Self-Neglect and Hoarding Disorders

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November 12, 2019
Housekeeping

• All on mute. Use Questions function for substantive questions and for technical concerns.

• Problems getting on the webinar? Send an e-mail to NCLER@acl.hhs.gov.

• Written materials and a recording will be available at NCLER.acl.gov. See also the chat box for this web address.
About NCLER

The National Center on Law and Elder Rights (NCLER) provides the legal services and aging and disability communities with the tools and resources they need to serve older adults with the greatest economic and social needs. A centralized, one-stop shop for legal assistance, NCLER provides Legal Training, Case Consultations, and Technical Assistance on Legal Systems Development. Justice in Aging administers the NCLER through a contract with the Administration for Community Living’s Administration on Aging.
About ABA COLA

The ABA Commission on Law and Aging is a collaborative and interdisciplinary leader of the American Bar Association’s work to strengthen and secure the legal rights, dignity, autonomy, quality of life, and quality of care of aging persons.

The Commission accomplishes its work through research, policy development, advocacy, education, training, and through assistance to lawyers, bar associations, and other groups working on issues of aging.
About North Shore Elder Services

North Shore Elder Services (NSES) is a team of specialists in social services, making life easier for elders and those who care for them. We offer information, support, and solutions.

NSES was founded in 1976 as a private non-profit corporation. As an Aging Service Access Point (ASAP) and an Area Agency on Aging (AAA), we service the communities of Marblehead, Salem, Peabody, Danvers and Middleton. The agency and its programs work closely with the Massachusetts Executive Office of Elder Affairs, the U.S. Administration on Aging and the Councils on Aging to ensure we meet the social services needs of the elders we mutually serve.
Key Lessons

1. Self-neglect is a failure of a person to meet personal needs such as food, shelter, clothing, and medical care.
2. The first line of help for self-neglect is social service based.
3. Lawyers should be part of the team to address legal challenges, while social services coordinates the human and personal services.
4. Hoarding disorder is a complex condition that requires specialized training to provide meaningful help.
Neglect Reported to Adult Protective Services

• The National Adult Protective Services Association reports on the most commonly reported types of neglect received by APS:

  • *Physical neglect*: includes failing to attend to a person’s medical, hygienic, nutrition, and dietary needs, such as dispensing medications, changing bandages, bathing, grooming, dressing, or failure to provide ample food to maintain health.

  • *Emotional neglect*: includes causing emotional pain, distress, or anguish by ignoring, belittling, or infantilizing the needs of adults. This includes neglecting or discounting the emotional well being of others, as well as actions to isolate adults from visits or contact by family and friends.
Neglect Reported to Adult Protective Services Continued...

• *Abandonment*: involves deserting the caregiving needs of an individual while neglecting to arrange sufficient care and support for the duration of the absence.

• *Financial neglect*: involves disregard of a person’s financial obligations, such as failing to pay rent or mortgage, medical insurance or invoices, utility and garbage bills, property taxes and assessments.

• *Self-neglect*: involves seniors or adults with disabilities who fail to meet their own essential physical, psychological, or social needs, which threatens their health, safety, and well-being. This includes failure to provide adequate food, clothing, shelter, and health care for one’s own needs. You can learn more about self-neglect here.

• More information: What is Neglect?
Self-Neglect

Characterized as the behavior of an older adult that threatens their own health or safety and generally manifests itself by failure to provide themselves with adequate food, water, clothing, shelter, personal hygiene, medication (when indicated), and safety precautions.

• More information: Department of Health and Human Services: [How Can I Recognize Elder Abuse?](#)
Self-Neglect Cont.

- Self-neglect may be a personal choice.
- Self-neglect be the result of a financial inability or physical inability to meet personal needs.
- Lawyers can help with access to benefits and assistance.
  - What kinds of help can lawyers provide?
- Social Services should be the first line of help for self-neglect.
Signs of Self-Neglect:

• Malnutrition, unexpected weight loss or gain due to lack of appropriate nutrition
• Extreme inappropriate clothing
• Marked decline in personal appearance, without explanation
• Untreated medical conditions
• Unsafe or unsanitary living conditions
• Unpaid bills, utility disconnects
• Noticeable decline in personal hygiene

More information: American Society on Aging: Elder Self-Neglect is a Growing and Largely Hidden Problem
When does Self-Neglect Become a Legal Issue?

- When the person lacks the ability to understand, even with decision supports, the impact of the choices they are making.
- When self neglect creates a serious risk of harm to others (public health or public safety).
- People who neglect themselves are more likely to suffer other forms of elder abuse as well.

More information: Journal of Aging and Health, 2012: Elder Self-Neglect is Associated with Increased Risk for Elder Abuse in a Community-Dwelling Population
Interventions to Reduce Harm

• Social interventions are important for harm reduction.

• Legal help is sometimes needed as others work on harm reduction.

