

THIS FULL HOUSE --

THE DANE COUNTY HOARDING TASK FORCE REPORT - 1999/2000

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INTRODUCTION TO REPORT

Dane County Elder Abuse Office

"The person who removes a mountain
begins by carrying away small stones."

(From a fortune cookie, Madison, WI, 2001)

Everyone working in Adult Protective Services and Elder Abuse and Neglect Offices knows that referrals of people who hoard will be simultaneously amazing and confounding. Can a person possibly be both legally competent and living on top of three feet of a mix of garbage and newly purchased gifts, trinkets, and food? Or living in an apartment or home in which all but one small corner of one room is totally filled? Or living amidst a few dozen pets and their waste?

Who are these people? How can we assess their problems? What interventions will actually serve to assist them and prevent future hoarding behavior? How can we work together to help them and their families?

The creation of the Dane County Hoarding Task Force began with a conversation between two social workers, one experienced at working with older people and one rather new to the field. Both were fascinated and challenged by the hoarders who were referred to their elder abuse office for "self-neglect." Usually these people were about to be evicted from rented apartments or houses. Occasionally they were about to have their home condemned as unfit for human habitation. In almost all cases, family members and neighbors sought help but the hoarders didn't seem to understand what all the fuss was about.

Propelled by sheer curiosity, the two social workers began thinking about how to learn more about the problems that lead to hoarding and to engage the many other people in our community and aging network who also seemed to be challenged and confounded by the problem. And, as most things go, putting our heads together to solve a problem facing individuals, neighborhoods, families, and communities led to some new and helpful working relationships as well as a few discoveries.

After selecting leadership for the effort, members of the Dane County Hoarding Task Force were off on a journey together to try to learn more about hoarding and figure out how to do a better job at helping some of the older people living the hoarding life.

OVERVIEW OF HOARDING TASK FORCE

The Dane County Hoarding Task Force was founded as an inter-disciplinary group focused on improving Dane County's elder abuse and neglect system's interventions with older people who hoard objects and animals. The Hoarding Task Force was initiated in early 2000 as a subcommittee of the Dane County Joint Coordinating Committee on Elder Abuse and Neglect – a community coordinated response modeled after the domestic violence approach across the country.

Mission & Goals

The goals of the Hoarding Task Force were established by a planning committee made up of representatives from the Area Agency on Aging of Dane County, Mobile Outreach for Seniors Team, and South Madison Coalition for the Elderly. The goals for the effort were:

1. To investigate and share information on the problem of hoarding from different professional and community perspectives.

2. To advocate for improvements in how agencies and organizations work together to help people who hoard.
3. To develop a community plan for how to support and intervene with people who experience problems with hoarding.

Members

The Hoarding Task Force included people from the following professions and agencies: City of Madison Public Health Department, City of Madison Building Inspection Office, Dane County Sheriff's Department, Dane County Board of Supervisors, State Elder Abuse and Neglect Office, senior services agencies, local organizing consultants, Mental Health Center of Dane County, Madison Gas and Electric Company, Dane County Long Term Support and Adult Protective Services Units, and private home health and personal care agencies.

Questions or Further Information

Questions about the work of the Hoarding Task Force and its report can be directed to Brenda Ziegler at the Area Agency on Aging of Dane County's Elder Abuse and Neglect Office at (608) 224-3660; 1955 W. Broadway, Suite #105, Madison, Wisconsin 53713; aaa@co.dane.wi.us

MEMBERS OF THE TASK FORCE

Pat Anderson: Co-Chairperson

Director, Mobile Outreach for Seniors Team
Mental Health Center of Dane County

Melanie McIntosh: Report Author

Manager, Elder Abuse and Neglect Office
Area Agency on Aging of Dane County

Brenda Ziegler: Co-Chairperson

Social Worker, Elder Abuse Office
Area Agency on Aging of Dane County

Myrna Peterson

Social Worker & RN
Visiting Nurse Service / Home Health United

Ginny Everson: Co-Chairperson

Case Manager Supervisor
South Madison Coalition for the Elderly

Deb Prine

Nurse
City of Madison Public Health Dept.

Gail Brooks

Case Manager
Colonial Club of Sun Prairie

Carol Reise

Nurse
City of Madison Public Health Dept

Jim Chorlton

Adult Protective Services
Dane County Dept. of Human Services

Valerie Reiter

Sanitarian
City of Madison Public Health Dept.

Jim Clark

Environmental Health, Division of Health
Dane County Dept. of Human Services

Jane Raymond

Advocacy and Protection Systems Developer
Bureau on Aging & Long Term Care Resources
Wisconsin Dept. of Health and Family Services

Huong Coleman

Social worker
Madison Gas & Electric

Pat Skubis

Retired RN
Belleville, WI

George Hank

Building Inspection Supervisor
City of Madison Public Health Dept.

Irene Tobis

Psychologist & Owner
Ducks In a Row, Madison

Linda Hilgers

Deputy, Community Officer
Dane County Sheriff's Department

Al Vorhees

Building Inspector
City of Madison Public Health Dept

Karin Lunder

Social Worker, Long Term Support Unit
Dane County Dept. of Human Services

Judy Wilcox

Dane County Board of Supervisors
Chair, Health and Human Needs Committee

TASK FORCE SUBCOMMITTEES

The Dane County Hoarding Task Force was organized into subcommittees listed below. Each subcommittee was given a number of assignments to research and report back to the full Hoarding Task Force. The following are the subcommittees and their responsibilities.

Needs Assessment and Protocol Development Committee Tasks

1. **Review Governance:** Review existing related statutes, codes, etc. at the federal, state, county, city and other levels.
2. **Compile and summarize** governance for practical application; e.g. Trespassing Statute, State Plumbing Code, etc.
3. **Resources:** identify local players and roles regarding above governance, system interactions, etc.
4. **System Assessment:** assess capacity, effectiveness and efficiency of the above with recommendations; e.g. overcoming budget restraints, improvement of coordinated response, etc.
5. **Protocol:** develop protocol from point of referral/complaint to point of successful intervention or impasse; address variations outside of Madison jurisdiction.

Intervention Committee Tasks

1. **Review** confidentiality guidelines and protective services/guardianship process.
2. **Engagement strategies:** voluntary, involuntary, etc., develop concise civil commitment reference guide [California model].
3. **Assessment:** Review and recommend assessment tools; create a symptom checklist.
4. **Treatment:** discuss options across the continuum of severity of hoarding, e.g. in/outpatient, individual/group, behavioral, pharmacological, role of significant others, logistics of organizing (cost, resources), etc.
5. **Maintenance:** review relapse profile and maintenance strategies.
6. **Resources:** identify local clinically-related providers with cost information and age-specific services.
7. **System Assessment:** review current clinical response options and capacities in Dane County with recommendations to fill gaps, e.g. development of Hoarding Response Team.
8. **Protocol:** develop a clinical decision tree/protocol.
9. **Create brochure:** consumer handout, i.e. Clutterers Anonymous – A Brief Guide, OCD – Questions and Answers.

Prevention, Training and Community Education Committee Tasks

1. **Review and Assessment:** review current training/materials in Dane County and elsewhere; identify training needs.
2. **Compile** list of speakers/presenters; recommend presentation format regarding identified training needs and audiences.
3. **Education:** Provide education to a variety of audiences, e.g. older adult (group and individual), family and other informal providers or affiliates, formal service providers (including doctors, judges, law enforcement), policy makers, community awareness campaign, etc.
4. **Develop** a resource book on who to call for help with hoarding.
5. **Establish** a library of collected resources.
6. **Create** a brochure for elders and service providers on hoarding.
 - a) Create written materials for families in Dane County.
 - b) Create written materials for families elsewhere.
7. **Host** a conference on hoarding.
8. **Develop** a protocol for prevention.

Evaluation and Research Committee Tasks

1. **Evaluation:** assess overall system response to hoarding and make recommendations for decision-makers.
2. **Article:** write a description of the organization of the task force and its outcomes for publication in professional journals.
3. **Research:** continue interview survey research with hoarding clients and collaborate with Dr. Jan Greenberg, UW-Madison on future research.

Useful References

- ◆ Report on the Area Agency on Aging of Dane County: Elder Abuse and Neglect System Improvement Project 1999 – 2000
- ◆ Anxiety Disorders Association of America: 1999 National Conference program packet
- ◆ Madison Institute of Medicine Information Centers: Specializing in Bipolar and Obsessive Compulsive Disorders

THE TASK FORCE WORK PLAN

At its first meeting, the Hoarding Task Force developed a detailed work plan. This outline guided the Hoarding Task Force over the course of 2000.

