGING THE CLIENT WHO HOARDS

- Self-determination theory postulates that motivation to change is influenced by the need for personal autonomy, the need for relatedness, and the need for competence
- Harm reduction approach assumes that the client can and will make his or her own decisions, fosters relatedness through empathy, mutual respect, and understanding, and enhances competence through realistic goal setting
- Motivation enhanced through a trusting, supportive relationship

# PRECONTEMPLATORS

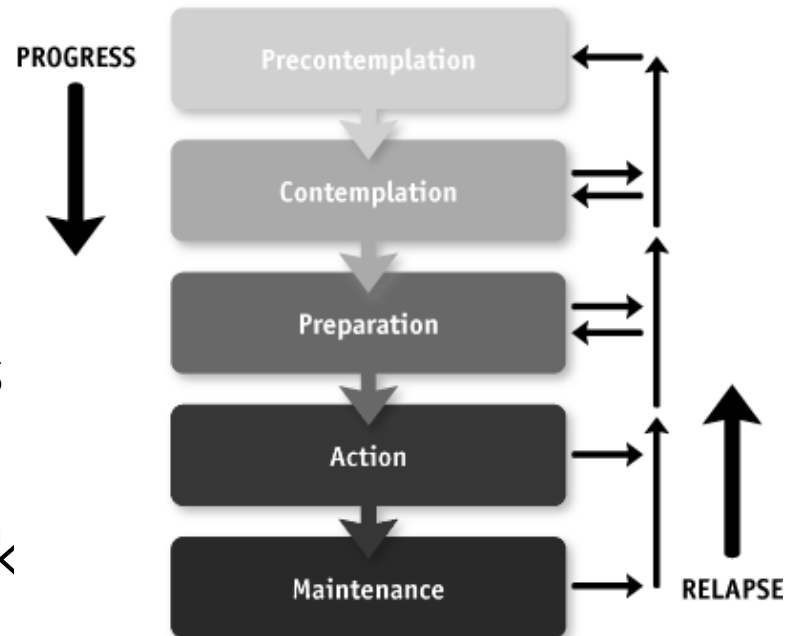
- **Reluctant precontemplator** – May have little information about the problem. Passively (rather than actively) resistant. Careful listening and providing feedback in a sensitive empathic manner is helpful.
- **Rebellious precontemplator** -- Often have a great deal of information about the problem but they do not like being told what to do. They argue and offer many reasons that they will not change. Provide freedom to express while directing their energy in a positive direction, “No one can force you to change and I would never dream of trying.”
- **Resigned precontemplator** -- Has surrendered to hoarding situation and is overwhelmed and given up on possibility of change. Instilling hope is crucial to these people.
- **Rationalizing precontemplator** -- Has all the answers or minimizes or rationalizes, “It’s not that bad,” or “I’m careful.” May believe behavior is result of a situation (Great Depression) or another person (My mother never let me have anything of my own). Reflective listening and start by asking client to tell you good things about the hoarding behavior.



# KEY MOTIVATIONAL INTERVIEWING STRATEGIES

(MILLER & ROLLNICK, 1991)

- Develop discrepancy
- Roll with resistance
- Express empathy
- Support self-efficacy
- Reflective listening
- Open-ended questions
- Summarize
- Encourage change talk



# WAYS TO SHUT DOWN MOTIVATION

- Focus prematurely on hoarding behavior rather than other problems person more concerned about (isolation, health, family)
- Argue about what to keep and what to discard, about the pace of progress, about contract failures
- Label the problem when the person does not find this helpful
- Blame client or side with client against others

