“Weighing the Ethical and Practical issues of Lifestyle vs. Risk to Community Safety“
“Ethics & The Hoarding Dilemma”

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Objectives

- Determine specific ethical actions
- Identify at least five client rights
- Increase ethical self-knowledge.
- Commonly Hoarded Items
- Discovery
- Functional Impairment
- Impact of Clutter
- Decision Making
ACTIVE LEARNING #1: Large group

Brainstorming:

What are some ethical issues you confront in your daily practice?
Ethical Dilemmas

- Protection vs. autonomy
- Lifestyle vs. risk to community safety
- Treatment vs. Prevention
Rights of APS Clients

The client has the right to:

- decline adult protective services
- participate in all decisions
- least restrictive alternative
- decline medical treatment
- have a prompt and thorough investigation
- protection from abuse
Ethics and Values in APS practice
ETHICS: Defined

- “Good” or “right” conduct
- Branch of philosophy dealing with values of human conduct
- Useful in assessing the rightness of decisions and the fairness of the decision-making process
Why do we need them?

How do they guide us professionally?
Every action taken by APS must balance the duty to protect with the right to self-determination.

Older people and people with disabilities who are victims of abuse, exploitation or neglect should be treated with honesty, caring and respect.
Napsa: aps ethical principles

- Adults have the right to be safe.
- Adults retain all their civil and constitutional rights unless some of these rights have been restricted by court action.
- Adults have the right to accept or refuse services.
- Adults have the right to make decisions that do not conform with societal norms as long as these decisions do not harm others.
- Adults are presumed to have decision-making capacity unless a court adjudicates otherwise.
Ethical concepts: Autonomy

- Right of individuals to make choices as long as they have decision-making capacity and cause no harm to others. Decisions should be voluntary, intentional and not due to coercion, duress, or undue influence.
Ethical concepts: Beneficence

- Right to receive care by others that maintains and/or enhances the client’s welfare.
Ethical concepts: Non-maleficence

- Right to expect others to “do no harm” in the maintenance or enhancement of the client’s welfare
Ethical concepts: privacy

- Right to maintain privacy regarding personal information, interpersonal relationships, physical environment, and lifestyle, as long as it does not infringe on the rights of others.
Ethical concepts: Fidelity

- Right to have others show loyalty or commitment to the client when they need help.
- Right and responsibility of family members to care for and assist one another (e.g. filial piety).
- **APS Workers**: Include and respect ideas of family members and significant others.
Ethical concepts: Accountability

- Right to expect others to tell the truth and be responsible for their actions.
- Right to expect others to expose the deception and irresponsibility of others.
Ethical concepts: Justice

- Right to be treated equitably whether they are a caregiver or care receiver.
An ethical dilemma presents a choice between two relevant sets of values, two good things.
“Clutter to Chaos”

Persons whose lives revolve around hoarding
What are the Ethical Situations with Hoarding Clients?

1.

2.

3.

4.
IT IS A HUGE PROBLEM!

This is a much bigger problem than most people think!
Hoarding

2012:

- More than 75 Hoarding Task Forces in US & Canada
- 3 Reality TV shows on hoarding
- More than 2 dozen hoarding research labs across the world
Recent Books

- **Compulsive Hoarding and Acquiring Workbook**
  - Gail Steketee • Randy O. Frost

- **Buried in Treasures**
  - David F. Tolin, Randy O. Frost, Gail Steketee

- **True Stories of Tackling Extreme Clutter**
  - Matt Paxton

- **Treatment for Hoarding Disorder**
  - Second Edition
  - Gail Steketee • Randy O. Frost
15% of nursing home residents
25% of community day care elder participants hoarded small items

Rate of hoarding among elders in private and public housing:
- Elders at Risk Program, Boston 15%
- Visiting Nurses Assn., NYC 10-15%
- Community Guardianship, NC 30-35%
Discovery

• APS/CPS – 40% hoarding complaints to local health departments are from elder services

• 84% of hoarding cases come through discovery by another agency or neighbors or family - Landlords, property managers,– Fire or police departments
Modern day cases