1. **Conduct a Needs Assessment**
 - a. What are the local ordinances regarding building conditions around Dane County?
 - b. How can we overcome budget restraints?
2. **Develop and/or Conduct Prevention Activities**
 - a. Develop a resource book.
 - b. Work at client level, including early intervention.
 - c. Educate family and neighbors.
 - d. Educate service providers.
 - e. Educate law enforcement.
3. **Develop Intervention Activities**
 - a. Create an assessment tool.
 - b. Create a decision tree.
 - c. Create a protocol for agencies.
 - d. Create a checklist.
 - e. Develop a team approach.
4. **Conduct System Evaluation & Research**

Interview clients who hoard to learn about their experiences with the helping system and the path their hoarding behavior has taken.

A CHRONOLOGY OF THE TASK FORCE WORK AND MEETINGS

March 2, 2000

The first meeting of the Hoarding Task Force was held in Madison Gas and Electric Company's conference room. The meeting began with a viewing of a segment on hoarding from a recent episode of the television newsmagazine "20/20." The taped segment depicted a case study of a woman who hoards and her children. The show revealed the devastating impact the problem has on an individual and family members. It also provided a glimpse into the extreme difficulty hoarders have in giving up some of their stuff to others, even if it seems to be "just" an old bagel or used Band-Aid.

The members introduced themselves and were invited to say a few words about the videotape and their own experience trying to work with hoarders. The group developed a work plan to guide their future meetings (see previous page) and set the meetings in advance for the remainder of 2000.

April 3, 2000

Folders including information related to hoarding and relevant to the day's discussion were distributed. Ginny Everson of the South Madison Coalition of the Elderly (SMCE) presented two case studies about hoarding. Each example depicted how different approaches led to different outcomes. Pat Anderson (MOST) presented a comprehensive outline from *Hoarding and Clinical Aspects of Hoarding* that displayed the complexity of backgrounds, characteristics, and behaviors of hoarders.

May 1, 2000

The Hoarding Task Force discussed three functional levels that are vital to know when working with a hoarder: physical, psychological, and social. These functional levels need to be scaled to determine the level of involvement from a community agency. Staff from SMCE and the Dane County Elder Abuse Office (EAO) illustrated that each situation requires a different strategy in order to gain access into the home and to be successful with treating/ improving the situation.

Gail Brooks [case manager from the Colonial Club] presented a hoarding case that the community was currently working with, and the Hoarding Task Force compared the functional levels of the client. It was determined that encouraging relationship building was key in working with this particular client. It was suggested that it might be helpful for the agencies involved to know about local ordinances that applies to each community. The Hoarding Task Force discussed inviting local inspectors to a meeting to discuss ordinances and using that information for future reference.

July 10, 2000

Hoarding is a multi-faceted issue involving multi-faceted responses. Since no one agency alone has the authority to address this concern, effective intervention often requires a community coordinated response. A guest panel of local professionals from the City and County Building Inspection Units, City and County Public Health Departments, Madison Fire Department, Housing & Urban Development, City Housing, and County Sheriff Deputies described their roles, capabilities, and limitations in dealing with large scale hoarding situations.

Presentations emphasized obstacles to intervention, including the pending State Trespassing Laws that would allow an individual to go to the door of a dwelling, but require owner consent or a warrant for entry. Practical strategies to overcome or modify these and other obstacles were also given. The panel presentation began the process of conducting a needs assessment to learn about local ordinances regarding building conditions. The Adult Protective Services Unit made a presentation on gaps within the legal system when dealing with hoarding situations.

August 7, 2000

The goals of this meeting were to review timelines and discuss in detail the various subcommittees identified at the June meeting. Subcommittees met for part of the time. Two documents were drafted including each subgroup's assignments, tasks, and timelines. In keeping with one of the Hoarding Task Force's goals to increase understanding of hoarding behavior and develop intervention strategies, an invitation was made to Dr. John Greist to attend the next meeting. Dr. Greist, a professor at UW Madison, is recognized internationally as an expert in the study and treatment of obsessive-compulsive disorders.

September 13, 2000

The meeting began with a brief overview of the Wisconsin elder abuse and neglect system and how interventions work within the legal framework of Wisconsin's elder abuse laws. Adult Protective Services reviewed Wisconsin Protective Service Laws, Chapter 55 and 880. The City of Madison Public Health Department discussed their role as public health officials, explained the city ordinances they work under and distributed materials describing how they work and the authority they work within

Guest speaker Dr. John Greist provided information about clinical treatments and the etiology of hoarding. About 20% of all people with obsessive-compulsive disorders (OCD) have hoarding symptoms. They feel an uncertainty and/or incompleteness if they don't follow the ritual of hoarding. He ended by describing the miraculous results that happened when one 70-year-old woman agreed to participate in treatment.

October 2, 2000

Ginny Everson (SMCE) gave an overview of the Elderly Services Network, which includes the Area Agency on Aging, the 16 focal points in Dane County, Dane County's Mental Health Center, and how all the agencies can combine their efforts. A member reported on the Obsessive-Compulsive Disorder Annual Conference, including information on hoarding statistics. Studies have shown that after a cleaning effort and without treatment of the disorder, almost half of the homes become cluttered again.

Brenda Ziegler (Elder Abuse Office) presented two brochures that the subgroups created. One brochure focused on hoarding from the hoarder's perspective. The other was an informational brochure for friends and family of the hoarder. The Hoarding Task Force requested time to review and revise the brochures.

November 6, 2000

New versions of the brochures were discussed in more detail. Possible financial backing sources for printing were explored. There was a discussion on how to improve the existing housing statutes and codes within Dane County.

December 14, 2000

Celebration with the Multi-disciplinary Team (M-Team), the Fiduciary Abuse Specialist Team (FAST), and the Joint Coordinating Committee on Elder Abuse & Neglect of the accomplishments made over the last two years toward developing a community response to elder abuse and neglect. Guest speakers: Jane Raymond [Bureau on Aging & Long Term Care Resources] and William Hanrahan [Attorney General, Milwaukee County].

January 8, 2001

The Task Force's report was discussed. It was decided how it would be organized and what materials would be included. A plan for disseminating the report was also created. Each member was asked to respond to the question "What are some positive outcomes of the Task Force?" Answers included: improvement to the M-Team, collaborating on home visits together, improved working relationships with the Corporation Counsel and Public Health Offices, new approaches being tried, increased referrals, and greater understanding of the problem from many perspectives. The group agreed that there should be a party held to wrap up the Task Force work.

May 21, 2001

Wrap up party. Preliminary drafts of the Hoarding Task Force Final Report were distributed along with final copies of the brochures.

DEFINITIONS OF HOARDING AND SEVERE HOARDING

Hoarding

To store up beyond one's needs.

- Webster's Dictionary

Compulsive Hoarding

"A debilitating disorder characterized by the acquisition of a large volume of possessions that clutter living areas to such a degree that living spaces cannot be used for their intended purpose. In addition, the disorder causes impairment in normal life functioning and often affects others in the environment."

- Randy O. Frost, PhD

“Hoarders can be divided into two groups: Generalists and Specialists. The Generalist tends to retain everything that comes into their possession. The Specialist tends to retain one type of item or a limited class of items.”

- Randy Blair, Environmental Health Specialist,
California

Self Neglect – Public Policy and Definitions

“... a significant danger to an elder person’s physical or mental health because the elder person is responsible for his or her own care but is unable to provide adequate food, shelter, clothing or medical or dental care.”

- 46.90 Wisconsin Statutes

Hoarding Behavior

“Hoarding behavior is defined here as the excessive collection and retention of any materials to the point that it impedes day to day functioning and creates a hazard or potential hazard for the individual ... in older adults (it) represents a complex set of psychological, physical, and sociological factors that requires multi-level responses.”

- Unidentified Source

INDICATORS OF HOARDING

Many people collect special items and put them in distinct places. People who save excessively or hoard are different. They collect and keep things to the point where it encroaches on living space and safety. People who excessively collect or hoard experience two or more of the following:

- Saving or collecting continues beyond what is needed or usable, even though the house and additional storage space is full.
- Value, uniqueness, and sentiment is found in much “stuff” that others do not find valuable, such as old papers, spoiling food, and animal waste.
- Strong emotional attachments are formed with many items for comfort or safety.
- Efforts to stop collecting or to discard things are unsuccessful, leading to a sense of anxiety, emptiness, vulnerability, and more collecting.
- The fear of losing things prevents discarding or putting them away, out of sight.
- “Stuff” interferes with safe and functional use of the home to sleep, cook, bathe, and socialize.
- Others suggest that the “stuff” should be reduced and are bothered by it more than the collector.
- The “stuff” is often overwhelming and immobilizing.