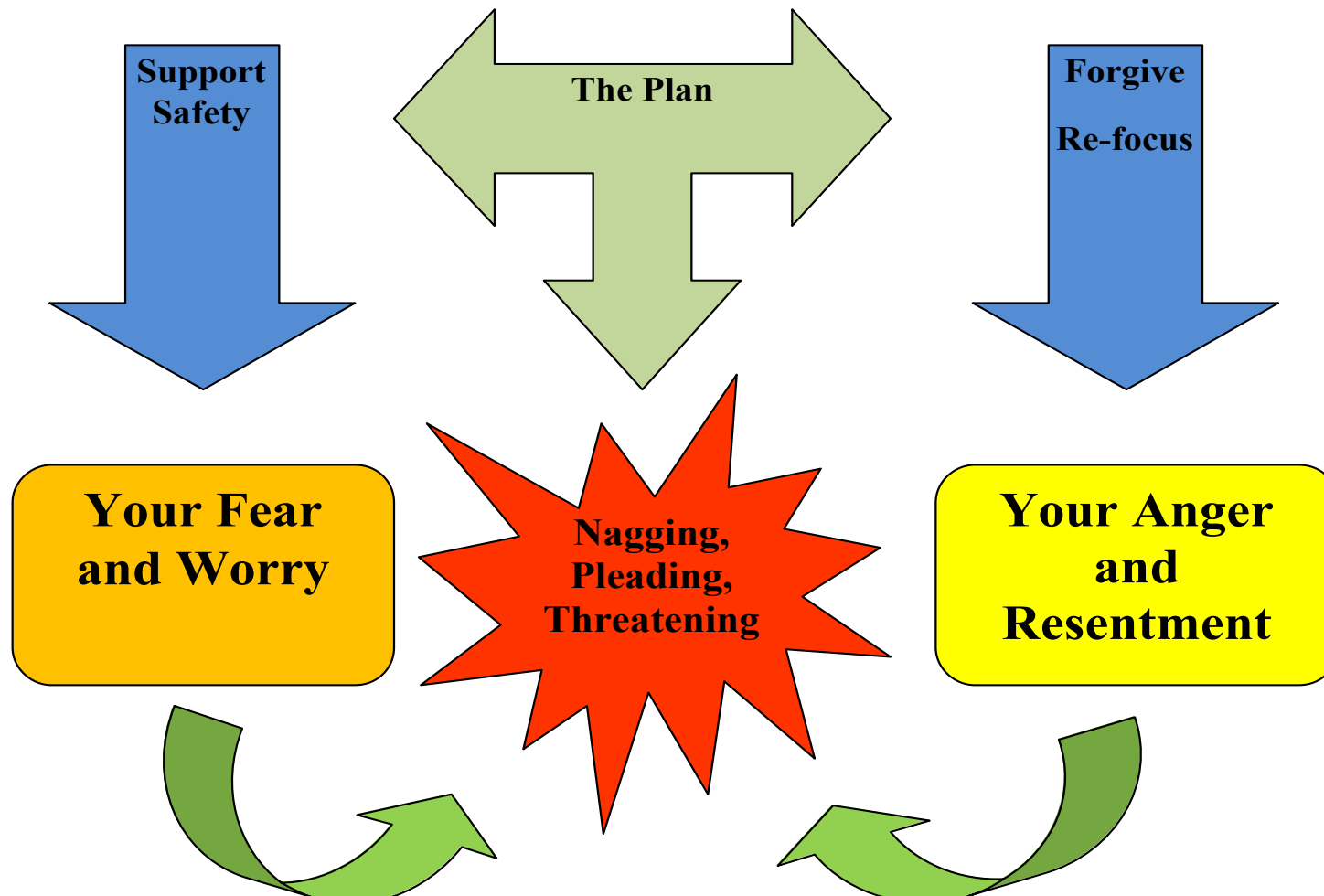
# WORKING WITH OTHERS TO ENGAGE CLIENT IN HARM REDUCTION PROCESS

- Other team members as participants in motivational interviewing with client
- Motivational interviewing with dyads with team members (that may or may not include client)
- Motivational interviewing that targets specific dyadic interactions

# WORK WITH FAMILY, FRIENDS TO DECREASE MISTRUST, DEFENSIVENESS

- Family-as-Motivators training associated with decreased negative impact of hoarding on family well-being, less negative coping, more hopefulness, and less family accommodation; Families reported ~25% decrease in hoarding severity (Chasson et al., 2013)
- Brief Family Consultation approach associated with decrease in family accommodation, no change in quality of life and help seeking of treatment refuse relative to control family education group; 45% of families reported hoarding as either a primary or secondary problem in the identified treatment-refuser (Pollard, 2012)
- CRAFT as applied to hoarding

# FAMILIES LEARN TO DISARM



# THE PLAN

- Develop a Road Map for Change
- Solve Problems Along the Way
- Improve Communication with the Loved One
- Increase Help Acceptance a Step at a Time
- Take Care of Yourself
- Forgive and Support Safety

# PIUS COMMUNICATION

- **P**ositive statement
- **I** statement
- **U**nderstand statement
- **S**hare the responsibility statement

Meyers, R. J., Miller, W. R., Hill, D. E., & Tonigan, J. S. (1999). Community reinforcement and family training (CRAFT): Engaging unmotivated drug users in treatment. *Journal of Substance Abuse*, 10 (3), 291-308.

# POSITIVE STATEMENTS

## With the sting

- **You** shouldn't take that home.
- **You** are a slob.
- **You** never listen to me when I'm talking to you.