• All alternatives should be exhausted, before considering guardianship.
Legal Assistance: Decision-Making Supports

- We all use help with making some decisions
  - Some things can be placed on automatic.
- Work with the person to develop a support network
- Take time to explain issues and options in a way that the person can understand
- Make recommendations
- Ask the person for a choice or preference
- Offer to help, as desired or needed
- Resource: Using Supported Decision-Making to Avoid Guardianship
Legal Assistance: Power of Attorney

- Is the person able to understand?
- Do they trust someone and want someone to help with business?
- Power of Attorney appoints a legal agent, and authorizes the agent to transact business for the person.
- Careful selection of the agent is essential to prevent harm.
- The agent should consult with the person, to support them in decision making, and act as needed to help carry out the decisions.
Assistance from Adult Protective Services (APS)

• Self-neglect accounts for more calls to adult protective services (APS) nationwide than any other form of elder abuse.
• Develop a relationship with your local APS.
• APS often has access to programs and resources that are only available through APS.
  • Emergency shelter, food, personal care and medical supplies, durable medical equipment, furniture, transit
• Know your state reporting rules, and your duties under those rules.
Interdisciplinary Approach

• Self-neglect and hoarding disorder require cross-disciplinary work.
• Social and human services intervention to meet needs, reduce harm.
• Legal help to assist in qualifying for benefits and programs.
• Legal help to defend as needed to allow time for harm reduction work.
Introduction to Hoarding Disorders
Hoarding Disorder Awareness Week
May 26- June 1, 2019

(Left to right: Hannah Mori (Sen. Lovely), Karen Sullivan & Eileen Dacey (NSCHC), and Matt Mogavero (Sen. Lovely))
Why hoarding?
Prevalence

• Affects approximately 3-6 % of the population
• Roughly 1 out of every 20 people
• Suspected 19 million people
• Underrepresented amount

• Is this just an American issue?
• What about SES?
Onset and Course

- **11-15**: Hoarding behavior emerges
- **24-26**: Hoarding behavior begins interfering with daily functioning
- **34-36**: Hoarding now creating clinically significant impairments
- **55 +**: Average age of treatment seekers is 55
  - Hoarding does not meet full criteria until late life because diagnosis linked to cluttered living spaces
What is Severe Hoarding?

- At risk for serious injury or even death because of the environment that they live in.
  - Falls, avalanches, structural concerns
- Also exhibit low functional capacity
  - Ability to perform tasks necessary to live their lives
    - Physical capacity
    - Social capacity
    - Cognitive/Psychological capacity
      - Low insight/refusal to accept help as most significant

(Tompkins, 2015)
Health and Safety Risks

*(Frost, et al. 2000)*
Clutter’s Interference with Basic Functioning

• Cooking
• Cleaning
• Moving through the house
• Sleeping

• Likelihood of:
  • Fire
  • Fall Risks
  • Poor Sanitation
  • Pest Infestation

• Risk to those who live in the home and neighbors
• Hoarding accounts for 24% of preventable fire fatalities
Help Refusal?

Variables that maintain hoarding behavior
Hoarding and Other Conditions

(Frost, Steketee, Tolin, & Glossner, 2011)
Why Someone Might Refuse Help

• Level of Insight
  • Good, fair, poor, absent

• Information Processing
  • Perception, Attention Span, Memory
  • Categorization, Decision Making Deficits

• History of complex trauma

• Beliefs/Attachments
  • Beliefs about Possessions
    • Sentimental, intrinsic, instrumental
  • Beliefs about Vulnerability
    • Maladaptive thoughts
  • Beliefs about Responsibility-waste
  • Beliefs about Memory and Control

• Emotional Reactions
  • Positive and Negative Emotions

(adapted from CBT model for hoarding)
Refusal of Help Continued...

- Sometimes seeing the problem differently than others
- “If I had more space this wouldn’t be a problem…”
- Fear of help and discovery
  - Not permitting repairs
- Hopelessness
- Resentment and mistrust
- Personal values

(Tompkins & Hartl, 2009, pp. 4-9)
For Those Accepting of Help

• Cognitive behavioral therapy (CBT)
  • Help control urges to acquire and save
  • To sort and organize possessions
  • Let go of possessions (a few at a time)

• Research shows CBT helps the majority (Tolin, Frost, & Steketee 2007)

• Medications: SSRIs
  • Managing comorbidities rather than hoarding

(Tomkins & Hartl, 2009, pp. 2-3)
What Isn’t Working?