In addition, people who hoard:

- Worry about having their possessions at hand when needed, so they often carry many items in their purses, pockets, and cars.
- Acknowledge that saving useless things makes no sense. Many try unsuccessfully to change; some attribute their hoarding behavior to frugality and view it as a positive trait.
- Buy extra supplies of necessities so they won't ever run out.
- Are likely to have close relatives who hoard.
- Tend to be overly indecisive and perfectionistic.
- Fear they will be unprepared or will make a mistake.

PRESENTATION OUTLINE ON CLINICAL CONSIDERATIONS FOR TREATING PEOPLE WHO HOARD – A Review of the Literature

**Prepared by: Pat Anderson, Director, Mobile Outreach for Seniors Team (M.O.S.T.)
Mental Health Center of Dane County**

Although hoarding is a significant problem for older people in both scope and severity, little research has been done in this area. This outline incorporates a growing interest in and understanding of the meaning, causes and treatment of this behavior.

HOARDING DEFINITION AND FEATURES

Definition

“Hoarding behavior is defined here as the excessive collection and retention of any materials to the point that it impedes day-to-day functioning and creates a hazard or potential hazard for the individual... in older adults (it) represents a complex set of psychological, physical and sociological factors that requires multilevel responses.” (Thomas)

Continuum

Hoarding excludes collectors who gather specific materials with defined purpose and distinct place for objects. It is a problem when the acquisition of seemingly useless possessions/clutter reaches the severity that it:

- Precludes activities for which living spaces were designed.
- Causes significant distress or impairment in functioning; subjective and objective suffering/danger.
- Most severe when individual's capacity is low and risk is high; involuntary action is often needed.

Associated Features

- Prevalence rates unknown; genetic/behavioral components; 84% had relatives with excessive saving.
- Hoarding is a symptom, not syndrome; often signals social distress/loss; defense regarding loneliness, cold.
- It is most closely associated with obsessive compulsive symptoms; OCD = 2% of community-based 65+ (depression is associated with OCD and found in 33% at treatment, 66% over lifetime).
- It is associated with psychopathology: OCD 25-33% hoard; dementia 20-25% hoard; schizophrenia 20% hoard; DD; personality disorder; anorexia, etc.

GENERAL CHARACTERISTICS (Dunn)

- Long-term behavior pattern – decades of conscious resistance-free collecting; element of choice. OCD onset: 1/3 before 15, 30's big jump (women catch up with men), under 10% after 40; look first for depression then brain abnormalities via PET scan re: hypermetabolism.
- Socially isolated – tend to live alone; alienate significant others; no trusted person in home to check extremism; animal collectors (2/3 female and single, educated) became isolated as a result of the animals.
- Socially eccentric – may be markedly eccentric but not necessarily mentally ill.
- Mentally competent – often oriented, able to make decision; isolation may reduce awareness.
- No common socioeconomic denominators – crosses class, education, income, culture, nations.
- Owns home – allows complete control over immediate environment.
- Lacking in self-care – appears unkempt with body odor, wears disheveled clothes.
- La Belle indifference – sees nothing wrong with chosen lifestyle; deny, minimize, rationalize, shame.
- Inability to differentiate trash from treasures – everything saved has value; nothing is trash.
- Elderly – age-related changes force opening home to providers, thereby exposing severity of hoarding.
- Gender – more women, longevity may allow hoarding to become full blown; more unmarried.
- Lack of full insight into problems with related lack of motivation for change or services.

CAUSAL FACTORS (Dunn)

Psychosocial Theories

- Instinct/fixated action pattern as in nesting animals.
- Obsessive compulsive; anal-retentive.
- Deprivation in early life, real or perceived; reaction to losses.
- Denial of aging; newspapers stop time; things for future; holding on vs. depletion; cover up against death.
- Symptomatic of mental illness; schizophrenic has full ordered versus internal chaotic and cold world.
- Regression of dementia; general collapse of functioning, self-neglect.

Physiological Theories (Neurobiological)

- Frontal lobe (dementias) and basal ganglia involvement
- Serotonin dysregulation
- Cognitive/perceptual deficits

COGNITIVE BEHAVIORAL MODEL OF COMPULSIVE HOARDING (Frost)

A. Information-Processing Issues

These deficits appear to be general (not limited to saving/hoarding); closely related /overlapping; hard to separate. Hoarding is an issue of organizing as well as saving.

1) Decision making

- a) Indecisiveness is a hallmark of compulsive hoarding; save or toss item, where to put it, etc.
- b) May be avoidance behavior to avoid mistakes associated with perfectionist.

2) Categorization / Organization

- a) Each item is examined, found unique, important and unsubstitutable.
- b) Hoarders have trouble determining the relative importance of possessions; calibrating.
- c) Mixing of important and unimportant possessions; very narrow categories vs. 3 or 4.
- d) Temporal organization of piles; reviews lead to churning, not discarding.

3) Memory

- a) OCD patients/nonclinical compulsive checkers suffer from subtle memory deficits.

- b) Memory – finding failed to reveal any actual memory deficits.
- c) Confidence in memory – findings did reveal *significantly lower confidence in their memories*.
- d) Excessive beliefs regarding the importance of remembering/recording information versus failure/distress.
- e) Visual cueing is an important memory aid for compulsive hoarders. “If I put it with this stuff (into a filing system), I won’t remember it!”

B. Emotional Attachment Issues

Buying objects seems to provide hoarders with some degree of comfort. Excessive emotional attachment to possessions among compulsive hoarders includes these types:

- Sentimental – getting rid of such a possession feels like the loss of a close friend, part of self.
- security-based – source of comfort and security, signaling a safe environment.

C. Behavioral Avoidance

Saving possessions allows the hoarder to avoid the loss of objects that may be needed someday.

D. Beliefs about the nature of possessions

Underlying many hoarding behaviors is a set of beliefs about the nature and meaning of possessions. Each of these beliefs is related to an overestimation of catastrophe or loss. Distorted beliefs about the probability and severity of negative consequences if possessions are discarded or placed out of sight may be a key feature connecting these distorted thoughts. These beliefs include:

- Perfectionism – perfection is not only possible, but also expected.
- Responsibility – feel more responsible to meet future need, “Just in case.” A second type of responsibility is for the proper care and use of possessions; guilt about waste. Ownership carries with it a responsibility to use a possession properly.
- Need for control – less willing to share or to have others touch or use their possessions.
- Unauthorized touching can prompt extreme anger; remove some of the safety value of the possession; personal violation. Touch by person hoarding items increases value/attachment. Excessive concern re: control over belongings was associated with decreased use of belongings.
- Emotional comfort – “Without my possession, I will be vulnerable.” “Throwing something away means losing part of my life.” “My possessions provide me with emotional comfort.” Hard to discard.

TREATMENT FOR COMPULSIVE HOARDING (Frost)

At present, very little information is available about the treatment outcomes.

1. Assessment

- What types of possessions are saved?
- What are the reasons for saving each type of possession?
- Where are saved items kept? Is there some form of organization?
- What is the actual amount of clutter? Spaces in the house should be evaluated in terms of their usability.
- Note parts of the house that are unusable because of clutter.
- Are family members involved? How does the problem affect relationships with family or friends?
- How are items acquired? Note how new items enter the house and where they go when they do.
- Does the patient have decision-making problems? A careful analysis of the nature and extent of decision-making problems and the creation of effective decision-making strategies are crucial.
- What avoidance behaviors are evident? A careful analysis of all things avoided by saving is necessary.

- How much anxiety or discomfort regarding hoarding is experienced during a typical day and during attempts to organize and discard possessions? This information is critical for setting up excavation sessions and hierarchies for discarding, and for setting the course of habituation to discarding.
- What is the patient's hoarding history and previous treatment? Circumstances surrounding the onset of hoarding and the results of attempts at treatment for the problem behavior may be helpful.

2. Standardized Assessments

- The Y-BOCS provides an overall index of severity of the problem.
- Hoarding Severity Scale and a Hoarding Cognitions Inventory
- A behavioral assessment of hoarding severity is necessary; one each re: floor space and furniture tops.