## Without the sting

- **I** would be so happy if you would leave that here.
- **I** worry that the state of your home makes it hard for you to keep yourself clean.
- **I** understand that some of our discussions are upsetting, but I'd love if we could work them out together.



# ASSERTIVENESS

- Step 1 – Describe problem behavior in a neutral and objective manner, keep your cool and (remember to be PIUS)
- Step 2 – Describe how the problem behavior makes you feel (feelings are single words, sad, frustrated, guilty)
- Step 3 – Describe the change you desire
- Step 4 – Ask, “Would you do that for me?”
- Step 5 – State consequence (optional) if loved one refuses to comply (remember to be PIUS) after several requests or refuses out right

# FORGIVENESS

- Forgiveness is for you – forgive to help yourself let go of past resentments, hurts, and disappointments
- Forgiveness does not mean that you condone the unkind, inconsiderate, or selfish acts that hurt you
- Forgiveness does not mean that you have to think what happened was okay
- Forgiveness means you make peace with a bitter part of your past and no longer blame your experiences on the offender

Luskin, F. (2002). *Forgive for good: A proven prescription for health and happiness*. San Francisco, CA: HarperCollins.

# LET GO AND FOCUS ON RELATIONSHIP



- Family relationships with client may have become over focused on stuff in the way the client is over focused on the stuff
- Encourage family members to let go of stuff and refocus on relationship with client

# HARM REDUCTION

- A set of pragmatic principles and compassionate strategies designed to minimize harmful consequences of high-risk behaviors to the sufferer and to the public



# RATIONAL FOR HARM REDUCTION APPLIED TO HOARDING

- Refusal to accept treatment
- Efforts to treat the problem are time-consuming, expensive, and marginally successful (Saxena et al., 1994)
- Significant health and safety risks to client who hoards
- Significant health and safety risks to public
- Significant public costs to manage problem
- Managing harm potential often more acceptable to client and more viable option for community