Hoarder Dies in Home; Removed Via Hole in Roof —
“A hoarder was stuck in so much garbage and debris and junk that when she died, she had to be removed through a hole cut into the roof of her hovel.”
CAUSES OF HOARDING

by: Dr Randy Frost
Hoardings as a Psychiatric Symptom
Collector

Hoarder
<table>
<thead>
<tr>
<th>Differences in Acquiring process</th>
<th>Collectors</th>
<th>HD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gather relevant information</td>
<td>95%</td>
<td>35%</td>
</tr>
<tr>
<td>Planning for acquiring specific objects</td>
<td>75%</td>
<td>35%</td>
</tr>
<tr>
<td>Getting attached</td>
<td>50%</td>
<td>35%</td>
</tr>
<tr>
<td>Searching for specific items</td>
<td>95%</td>
<td>18%</td>
</tr>
<tr>
<td>Feeling rewarded by purchase</td>
<td>95%</td>
<td>77%</td>
</tr>
<tr>
<td>Organize collected items</td>
<td>95%</td>
<td>47%</td>
</tr>
</tbody>
</table>

Mataix-Cols et al., 2012
# Reasons for Difficulty Discarding

<table>
<thead>
<tr>
<th>Reason</th>
<th>Collectors</th>
<th>HD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Useful in future</td>
<td>95%</td>
<td>100%</td>
</tr>
<tr>
<td>Sentimental attachment</td>
<td>90%</td>
<td>90%</td>
</tr>
<tr>
<td>Monetary value</td>
<td>50%</td>
<td>59%</td>
</tr>
<tr>
<td>Avoid waste</td>
<td>10%</td>
<td>55% **</td>
</tr>
<tr>
<td>Object is unique</td>
<td>55%</td>
<td>69%</td>
</tr>
<tr>
<td>Misuse of personal information</td>
<td>0%</td>
<td>31% **</td>
</tr>
<tr>
<td>Part of personal identity</td>
<td>80%</td>
<td>86%</td>
</tr>
</tbody>
</table>
# Key Differentiating Features

<table>
<thead>
<tr>
<th>Feature</th>
<th>Normative collecting</th>
<th>Hoarding Disorder</th>
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<tbody>
<tr>
<td>Onset &amp; Course</td>
<td>Childhood; intermittent</td>
<td>Childhood; Chronic</td>
</tr>
<tr>
<td>Prevalence</td>
<td>70% children; 30% adult</td>
<td>1-5% adult</td>
</tr>
<tr>
<td>Use of Objects</td>
<td>Common</td>
<td>Rare</td>
</tr>
<tr>
<td>Object Content</td>
<td>Very focused</td>
<td>Unfocused</td>
</tr>
<tr>
<td>Acquisition Process</td>
<td>Structured</td>
<td>Unstructured</td>
</tr>
<tr>
<td>Excessive Acquisition</td>
<td>Possible, but less common</td>
<td>Very Common</td>
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<tr>
<td>Level of Organization</td>
<td>High</td>
<td>Low</td>
</tr>
<tr>
<td>Presence of Distress</td>
<td>Rare</td>
<td>Very Common</td>
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<td>Social Impairment</td>
<td>Minimal</td>
<td>Severe</td>
</tr>
<tr>
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- **Feature**: Normative collecting vs. Hoarding Disorder
- **Onset & Course**: Childhood; intermittent vs. Childhood; Chronic
- **Prevalence**: 70% children; 30% adult vs. 1-5% adult
- **Use of Objects**: Common vs. Rare
- **Object Content**: Very focused vs. Unfocused
- **Acquisition Process**: Structured vs. Unstructured
- **Excessive Acquisition**: Possible, but less common vs. Very Common
- **Level of Organization**: High vs. Low
- **Presence of Distress**: Rare vs. Very Common
- **Social Impairment**: Minimal vs. Severe
- **Occupational Impairment**: Rare vs. Common
DIAGNOSIS OF HOARDING AND THE DSM–5
American Psychiatric Association
DSM–5 Development

A. Persistent difficulty discarding or parting with possessions, regardless of their actual value.

B. This difficulty discarding is due to a perceived need to save the items and distress associated with discarding them.
American Psychiatric Association
DSM–5 Development

C. The symptoms result in accumulation of possessions that congest and clutter active living areas and substantially compromise their intended use. If living areas are uncluttered, it is only because of the interventions of third parties (e.g., family members, cleaners, authorities).