3. Treatment Goals

- The first and primary goal of this treatment program is the creation of uncluttered living space.
- Increase the appropriate use of space.
- Improve decision-making skills, and to develop an organizational plan.
- Discarding unneeded possessions.
- Reducing the accumulation of new possessions.
- Developing skill of self-instruction and cognitive correction.

4. Treatment Rules

- The therapist may not touch or throw away anything without explicit permission.
- All decisions regarding saving, discarding, and organizing are made by the patient.
- Any possession touched during an excavation session should be placed in a final location.
- Categories for possessions must be established before handling them.
- Treatment should proceed systematically.

5. Treatment Recommendations

- Pharmacological: SSRI.
- Psychosocial: exposure with response prevention.

HOARDING TREATMENT & INTERVENTION PRESENTATION

Coordinated by Pat Anderson, Director, Mobile Outreach for Seniors Team (MOST)
Mental Health Center of Dane County

Jane Raymond [Department of Health and Family Service's Adult Protective Services Specialist] gave a brief overview of the elder abuse and neglect system and how interventions work within the legal framework of Wisconsin's elder abuse laws. She distributed the Department of Health and Family Service's 1999 Elder Abuse Report.

Carol Riese [RN], **Tommy Schneider** [City of Madison Public Health Department], and **George Hank** [Madison building inspector] talked about their roles as public health officials, city ordinances they work under and distributed materials describing how they work and the authority they work within.

Jim Chorlton [Dane County Adult Protective Services social worker] gave an overview of Wisconsin's Protective Services Laws Chapters 55 and 880. Pat Anderson described Wisconsin laws governing mental health services and involuntary commitments for treatment.

Dr. John Griest, MD, guest speaker and expert on obsessive-compulsive disorders (OCD) [Madison Institute of Medicine] presented information about clinical treatments, the etiology of hoarding and the definition of hoarding used by Dr. Randy Frost:

“The acquisition and failure to discard possessions which appear to be useless or of limited value and sometimes (there is) the absence of sentimentality for these objects.”

At the extreme end of the continuum, items that may be hoarded are food and human or animal excretion. Hoarders are often estranged from their families, extreme in their habits, oblivious to usual standards of housekeeping, and seemingly unaffected by the situation they are in [“La Belle Indifference”]. Hoarders have rationales for the things they save (“I might need it in the future”), cannot adequately describe the great importance of individual items to them, and fear losing something of value. They are afraid to discard things without examining them first and get so far behind in this save-and-examine ritual they can’t possibly discard or sort items.

About 20% of all people with OCD have hoarding symptoms. They feel uncertainty and incompleteness if they don’t follow the ritual of hoarding. The mean age of OCD onset is about 20 years of age, so older hoarders may have a lifetime of experience with the problem. Hoarders with OCD are quasi-delusional, having lost touch with reality, but do not present themselves at assessments or court hearings as “incompetent.”

Is OCD treatable? Yes, assured Dr. Greist. There are two main methods of treatment:

- 1) Medication (serotonin reuptake inhibitors or select tricyclics)
- 2) Cognitive/behavioral therapy.

These approaches are very effective; 50% of people with OCD improve with medication. Once symptoms are alleviated a bit, the way is paved for behavioral treatment, the most effective being an initial exposure to the anxiety caused by the OCD, followed by an interference with the person’s relief ritual. If the relief ritual to anxiety is prevented, healing can occur. Through repetition of the exposure and ritual prevention, the person eventually becomes “habituated” to the new way of responding. According to Dr. Griest, 97% of people will form new behavior patterns given a specific and careful behavioral intervention.

The challenge arises when hoarders refuse treatment; they may be unwilling to take medication or participate in treatment programs. However, when they do receive treatment, it works. In a University of Iowa study of people with OCD, researchers found that 60% of the participants reported much or very much improvement in their symptoms after behavioral therapy; 50% reported the same after just medication; and 12% reported the same after a placebo. In summary, much of the hoarding seen is related to the presence of OCD. Some hoarding stems from brain injuries or developmental disabilities. Occasionally, it may start when dementia sets in. The prognosis is very good; OCD is quite treatable when the hoarder agrees to help.

In a Q&A session, Dr. Griest made some additional points. A history of hoarding throughout a person’s life is a significant factor in diagnosing hoarding as a result of OCD. Theories abound about what causes it but don’t generally lead to new treatment approaches. Keep raising the “Why?” question to understand the cause of things. It is not correct to assume an event precipitates OCD; if there is one, research indicates it is childbearing related events and issues. He finished by describing the miraculous results that happened when one 70-year-old woman agreed to participate in treatment. He encourages clinicians prescribing medications for OCD/hoarding to keep trying different SSRI medications because they are so likely to be successful for patients.

HOARDING TASK FORCE DISCUSSION

Coordinated by Brenda Ziegler, Ginny Everson, and Gail Brooks

Assessments of hoarders was the topic at one Task Force meeting. Members agreed that it is vital to know how a person functions on a physical, psychological and social level. Those functional levels need to be assessed in

some way in order to determine the level of involvement from a community agency. Ginny Everson [South Madison Coalition for the Elderly] and Brenda Ziegler [Elder Abuse Office] described a number of cases that illustrate the point that each situation requires a different strategy in order to gain access into the home and to be successful with treating / improving the situation.

Gail Brooks [Case Manager at the Colonial Club in Sun Prairie] presented a case and described how she assessed the person's challenges, strengths, and functional levels. Based on what Gail presented, it was determined that activities and interactions encouraging relationship building are key. The level of functioning by the people involved in this case was too high to justify any involuntary government intervention.

Clearly, it is difficult to conduct assessments when the older person is not cooperative. Sometimes it is important to slow down the clock or stop focusing on the assessment and concentrate on relationship building instead for a while. Brenda gave an example when she stopped to visit an older woman weekly just to see how she was doing and, eventually, the woman allowed Brenda to enter the home and talk with her. While any approach may fail to achieve cooperation or consent, we are continuing to look for intervention ideas and guidelines.

A number of assessment tools specific to hoarding were collected and are included in this section. An article about the decisions to intervene "Hoarding: Eccentricity or Pathology: When to Intervene?" is an excellent reference (see Bibliography). Author Norma Thomas [ACSW from Widener University in Pennsylvania] does a good job of discussing the various case worker skills needed to overcome the resistance of people who exhibit hoarding behavior.

Copies of articles are available through the Area Agency on Aging of Dane County, 1955 W. Broadway, Suite #105, Madison, WI 53713. (608) 224-3660

CLUTTER SCREENING QUESTIONNAIRE

Gail Steketee, Ph.D.

Boston University School of Social Work

A. Do you have a problem with excessive clutter in your home? YES NO

B. Have family, friends, or visitors ever suggested that you need to reduce the clutter in your home?

YES NO

C. To what extent does the clutter interfere with using rooms in your home in a normal way?

0 = *No interference.*

1 = *Mild interference.* Up to ¼ of the home cluttered and not easily usable for normal activities (sitting, eating, sleeping, socializing, cooking, etc.).

2 = *Moderate interference.* Approximately half of the home cluttered and not easily usable for normal activities.

3 = *Severe interference.* Approximately ¾ of the home cluttered and not easily usable for normal activities.

4 = *Extreme interference.* Nearly all of the home cluttered and not easily usable for normal activities.

D. When you try to clear out the clutter, how much distress or emotional upset do you experience?

0 = *None.*

1 = *Mild.* Not too disturbing.

2 = *Moderate.* Disturbing but still manageable.

3 = *Severe.* Very disturbing.

4 = *Extreme.* Near constant and disabling distress.

E. To what extent do you have a problem with collecting or buying more things than you need or can use?

0- No problem.

1- Mild problem. Occasionally (less than weekly) acquires items not needed, or acquires a few unneeded items.

2- Moderate. Regularly (once or twice weekly) acquires items not needed, or acquires some unneeded items.

3- Severe. Frequently (several times per week) acquires items not needed, or acquires many unneeded items.

4- Extreme. Very often (daily) acquires items not needed, or acquires large numbers of unneeded items.

THE TOP TEN CLUTTER LIST

Gail Steketee, Ph.D.

Boston University School of Social Work

1. Am I afraid I will get in trouble with my landlord because of clutter or have I already gotten in trouble?
2. Do I have too much stuff? Have I fallen over my clutter?
3. Do I have to move stuff off the furniture in order to use it?
4. Do people tell me that my place is dirty, a mess, or that it smells bad?
5. Am I reluctant to have people come over because of clutter?
6. Do I have to move stuff off the bed to go to bed at night?
7. Do I lose things all the time in the clutter?
8. Am I unable to get to my windows, fire escape, and doors?
9. Do I bring things home even though my place is already cluttered?
10. Do I get anxious when I think someone might take, rearrange, or throw away my clutter?