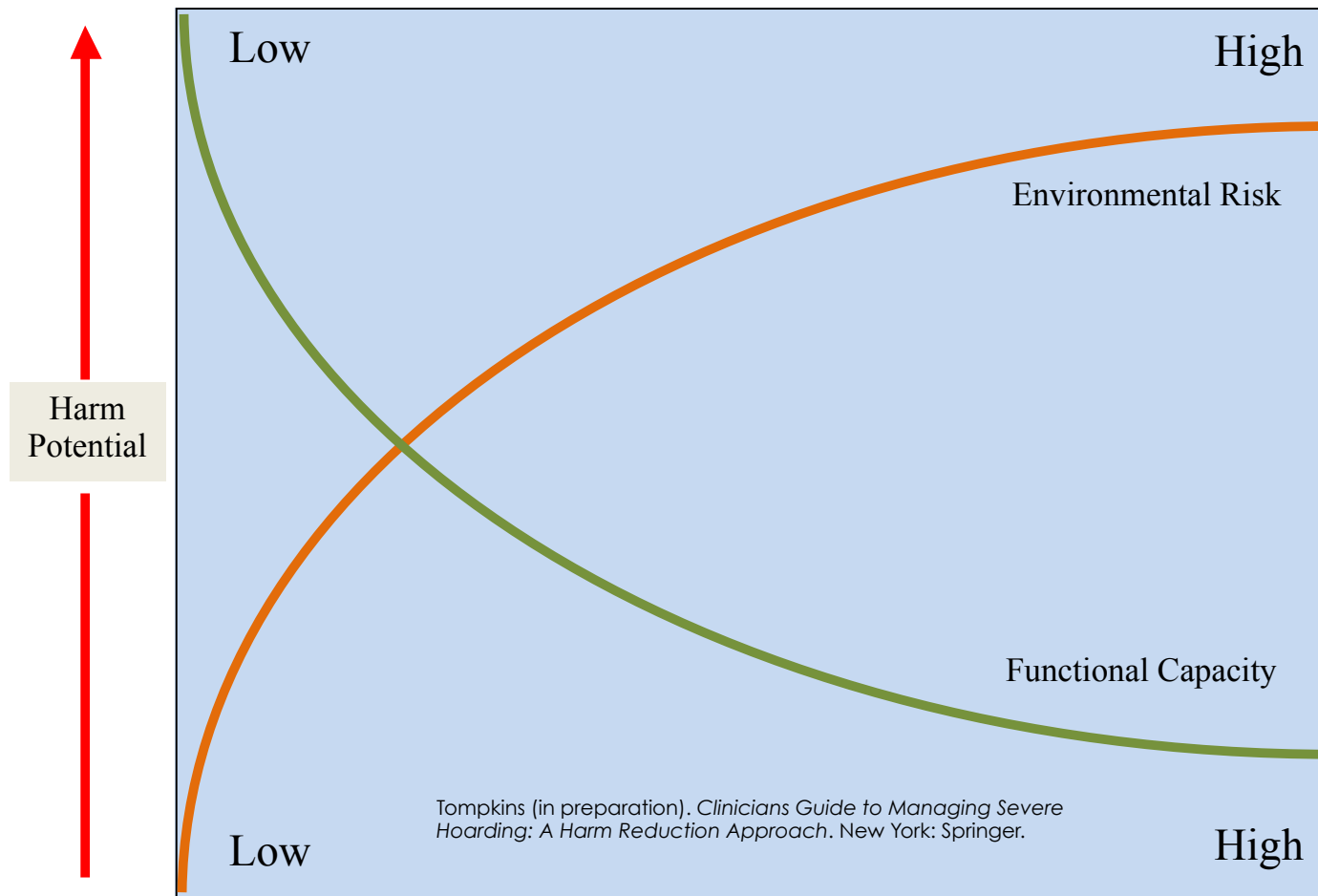


# PRINCIPLES OF HARM REDUCTION APPLIED TO SEVERE HOARDING

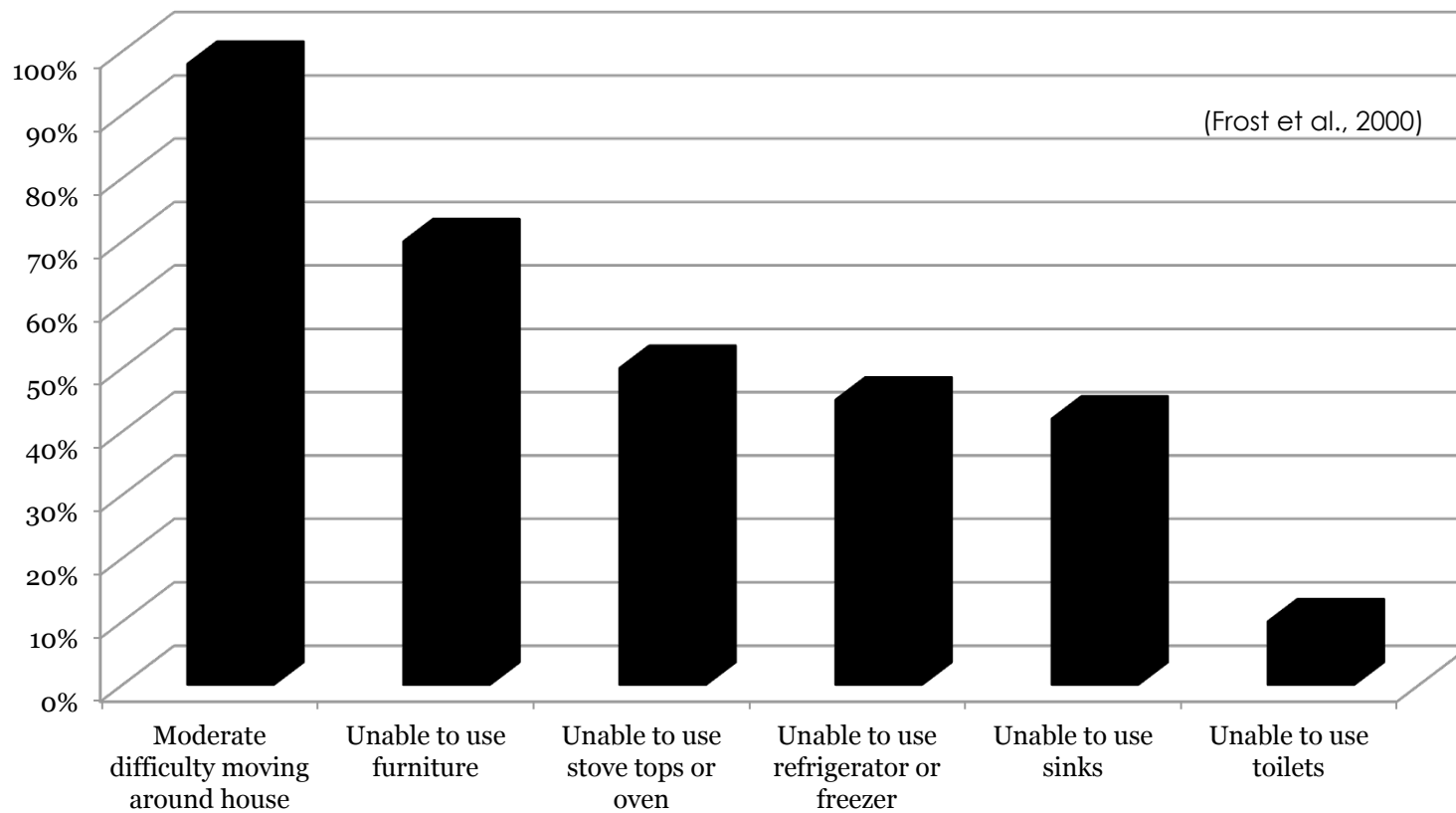
- First, do no harm
- Not necessary to stop all hoarding behavior
- No two hoarding situations are identical, hoarding is a unique interaction between person, condition, and person's environment, and therefore requires a unique plan
- Person who hoards is an essential member of the harm reduction process
- Change is slow and failures to honor the harm reduction plan are part of the approach and do not mean the approach is failing
- People who hoard can make positive changes in their lives even though they continue to hoard