• Horizontal vs. vertical
  • Sometimes seeing that every possession is assigned its own unique category—impossible to organize or group possessions

• Churning—inefficient strategies continued

• Clutter blindness

• Varying attributes of each item

(Tompkins & Hartl, 2009, pp. 18-19)
Assessment Tools

• Clutter Image Rating
  • Assessing ‘volume’

• H.O.M.E.S. – Multi-disciplinary Hoarding Risk Assessment
  • Assessing risk
  • Mass Housing: Hoarding Resources

• Uniform Inspection Checklist – Hoarding / Excessive Clutter
  • Minimum safety and sanitation standards
Clutter Image Rating: Bedroom
Guidelines for Working with Clients Who Have a Hoarding Disorder

• Imagine yourself in the client’s position
• Model positive, adaptive behaviors
• Provide encouragement and emotional support
• Share your opinions when asked, emphasizing transparency
• Believe in the client’s ability
• Highlight strengths—always provide positive validation
• Stay calm...even when it is tough
• Take care of yourself
Guidelines for Working with Clients Who Have a Hoarding Disorder Cont.

Do NOT:

• Use judgmental language
• Touch belongings without explicit permission
• Declutter behind the client’s back, or say you will donate something and throw it away instead
• Minimize the challenges faced
• Make decisions
• Equate the clutter with the person
• Argue or try to persuade
Harm Reduction
Varying Approaches for Hoarding Disorders

• Typical approaches for hoarding include treatment, most often, Cognitive Behavior Therapy (CBT)
• What happens when the case is not a self-referral?
• How do you help someone who doesn’t want help?
  • To intervene in cases of severe hoarding through an alternative approach
    • When a person refuses help, yet faces serious consequences
Harm Reduction Is..

- Every person is different and driven by their own internal and external needs
- HR is meeting the client where they are
- Think of staying with them, not ahead of them

(Denning & Little, 2012, pp. 42)
Harm Reduction for Hoarding

• Pragmatic principles and compassionate strategies designed to minimize harmful consequences of high risk behaviors

• Avoid consequences associated with severe hoarding such as death, injury, and homelessness

• People with severe hoarding do not typically seek treatment
  • Yet...
    • Face severe risks
    • Little awareness of the severity of the problem

(Tompkins, 2015)
Principles of Harm Reduction

• First, do no harm
  • (ill-conceived cleanouts)
• It is not necessary to stop all hoarding behavior
  • Identify the specific ways the hoarding problem puts the client in harm’s way
• No two hoarding situations are identical
• Generate a team approach
• The client is an essential member of the HR team
• Change is slow
• Agreement failures do not mean the HR approach is failing
• The client may have more pressing problems than hoarding
Harm Reduction:

(Image from: “What is Harm Reduction?” by McGill University)
Principles of Harm Reduction Cont.

• Respect: nonjudgmental understanding of each individual and “where they are at”

• Acceptance: that hoarding is a complex, multi-faceted phenomenon

• Empowerment: of the individual as the primary agent of change

• Compassion: towards the realities of social isolation, past trauma, discrimination, and other social inequalities and vulnerabilities people face

• Collaboration: supporting individuals in developing & implementing strategies that are personally meaningful
What About Clean-Outs?

• By the time hoarding cases gain public attention, they likely:
  • Require intensive, lengthy, costly, strategic, and complex responses
  • Enormous emotional and psychological costs to the homeowner

• Creates psychological and emotional impact on clients
  • It is not sustainable
  • BUT sometimes it is necessary
  • Clean-outs are NOT effective
  • They can be traumatizing, can do more damage than good in the long run

• Individuals in crisis cannot make basic decisions
  • Limbic system on overload
Engagement & Motivation

1. If you woke up tomorrow and your home was just the way you want it to be, how would your life be different?

2. What is something you want to do that you currently are not doing or cannot do because of the clutter in your home?

- Taking a Strengths-Based Approach
Redefining our perception of success

• Have we minimized the risks?
• Is it safe and functional for the resident?
• Is the client aware of the risks?
Additional Resources

**SELF NEGLECT**

- Karen Boothroyd, American Society on Aging Blog: [Self-Neglect is a Growing and Largely Hidden Problem](#)
- Sarah Nicolay, Farida Ejaz, PhD, Courtney Reynolds & Jessica Bibbo, Benjamin Rose Institute: [Protecting a Loved One from Self Neglect](#)
- National Adult Protective Services Organization: [Get Help in Your Area](#)
- David Godfrey and Charlie Sabatino, National Center on Law and Elder Rights: [Understanding Legal Capacity and Ethics](#)

**HOARDING**

- North Shore Center for Hoarding and Cluttering
- ASPCA
- Hoarding Task Force Network
  - Individual Support
  - Family Support
- Massachusetts Housing Hoarding Resources
- International OCD Foundation
- Mutual Support Consulting
- The Hoarding Project
Questions?

Type your questions in the question box on the webinar interface.
Elder Justice Toolkit

Practice-oriented, national online resource with information on pursuing civil legal remedies in elder abuse cases, practice tips, and sample documents for attorneys.

Contribute to the Toolkit! Customize a state-specific financial exploitation guide, or share your documents, letters, and pleadings at ConsultNCLER@acl.hhs.gov.

Visit Our Website: NCLER.acl.gov

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Case consultation assistance is available for attorneys and professionals seeking more information to help older adults. Contact NCLER at ConsultNCLER@acl.hhs.gov.