If you answered yes to two or more of these questions, you may have a hoarding/cluttering problem. This problem can be caused by depression, obsessive-compulsive disorder, or other disorders, and there is help.

You might want to show this checklist to your therapist. Please be advised that optimal treatment for obsessive-compulsive hoarding should take place in your home.

If you feel your therapist is not helping with your hoarding/cluttering problem, you can call your county's mental health patient's rights office. This number should be available from your County Mental Health Department.

“WHEN THE BUBBLE BURSTS” by Randy Blair, Environmental Health Specialist, California

Hoarders can be divided into two groups: **Generalists** and **Specialists**. The Generalist tends to retain everything that comes into their possession. The Specialist tends to retain one type of item or a limited class of items. People who gather large numbers of animals are Specialists. Those who retain literature such as newspapers are Specialists. A lady in Redwood City, California had 46 years of bar soap remnants from her family of five children and numerous grandchildren. The Generalist will have every piece of mail, every newspaper, all the food wrappers and containers, etc. that ever came into their home. In the extreme, the Generalist will have all their excrement, their shed hair, used bandages, etc.

Outside the home environment these compulsive hoarders are almost always undetectable. However, sooner or later the compulsion will create a problem at the home that brings local government agents to their door. The neighbors may call the Health Department because of rats, flies, odor, etc. The hoarders are more prone to fires or other emergencies than are people with more orderly properties. Animal hoarders get into trouble with animal control agencies more easily than normal pet keepers. Very often hoarders have a very long history of involvement with public agents. A time always comes when short-term corrections no longer puts off the governmental agencies. That time is the day when the visiting official recognizes that the hoarder is no longer able to improve the situation to minimal accepted standards. The hoarder is violating laws and has no prospects of being able to stop violating laws. The hoarder has become a danger to the health and welfare of themselves and their community. Very often the hoarder is prone to being victimized by the predators in the community. In short, the “bubble” that the hoarder has spent years creating has burst!

At this point the governmental agencies are obliged to act. In some cases the hoarder and their properties can be declared a public nuisance and be subject to summary abatement. The person may be forcibly removed to a protected care situation. If there are no relatives or other acceptably responsible people to aid and act for the hoarder, he or she may be ordered by the courts into permanent involuntary protection. Even when the hoarder is free there are some conditions, such as rat infestation, that are required to be abated forthwith. When the public agency does the abatement the cost of the abatement is a lien against the property and must be collected. Often the actual work of the abatement is performed by private operators. Few local government agencies are able to undertake these abatements in a cost-effective manner. Unfortunately it is the inability to find reliable, economical means of abating that often causes these problem properties to go through incomplete abatement repeatedly.

It is during these visits by governmental agent long before the “bubble bursts,” in some case repeated over many years, that the system is failing. The instances of “burst bubbles” for hoarders are growing in number. More citizens are finding themselves alone and unable to cope with their hoarding. Once the “burst bubble” stage has been reached the citizen and those of us who are paid to protect and serve the citizenry have lost the war. Very often the citizen has lost their ability to live and act for themselves. The governmental agencies have spent a great deal of money in a lost cause. There must be some way to help the hoarders long before their “bubble bursts.”

CALIFORNIA LAWS

Chapter 1.12 Abatement of Nuisance

1.12.010 Definition of a nuisance

A nuisance is anything which (1) is injurious to health, (2) is indecent or offensive to the senses, (3) obstructs the free use of property in a manner that interferes with the comfortable enjoyment of life or property, (4) obstructs

the customary free use or passage of any navigable lake, river, bay, stream, canal, basin, public park, square, street, or highway, or (5) is specifically declared by this code or state law to be a nuisance. Examples of a nuisance include but are not limited to:

1. Any explosives, flammable liquids or hazardous materials which are stored in a manner or an amount contrary to state law or this code;
2. Any building or structure which is made, erected, altered, maintained, partially destroyed or abandoned contrary to state law or this code;
3. Any obstruction or excavation which interferes with the ordinary use of public streets, ways, alleys, thoroughfares, sidewalks or public grounds unless otherwise permitted by law;
4. Any accumulation of debris, garbage, refuse, weeds, overgrowth, or machine or equipment parts which constitute:
 - a) A fire hazard;
 - b) A hazard to pedestrian or vehicular traffic;
 - c) A harborage for rats, vermin, or insect infestation;
 - d) Any other hazard to public health or safety.
5. Any inoperative, abandoned, wrecked or dismantled vehicle which shall be abated in accordance with Chapter 7.60 of this code; or
6. Any swimming pool, pond, well, or other body or container of water which is abandoned, unattended, unfiltered, polluted or otherwise maintained in an unhealthy or unsafe condition. (Prior code 1210; Ord.2830, 6/7/83; Ord. 3161, 11/8/88).

“PREPARING TO CLEAN UP A TRASH HOUSE” by Alan Merrifield, Peninsula Community Services

Peninsula Community Services is a local non-profit organization that has, for over 20 years, worked with various City and County departments, private conservators, realtors, owners and tenants in cleaning up more than 200 residential properties. As a result of our experiences with pack rats and neighborhood trash houses, we offer the following suggestions to those who need to *find* a cleanup organization or to *clean up* trash houses.

1. Make sure all insurance policies are current and provide adequate coverage.
2. Find out who the decision-maker is.
3. Bring appropriate inspection equipment.
4. Gather information to help define the scope of work and prepare an estimate of costs.
5. Obtain a general verbal description of how this property looks.
6. Ask the decision-maker to answer the following questions.
 - a) Will the pack rat be participating in this cleanup work?
 - b) Who besides the cleanup crew will have access to the property after working hours?
 - c) Will all things of value be removed prior to our entry?
 - d) Will we be asked to search for any particular item(s)?
 - e) Who will see that the water and electrical services are restored to the house?
 - f) Are there any known biohazards present on this job?
 - g) What code violations must be addressed?
 - h) Is there any known pest problems such as fleas, rodent mites or rats?
 - i) Are there any hazardous materials on this property?
 - j) What items in the house are to be discarded?
 - k) How should the trash be removed from the property – by truck or debris box?
 - l) Where is the nearest public dump? Can non-residents use the dumpsite? What are their surcharge fees for appliances, tires, mattresses, etc?
 - m) What items in the house are to be saved? Floor coverings, window coverings, appliances, etc?
 - n) Will anything be put into public storage?
 - o) What is to be cleaned? What is to be left as is?

- p) Will the house have electricity, running water, phone service?
- q) What tools must be rented to do the job, e.g. generator, pressure washer, rug shampooer?
- r) Does the house require animal proofing?
- s) How much will this all cost and who will pay for it?

DANE COUNTY HOARDING REFERRAL GUIDELINES – 2001

Referral Sources

Law enforcement, family members, housing units, landlords, neighbors, health clinics, and caregivers often are the people who begin seeking help for people with hoarding problems. All of the agencies involved in the Hoarding Task Force make referrals to each other as well.

General

Any older individual or concerned person may make a referral directly to the Area Agency on Aging of Dane County's Elder Abuse Office (EAO) – the county designated elder abuse agency. People may also choose to initially contact an agency right in their neighborhood or town that has expertise in services for older people such as the senior centers or senior coalitions that have been designated by the county as "Focal Points for Services to Older People." Direct contacts may also be made to the Mobile Outreach for Seniors Team (M.O.S.T.) at the Mental Health Center of Dane County when an older person is known to have mental health problems. Some additional helpful guidelines about referrals are provided below.

When to make a referral to the Elder Abuse Office (EAO)

There is no legal mandate for elder abuse reports. In addition, victims also have the right to refuse the investigation and services (unless they have been found to be incompetent and their guardian makes such decisions on their behalf). The identity of the referral source is protected by law. The law also provides immunity from liability for all referrals made in good faith. EAO will seek involvement of the Adult Protective Services Unit when it appears that court involvement will be needed. EAO will always contact M.O.S.T. for a team approach when a hoarding referral is received.

Referrals to the EAO are strongly suggested when there is severe hoarding or hoarding plus one or more of the following:

- a. Financial abuse or exploitation
- b. Physical or sexual abuse or assault
- c. Domestic violence
- d. Danger to health and person won't accept services
- e. Threat of eviction or condemnation
- f. Animal abuse or neglect
- g. Suspicion of dementia and/or untreated mental illness

Referring to Senior Coalitions & Senior Centers

All referrals or requests for help for older people can be made to these agencies, also known as “Focal Points for Services” (local versions of the Aging Units in other counties). They provide advocacy, case management, assessments, arrange services, and monitor case plans. They also provide information and referrals about a wide range of aging related programs and resources including housing, benefits, educational, and social/cultural opportunities.