Tompkins (in preparation). *Clinicians Guide to Managing Severe Hoarding: A Harm Reduction Approach*. New York: Springer.

# HARM POTENTIAL IS AN INTERACTION



# HIGH ENVIRONMENTAL RISK





# FUNCTIONAL CAPACITY

- Functional capacity is interaction between physical, psychological, and social capacity of the individual evaluated within the living environment
- Functional capacity is not decisional capacity but both can influence harm potential

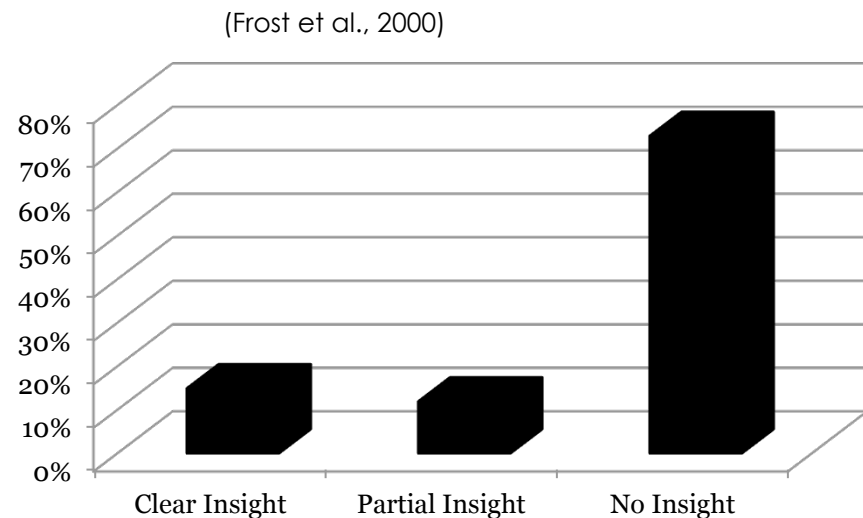


# LOW FUNCTIONAL CAPACITY

- **Physical capacity** – Can the client perform activities of daily living? Does the client have chronic or serious medical problems? Is the client frail and weak?
- **Psychological capacity** – Does the client know his name and is his judgment good? Does he see the hoarding behavior as a problem? Does he have other psychiatric or neurocognitive problems? Does the client want help?
- **Social capacity** – Does the client have friends and is he interested in spending time with them? Are the client's social relationships supportive and caring or strained and distant? Does the client have good relationships with professionals or others involved in her care?

# LOW INSIGHT INFLUENCES PSYCHOLOGICAL CAPACITY

- Low insight effects functional capacity of people who hoard
- Poor motivation may reflect untreated depression (Velasquez et al., 1999) or other medical or psychiatric problems