D. The hoarding causes clinically significant distress or impairment in social, occupational, or other important areas of functioning (including maintaining a safe environment for self and others).
E. The hoarding is not attributable to another medical condition (e.g., brain injury, cerebrovascular disease, Prader-Willi Syndrome).

F. The hoarding is not better accounted for by the symptoms of another DSM-5 disorder (e.g., hoarding due to obsessions in Obsessive-Compulsive Disorder, decreased energy in Major Depressive Disorder, delusions in Schizophrenia or another Psychotic Disorder, cognitive deficits in Dementia, restricted interests in Autism Spectrum Disorder).
Specify if: ‘With Excessive Acquisition: If symptoms are accompanied by excessive collecting or buying or stealing of items that are not needed or for which there is no available space.’
Specify if: **Good or fair insight:** Recognizes that hoarding-related beliefs and behaviors (pertaining to difficulty discarding items, clutter, or excessive acquisition) are problematic.

Poor insight: 
Absent insight:
Specify if:
Good or fair insight:

**Poor insight:** Mostly convinced that hoarding-related beliefs and behaviors are not problematic despite evidence to the contrary.

Absent insight:
Specify if:
Good or fair insight:
Poor insight:

Absent insight (Delusional beliefs about hoarding): Completely convinced that hoarding-related beliefs and behaviors are not problematic despite evidence to the contrary.
PERCENTAGE WITH SIGNIFICANT ACQUISITION PROBLEMS

Patient Report

Frost et al., J A 639
Anxiety Disord 2009;23:632-
Comorbid Disorders In HD%
Age of Onset in Hoarding

% Reporting Onset

5 10 15 20 25 30 35 40 45 50 55 60+

0 5 10 15 20 25 30
COURSE OF COMPULSIVE HOARDING

- Saving begins in childhood or adolescence
- Clutter does not become severe until adulthood
- Chronic or worsening course
  | Insight begins later than the symptoms, and fluctuates
Intervention Differences: Elders vs. Younger Adults

- Strong ambivalence
- Need for strong relationship building
- Stronger emphasis on cognitive remediation: goal setting, list making, scheduling time, calendar
- Importance of socializing as a function of therapeutic intervention
- Need for in-home coaches to assist
Impact of Clutter-

- 98% have at least moderate difficulty moving around the house
- 70% unable to use furniture
- 50% unable to use Stove tops or ovens
- 45% unable to use refrigerator or freezer
- 42% unable to use tubs or kitchen sinks
- 10% unable to use toilets
HAZARDS OF HOARDING

Poor Sanitation | Mobility Hazard | Blocked Exits | Community Cost | Homelessness | Fire Hazard
Clinical Features
Older Hoarders

90% have mild or no memory/cognitive deficits

85% have little or no insight that clutter is problem

30% have severe to substantial interference with self-hygiene because of clutter

77% have or may have mental disorder

More often women

More often live alone and clutter more severe if never married
What Are the Links between Elder Abuse and Animal Abuse?

Key Statistics:

- **92%** of Adult Protective Services case workers saw animal neglect co-occurring with clients’ inability to care for themselves.
- **45%** observed intentional animal abuse or neglect.
- **75%** reported clients’ concerns for animals’ welfare impacted their decisions to accept interventions or services.
What Are the Links between Elder Abuse and Animal Abuse?

What Is Animal Hoarding?

- Not a harmless eccentricity but a serious mental health, public health and environmental issue requiring multidisciplinary interventions.
- 100% recidivism rate.

[Diagram showing overlaps between Animal Abuse, Child Abuse, Elder Abuse]
What Are the Links between Elder Abuse and Animal Abuse?

Who Are Animal Hoarders?

- Many mental health disorders identified with animal hoarding.
- Current thinking: An Attachment Disorder stemming from early childhood traumas. Hoarders seek comfort in non-threatenining, non-judgmental, non-humans.
Service Planning & Compulsive Hoarding

Who do you want on your team?
What can we do?
Service Planning is still what it has always been.....

Client centered
What two things will you take away with you from today’s workshop?
Thanks Y’all !!!!

Mahalo!!!!

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28th Annual
NAPSA Conference
Justice for All: Protecting Vulnerable Adults
August 28 – 30, 2017