Referring to Mobile Outreach for Seniors Team (M.O.S.T.)

Elders and other members of the community can make direct referrals to this mental health agency that specializes in help for people over 60 years of age. A referral is indicated when a person is known or suspected of having a mental health problem. Referrals are also made here by focal point agencies, EAO, APS and others. All referrals to EAO for hoarding are referred immediately to M.O.S.T. for a team response.

DANE COUNTY ELDER ABUSE & NEGLECT OFFICE’S PROTOCOL FOR FIRST CONTACT WITH PEOPLE REFERRED FOR HOARDING

- Step 1:** Contact Mobile Outreach for Seniors Team (MOST), Mental Health Center of Dane County. Plan first contact. When appropriate and possible, MOST staff will accompany.
- Step 2:** Contact focal point agency. Inform about referral and see if they have prior relationship with client. Make mutual decision about whether case manager will accompany on first contact and plan immediate future roles for case manager and investigator.
- Step 3:** Contact community officer for area, if appropriate or necessary.

DANE COUNTY ELDER ABUSE OFFICE (EAO) HOARDING DECISION TREE – 2001

EAO Protocol when Services are Accepted

Older person requests or accepts offer of help from senior service agency or the county EAO, LTS or APS units.



Make referral to local focal point agency, cleaning agencies, or organizational experts such as Ducks in a Row.



Note: Funding for cleaning services may be available through the county Elder Abuse and Neglect Direct Services Funds: either allocated to focal points or those at the EAO.



Option: *If needed, make referral for supportive home care services to focal point agency or other providers.*



Follow-along case management by senior services focal point agency.



Crisis services may be requested or accepted by an older person. See next page.

EAO Protocol when Services are Not Accepted: Low Needs

When older person does not have strong needs or an imminent crisis:



Inquire about other service needs and provide information about hoarding.



*Provide list of local agencies and Senior Hotline to Help number. If person is willing to accept information, make referrals to other agencies or resources.
(Agencies described on previous page will be helpful).*

EAO Protocol When Services are Not Accepted: High Needs

When elder appears to have strong needs and will not accept help:

↙ ↘

Elder in Crisis

Assess crisis intervention need and take care of it immediately: 911. (Fire, Mental Health Crisis or Law Enforcement summoned).



If concern exists for elder's physical safety, EAN, MHCU, MOST and/or law enforcement (if not already called) should be contacted to assist with beginning to seek emergency placement when needed. *



Refer to Mental Health Center for crisis assessment of emergency detention needs, refer to APS and Corp Counsel for protective placement. *



Elder not in Crisis

Continue to evaluate physical safety and health. Consider involving a significant person the elder trusts and/or contact EAO.



EAO refers to MOST and/or APS to accompany on home visit. If elder won't admit EAO to home and there is no known danger to physical health:



EAO, Focal Point, and/or LE evaluate outside of home and property. If there is no septic system or indoor plumbing, request assessment from DCDHS Environmental Health Office or Building Inspectors (Madison).



Continue efforts to collect information to assess competency.



Try to obtain elder's consent to participate in thorough geriatric assessment or arrange for one as part of emergency placement.



Elder in Crisis (continued)

Review need for temporary guardianship or restraining order when competency seems reduced and more protection is warranted.



DECISION: No placement needed or none will be ordered. There is not sufficient evidence for emergency placement or guardianship.



Continue to try to offer voluntary services or find a new way to make contact with elder and elder's family.



Seek M-Team consultation and review at any point in time.



Go to next column. Continue to involve M.O.S.T. and evaluate the home.

If there is a presence of rodents, infestation of insects, animal carcasses, or other possible health hazards, EAO may make a referral to the Madison Public Health Office or the DCDHS Environmental Health Office.



IMPORTANT NOTE: In any case, call the Humane Society or Animal Control Officer if animal carcasses or other signs of animal abuse are apparent in or around the home.



Elder not in Crisis (continued)

DECISION: Elder continues to refuse intervention / voluntary help:



Seek M-Team consultation and review.



If permitted by client consent or other laws governing confidentiality, let referring party know that there is not sufficient evidence for involuntary intervention. Inform family members of the city, county or village ordinances.



City, county or village ordinances with penalties will apply.



Periodic reoffers of services may be made by EAO and/or the focal point agency.

** Work continues on creating a protocol for agencies involved in protective placements.*

***REFERRAL TO CITY OF MADISON
PUBLIC HEALTH DEPARTMENT
HOUSING INSPECTOR***

Completed by		Phone	
Date of contact	Referred to	Date	
Name		Phone	
Address			
Are there any infants or children living in the house?		YES	NO
Is the owner/occupant possibly not competent to maintain the property in a sanitary condition?		YES	NO
Are there any items of public health concern visible in the yard outside the house? [Example: garbage, tires, stacks of wood debris.]		YES	NO
Are there any signs of rodent infestations visible in <u>the yard or around the house</u> ? [Example: actually see rats, see rat holes by dog pen, see paths worn by rats in grass.]		YES	NO
Is there any evidence of serious insect (cockroach) infestation?		YES	NO
Does the owner-occupant currently receive any services from the Human Services Department?		YES	NO
Has anyone contacted the local building inspector about this problem? Who: _____ When: _____		YES	NO
Does the complainant know of any relatives of the owner that live in Dane County? Name: _____ Phone: _____		YES	NO

Comments:

COMMUNITY AGENCIES REPRESENTED ON THE HOARDING TASK FORCE & THEIR INVOLVEMENT WITH HOARDING

- **City of Madison Fire Department**
(608) 266-4420

Has no inspection or code enforcement authority, responds by making referrals

- **City of Madison Department of Public Health**
(608) 266-4821

Referrals can be made at any step in process; they will be assigned to the specific department responsible. Departments included of interest:

- **Environmental Health**
(608) 294-5335

Respond to all safety and sanitation concerns for owner occupied property. Assists building inspection on rental property complaints as needed.

Violation Procedure: Write orders to owner of property (or landlord in rental property) to remove collection and be in compliance with City Ordinances.

- **Animal Control**
(608) 266-4821

Responds to animal complaints. Assists Environmental Health on owner occupied and rental property complaints.

- **Public Health Nurse**
(608) 266-4821

Assists Environmental Health and Animal Control on owner occupied and rental property complaints. Have no code enforcement, but assists in assessment of health of individual.

- **City of Madison Housing Inspection Office**
(608) 266-4551

Lead agency for rental property complaints. Responds to owner occupied complaints, specifically for exterior issues. Assists Madison Department of Public Health on inside of property. Referrals can be made at any step in process.

Violation procedure: Orders are written to tenant or owner of property and compliance to City Ordinances must be made within 21 days. Enforcement liberal but aggressive. If progress made, inspections are made until property is cleaned up. Referrals made to city attorney for noncompliance.

- **Dane County Department of Human Services**
(608) 242-6200

Led by Charity Eleson, this department provides social services for children, youth and families, persons with developmental or physical disabilities, older people (including those with long-term support needs), and persons with mental illness. It also provides public health, economic assistance and work programs. Departments included of interest:

- ♦ **Adult Protective Services Unit**
(608) 242-6200

Provides assessments and court reports for Guardianship and Protective Placement cases for older persons and vulnerable adults with developmental disabilities, mental illness, or chronic/serious alcohol/drug dependence.

◆ **Elder Abuse and Neglect Office**

(608) 224-3666

Located in the Area Agency on Aging of Dane County. Designated by the county board to do legally mandated investigations and crisis interventions for persons over 60 years of age, including self-neglecting persons and hoarding. Created community coordinated response to elder abuse and neglect including a Multi-disciplinary Consulting Team (M-Team), a Joint Coordinating Committee (JCC), a Fiduciary Abuse Specialist Team (FAST), the Hoarding Task Force, and a Law Enforcement training project.

◆ **Long Term Support Unit**

(608) 261-9887

Provides community services for persons needing long-term care due to disabilities, including those related to aging. Case managers provide comprehensive assessments, care planning, advocacy, and services under the Community Options Program and related Medicaid Community Waiver Programs. Operates the Senior Hotline to Help (608) 266-9007, Dane County's Information & Referral line for older persons.