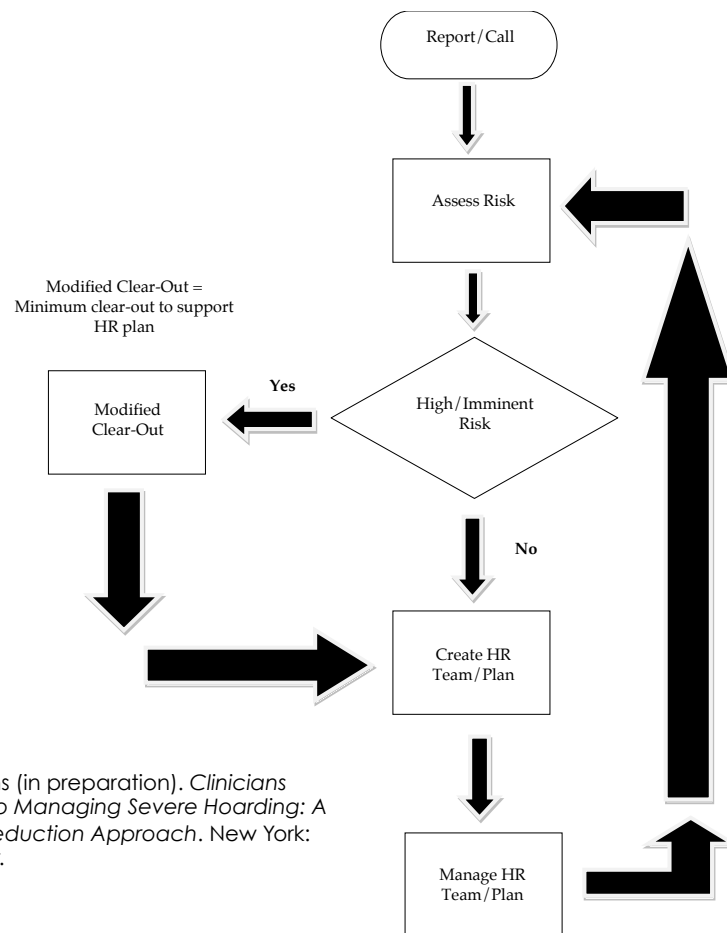
# GOALS OF HARM REDUCTION

- Keep people safe and comfortable in their homes
- Focus on moving possessions away from high-risk areas
- Focus on creating systems to minimize acquisition and maintain safety
- Focus on creating systems to enhance effective living
- Focus on managing other problems and conditions that influence harm potential

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# FEATURES OF HARM REDUCTION PROCESS

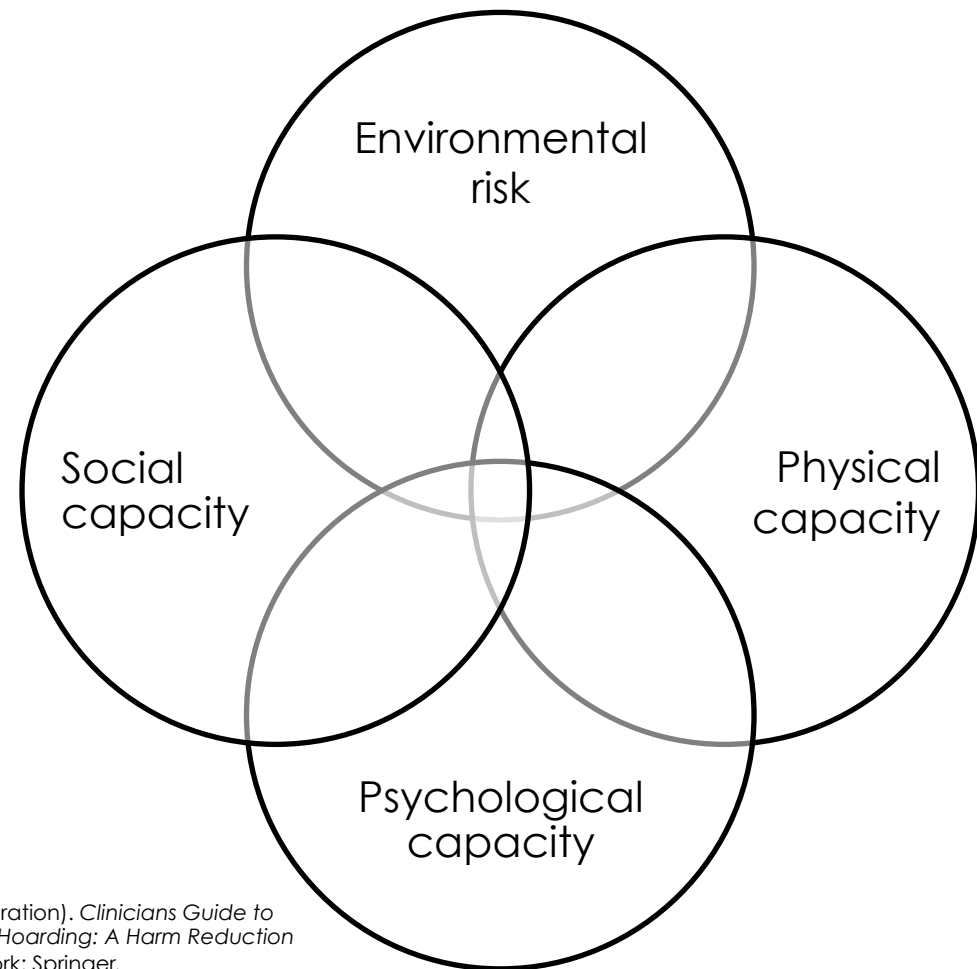


- Assess risk
- Modified or full cleanout
- Engage client in harm reduction approach
- Assess harm potential
- Create harm reduction team
- Develop harm reduction plan and formalize harm reduction agreement
- Manage harm reduction team and plan