◆ **Environmental Health Office (Public Health Department)**

(608) 242-6515

Sanitarians will assist in evaluating public health risks associated with hoarding when circumstances allow. Responds to safety and sanitation concerns for owner occupied property if owner allows entry; will seek special inspection warrant as necessary if conditions pose public health threat to adjacent property owners or if children are at risk. Assists building inspection in rental properties if entry authorized by tenant or landlord; will take enforcement actions to assure correction of public health code violations.

Violation Procedure: Write orders to owner of property, or to landlord in rental situations, to correct violations of Dane County sanitary ordinance. Enforcement actions may include citations, long form complaints or injunctions.

▪ **Dane County Corporation Counsel Office**

(608) 242-6200

Provides for court proceedings for emergency mental health, protective placements, and guardianship actions.

▪ **Dane County Humane Society**

(608) 242-6200

Responds to animal complaints throughout the county. Assists Animal Control within the city of Madison.

▪ **Dane County Sheriff's Office**

(608) 284-6170

Led by Sheriff Gary Hamblin, this law enforcement agency has special officers designated to work on domestic violence and other sensitive crimes. In addition, each section of the county has a trained Community Officer assigned. Deputy Linda Hilgers, one of the Community Officers, has been an organizer of Dane County's community elder abuse response system.

OTHER AGENCIES

▪ **Colonial Club of Sun Prairie**

(608) 837-4611

One of 16 community agencies designated by Dane County as a "local focal point" for services for older people, the Colonial Club provides a nutrition program, case management and day services, housing and social/cultural opportunities.

- **Dane County Board of Supervisors
Health & Human Needs Committee**

(608) 266-9388

Supervisor Judy Wilcox, an experienced elected official and chairperson of this committee, served on the Task Force.

- **Ducks in a Row Organizing Consultants**

(608) 249-3321

This agency provides consulting services and hands-on help on a fee-for-services basis. The agency is led by a licensed psychologist who has a special interest in assisting people who hoard possessions. See their website at www.ducks-in-a-row.com.

- **Home Health United / Visiting Nurse Service**

(608) 257-6710 x158

This home health care agency serves 17 counties in south and central Wisconsin. Services include nursing care, physical therapy, occupational therapy, hospice care, respiratory therapy and medical social services.

- **Independent Living, Inc.**

(608) 274-7900

This agency provides housing, personal care, health care (including occupational and physical therapy), respite care, financial counseling, transportation, nutrition and other supportive services for older people.

- **Madison Gas & Electric**

(608) 252-5646

This utilities company has a social services office that works with low income and other elders who are identified by meter readers and others as being at-risk. Huong Coleman, an experienced social worker, has been active in Dane County's aging network for many years.

- **Mental Health Center of Dane County**

- ♦ **Mobile Outreach for Seniors Team (MOST)**

(608) 280-2480

Located administratively in the Mental Health Center of Dane County, this group of mental health professionals is specially trained and experienced in working with older adults. The MOST staff go into clients homes to provide services and work closely with staff from the county's 16 senior services agencies that have been designated as "focal points" for services and also with the various units of DCDHS, including the Elder Abuse and Neglect Unit.

- ♦ **Emergency Services (CRISIS) Unit**

(608) 280-2700

See following pages for description of this unit's services.

- **South Madison Coalition of the Elderly**

(608) 251-8405

One of 16 community agencies designated by Dane County as a "local focal point" for services for older people. Provides a nutrition program, case management and specialized services for Asian American and African American elders, housing and social/cultural opportunities. Operates the county's Guardianship Project, and Community Options Program's (COP) Hospital Link Program. Also provides COP and Medicaid case management.

- **Wisconsin Department of Health & Family Services
Bureau on Aging & Long Term Care Resources**

(608) 266-2568

Specialist on statewide adult protective services, Jane Raymond, joined the Task Force and brought a broader perspective and expertise to its work.

MENTAL HEALTH CENTER HOSPITALIZATIONS THROUGH EMERGENCY SERVICES (CRISIS) UNIT (ESU)

General criteria & guidelines

The treatment philosophy of ESU places a high priority on trying to manage even serious psychiatric emergencies on an outpatient basis whenever possible. Deciding about hospitalization is always a matter of weighing potential benefits versus negatives.

Voluntary hospitalization

If hospitalization is decided upon, voluntary admission is preferable to involuntary. ESU has several responsibilities regarding voluntary admissions.

Involuntary hospitalization

When a person is mentally ill, meets one of the statutory standards of dangerousness to self or others, is a fit subject for treatment but refuses treatment, it may be necessary to initiate a process for involuntary treatment. For definition of the four standards of dangerousness, see Definition #6 in the document entitled “Brief Definitions of Terms & Phrases” (page 47), dated 4/28/92. Crisis staff has a role to play in most of these involuntary actions, because ESU has been designated by Dane County to be a central screening point. The two most frequently used methods of starting involuntary psychiatric treatment are the Emergency Detention (ED) and the Petition for Examination. Please refer to the flow chart describing the involuntary commitment process (attached) as well as “Brief Definitions of Terms & Phrases.”

The **Emergency Detention** is done in acute situations where dangerousness is felt to be imminent, and a law enforcement officer, after consultation with the Crisis Unit, immediately takes a person either to Mendota Mental Health Institute, or in some instances University Hospitals. Face-to-face evaluation of the person by Crisis is preferable, but occasionally there are times when it isn't possible, and after telephone consultation with Crisis staff, the ED is done by the police. Evidence of the dangerous behavior must be clear and immediate for the ED to occur. Details on the ED process follow. In most cases, police and Crisis staff arrive at the decision about ED collaboratively, but in the event of disagreement **THE LAW ENFORCEMENT OFFICER HAS THE FINAL WORD.**

The **Petition for Examination** is a civil action wherein three adults, at least one of whom has personal knowledge of the individual's behavior, sign a petition drafted by the County Corporation Counsel alleging that the individual is mentally ill, dangerous, and a fit subject for treatment. The Petition does not involve a police officer, and while the same four standards of dangerousness apply [see Definition #6 in the document entitled “Brief Definitions of Terms & Phrases” (page 47)], the petition may document an accumulation of smaller incidents, dating back over the previous month or so. Thus, the advantage of the Petition is that there needn't be immediate and obvious danger that a police officer must be convinced of. However, the Petition isn't practical in an acute, emergency situation, because it can take up to several days to accomplish. If Crisis staff think a Petition may be appropriate, they refer the prospective petitioner to the Corporation Counsel's office for the Petition to be drafted and sent through channels. This will result in either an initial Court hearing, following which the person may be hospitalized at Mendota Mental Health Center or University Hospitals, or the immediate issuing of a Body Attachment by which the individual is picked up by the police and hospitalized at Mendota Mental Health Center or University Hospitals.

Crisis staff receives many requests to evaluate someone for an ED. These requests come from all over the community – from families, other mental health workers or agencies, or from the police. Doing a good assessment for an ED ideally involves gathering of reliable information from collateral sources, having treatment history available, evaluating for current mental illness, and collaborating with police on assessing dangerousness. There are times, unfortunately, when the ideal conditions are not present, and the decision must be made with the best information that is available. An ED evaluation, from ESU's point of view, answers not only the question “Are the conditions met in which an ED can be done?” but “Is an ED absolutely necessary at this time?” and “Is

there anything else that can be done?” Sometimes it is possible to persuade the individual to enter a hospital voluntarily rather than be taken by police to Mendota Mental Health Center. Sometimes a voluntary outpatient plan can be arrived at which it seems worthwhile to try, before going to the most restrictive step of an ED.