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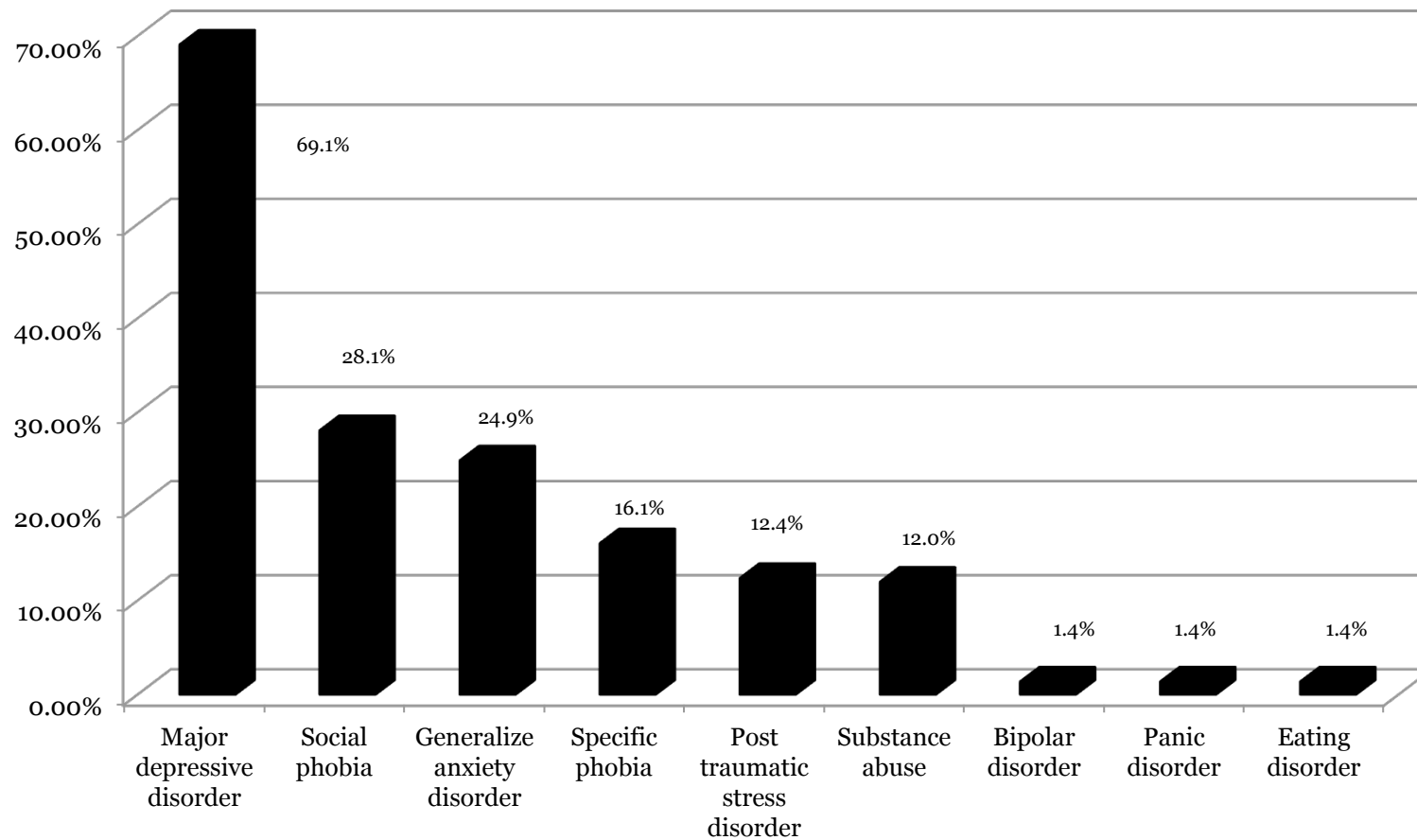
# ASSESS HARM POTENTIAL

- **Environmental risk** – what in the environment contributes to risk and discomfort.
- **Physical capacity**– how well does the client function in the environment, physical disabilities, medical problems.
- **Psychological capacity** – what is client's motivation and openness to help; decisional capacity, other psychiatric conditions.
- **Social capacity** -- how extensive is the client's support system and how willing are members to participate; what are formal and informal social supports; financial resources.



Tompkins (in preparation). *Clinicians Guide to Managing Severe Hoarding: A Harm Reduction Approach*. New York: Springer.

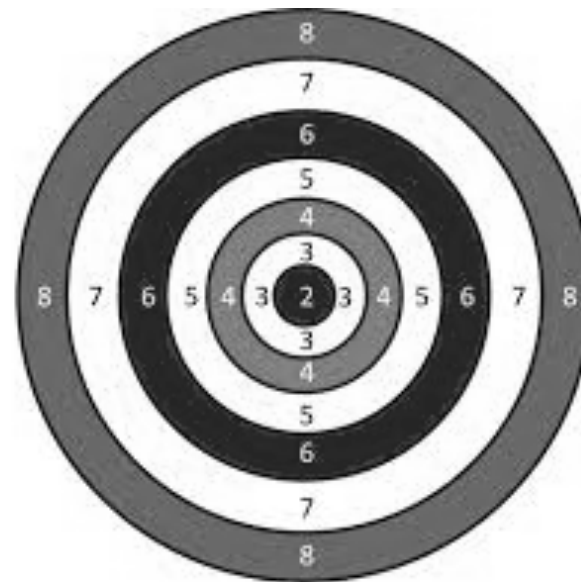
# HOARDING AND OTHER CONDITIONS



Frost, Steketee, Tolin, & Glossner (2011)

# IDENTIFY AND DEFINE EFFECTIVE HARM REDUCTION TARGETS

- **S**pecific
- **M**easurable
- **A**ttainable
- **R**elevant
- **T**ime-bound



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# SMART HARM REDUCTION TARGETS

- “Keep clutter out of swing areas of front and back doors.” (specific)
- “Keep clutter out of swing areas of front and back doors so *that doors swing fully to the door stops.*” (specific and measurable)
- “*Work with team member to clear clutter from swing areas* (attainable) of front and back doors so that doors swing fully to the door stops.” (specific, measurable, attainable)
- Target is relevant when focused on safety (and then comfort)
- “*Work with team member to clear clutter from swing areas of front and back doors so that doors swing fully to the door stops between harm reduction visits* (time-bound).

# KEEP HARM REDUCTION TARGETS CLEAR (W.A.T.C.H.)



- **W** -- Why do you have this here?
- **A** – affirm explanation that client gives
- **T** – touch only with permission
- **C** – creatively brainstorm with client other locations for possessions that maintain similar function and convenience
- **H** – help client clear, relocate, and protect (CRP)

# L.E.A.R.N. TO CLEAR TARGETS

- **Listen** – to client's ideas and plans for belongings; explore client's solutions to the problem, both realistic and unrealistic, and accommodate client if possible
- **Empathize** – let client know you have similar feelings about possessions and sometimes it is difficult for you to part with them too
- **Affirm** – let client know you understand how attached they are to their belongings and how much the possessions mean to them
- **Redirect** – client back to harm reduction target and agreement, be gentle but clear
- **Negotiate** – be creative and negotiate, generally around adherence to the harm reduction contract

# 3 P' S OF DECLUTTERING



- **Plan** – prior to each visit, review client's harm reduction targets, how you will remove items from the environment, and when you will visit again
- **Pace** – begin with short periods of decluttering; some clients cannot tolerate even a half hour in the beginning; keep in mind, however, that your client's pace is usually slower than the eviction process pace
- **Partner** – with other agencies, professional organizers, home care workers, or visiting nurses to clarify the safety and cleanliness level required to prevent eviction or maintain safety; remember you must meet certain standards, but you do not need to exceed them

# EXAMPLES OF HARM REDUCTION STRATEGIES

Harm Reduction Target	Harm Reduction Strategy
Keep back door clean	Maintain a clean path to back door and clean exit (door can open completely)
Decrease incoming paper	Limit magazine subscriptions to 2 per year Limit cookbook purchases to 1 per month
Remove or repair ceiling tiles in kitchen	Remove or repair dangling tiles
Eliminate old and unsafe foods from freezer and refrigerator	Only buy food for the week Discard spoiled food older than 4 months
Keep stove top clean	Keep 24 inch clearance around stove top (no clutter)
Protect important documents and decrease late payments and charges	Set up filing system for important documents Set up auto payment system or box for bills, checkbook, stamps

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# SUMMARY

Hoarding is a problem of high risk  
and low functional capacity

Insight in hoarding is poorly  
understood and multiple  
factors may influence those  
who are partially unaware

Harm reduction may be a  
pragmatic option, either as  
preliminary to treatment or as  
an alternative to treatment for  
some people who hoard

Harm reduction is a process with  
a beginning, with a middle but  
with no end