BRIEF DEFINITIONS OF TERMS & PHRASES RELATED TO EMERGENCY PROTECTION ACTIONS

1. **Chapter 51, Wisconsin Statutes (Mental Health Act)**
Provides legal procedures for voluntary and involuntary treatment and rehabilitation of individuals afflicted with mental illness, alcoholism, or drug dependency.
2. **Chapter 55, Wisconsin Statutes (Protective Service System)**
Provides legal procedures for services or placement of incompetent individuals afflicted with permanent and untreatable mental conditions such as infirmities of aging, mental retardation or other developmental disabilities or like incapacities. Court appoints a guardian to have care, custody and control of the incompetent person.
3. **Emergency Detention (s. 51.15 Stats.)**
Police officer immediately takes a person to a mental health facility upon the belief from either personal observation or reliable reports of others that the individual is mentally ill and dangerous.
4. **Petition for Examination (s. 51.20, Stats.)**
Three adults, at least one of whom has personal knowledge of the individual’s behavior, sign a petition drafted by the county corporation counsel alleging that the individual is mentally ill, dangerous, and a proper subject for treatment.
5. **Mental Illness (s. 51.01(13), Stats.)**
For the purposes of involuntary commitment, mental illness means a substantial disorder of thought, mood, perception, orientation or memory which grossly impairs judgment, behavior, capacity to recognize reality or ability to meet the ordinary demands of life.
6. **Standards of Dangerousness (ss. 51.15 and 51.20, Stats.)**
 - a. Recent acts, attempts, or threats of suicide or other self-harm; or,
 - b. Recent acts, attempts or threats of physical harm to others; or
 - c. Such impaired judgment causes the person to be an inadvertent danger to self; or,
 - d. Mental illness causes the person to be unable to satisfy life’s basic needs.
7. **Proper Subject for Treatment (Wis. Civil J.I. 7050)**
An Individual is treatable if the administration of any treatment techniques may control, improve, or cure the mental illness.
8. **Probable Cause Hearing (s. 51.20(7), Stats.)**
Within 72 hours of the individual’s detention at a mental health facility (excluding weekends and holidays), the court holds an evidentiary hearing to determine if there is reason to believe the allegations in the petition or statement of emergency detention. The case is either dismissed, bound over for trial, resolved through a negotiated settlement agreement, or converted to guardianship and protective services.
9. **Settlement Agreement (s. 51.20(8)(bg), Stats.)**
Written negotiated voluntary treatment agreement between the individual and the county corporation counsel, and approved by the court, which specifies treatment for the individual’s mental illness for a period not to exceed 90 days. Failure by the individual to comply with the settlement agreement will result in the case going back to court for commitment.

10. **Conversion to Guardianship and Protective Services (s. 51.20(7)(d) and 51.67, Stats.)**

After probable cause or final hearing, the mental commitment case may be converted to a guardianship and protective services proceeding if the court determines that the mental condition is likely to be permanent, untreatable, and renders the individual incompetent.

11. **Commitment for Treatment (s. 51.20(13), Stats.)**

An individual is court ordered to the care and custody of the county department for either inpatient and/or outpatient treatment for up to six (6) months if there is clear and convincing evidence that the individual is mentally ill, dangerous to self or others, and a proper subject for treatment. At the end of the term of commitment the court may order subsequent recommitments for up to one year each if the person is not likely to continue treatment voluntarily.

12. **Right to Refuse Psychotropic Medication (s.51.61 (1) (g), Stats.)**

An individual may refuse medication treatment after probable cause hearing and/or commitment, if the individual is competent regarding psychotropic medications (i.e. capable of expressing and understanding of the risks and benefits of the treatment). Court can order treatment with medications involuntarily only if patient is not competent.

13.

HOUSEHOLD HYGEINE ISSUES: A LEGAL DISCUSSION

Notes from Presentation by Attorney Kitty Noonan, City of Madison, Wisconsin

INTRODUCTION

I have been asked to speak about legal issues relating to health inspections and “dirty” houses – hence the title “Household Hygiene Issues.” I am an assistant City Attorney in Madison and besides traffic and general ordinance prosecution, I do all the building code prosecution. Because I do not prosecute health code violations, I talked with Jim Steinhoff in the Madison Health Department to find out about the unique problems that health inspectors may face when dealing with living conditions that present health concerns. There are many similarities:

- Small percentage of cases.
- Concerns may vary depending on the particular living situation, such as single family, multifamily, etc.
- Ordinances relating to cleanliness, insect infestations, presence of vermin, animal waste, and open space. The cases I have dealt with relating to conditions of the home for Building Inspection have been based on the open space requirements – houses packed so full that only small paths remain.

POLICE POWER

- Source of power for municipalities to act.
- Goal is to preserve and further public peace, order, health and welfare.
- Basic premise is a reasonable preference of public over private interests.
- Fundamental tension between public and private rights.
- Authorize laws to require conduct and use of property that does not unnecessarily injure other.

In specific terms: tension between police power (reflected in Chapter 254) and fundamental rights, such as having our private space safe from governmental intrusion. There are no bright lines in the law. Under the law, police power must be exercised in a reasonable manner. The question is “What is reasonable?” I will talk about two areas where departments and courts must deal with these determinations.

1. Inspections and inspection warrants.
2. Different treatment of similar problem with different groups or living conditions.

INSPECTION WARRANTS

The issue of gaining entry is often a problematic one when dealing with “dirty houses.” *Camara vs. Municipal Court*, [387 US 23 (1967)] addressed the main concerns with administrative searches. The court acknowledged that this is a different concept than the criminal search. Some of the court’s holding were that administrative searches are significant intrusions upon interests protected by the Fourth Amendment; therefore searches without warrants lack the traditional safeguards guaranteed by the Fourth Amendment. This is not the end of the story.

- Important public interest in preventing hazards to public health and safety.
- Balance intrusiveness of search and “reasonable” goal of enforcing safety codes.
- Some final words of the court: After focusing on protecting private interests, requirement of warrant procedure does not suggest any change in what seems to be the prevailing local policy of authorizing entry (but not entry by force) to inspect.
- Bottom line: Warrant only required when entry is refused.
- §66.122, Stats: not for public property and issued only when consent to enter has been refused.

HOW TO GET A WARRANT:

- Either municipal or circuit court can issue.
- Necessary information: probable cause to issue.
- *Camara’s* requirement was a building code case – no health cases.
- “Reasonable” legislative or administrative standard for conducting an inspection.
- Can be based on passage of time, nature of property, conditions of entire area.
- Building Inspector example of bad outside so desire to see inside, programmed inspections.
- Will not depend on specific knowledge of the condition of a particular dwelling.
- Much lower standard than criminal warrant.
- For health, could be complaint of odor that was checked out.
- Programmed inspection – probably more likely to be complaint based.
- Evaluation of complainant – affidavit to court.

As recently as 1995, courts were still following *Camara*. The Kansas Supreme Court upheld yearly fire inspections of commercial property. Sufficient to issue warrant with refusal of entry. 1997 Washington state case: Seattle developed a new way of proactively identifying code violations in apartment buildings. Used age, assessed value, number of code violations in the past five years. Court found it to be a reasonable program and issued warrant.

SO ONCE YOU’RE IN

How does the law affect how we deal with different situations? Go back to the public/private tension – no bright line – must act reasonably. Public health means affecting the public in some way. Becomes trickier when considering private homes.

Courts have allowed different treatment. *Tenement House Department* (1904) required installation of individual water closets in place of school sinks – only tenements had to do it. Court said that “dirt, filth, nastiness in general, are great promoters of disease, that they breed pestilence and contagion, sickness and death, cannot be successfully denied.”

1997 – US District Court in Illinois: Licensing of multifamily dwellings to protect, preserve, promote physical and mental wellbeing, prevent and control incident of communicable diseases, maintaining adequate sanitation and public health.

MODEL ORDINANCES & LAWS – TASK FORCE DISCUSSION NOTES

The Dane County Environmental Health Department works under two Environmental Health codes, the Wisconsin State Statute and the County Ordinance. Each city, town and village may choose to create a more detailed ordinance or use the Dane County Ordinance. In 1999 the local focal points/senior centers and the Elder

Abuse Office reported 166 hoarding cases in Dane County. Even though there may be some duplicated cases, this is still a staggering amount. In Dane County, there is a combination of state, county, and municipality ordinances used to address the potentially serious problem of hoarding.

All ordinances address structural issues of the home. County and state ordinances primarily address septic and water systems. Private wells need to meet state plumbing codes. City of Madison ordinances address safety and sanitation issues by defining living space and conditions; heat and water are primary concerns. Safety in the living space is defined as a three-foot pathway through and access to all rooms. Electrical outlets and heating ducts have to be accessible.

Ordinance enforcing agencies require direct knowledge of situations before they will start an investigation process. All agencies have to follow pre-established guidelines when dealing with violations. It is easier to address hoarding issues in rental property versus private dwellings. The city and county have animal control agencies to effectively deal with animal neglect and abuse issues.

The goal of our subgroup was to evaluate current ordinances and consider developing a model ordinance that would be explicit but simple enough for all local communities to adopt. We talked about changes that might be necessary and it was determined that the ordinance may not be the issue. The **Human Health Hazard** subsection under the County Ordinance states that:

“If the local health officer finds a human health hazard, he or she shall follow the procedures set forth in s.254.59, Wis. Stats. and the procedures set forth in said section of the statutes, and acts amendatory thereto, are adopted and referenced as though fully set forth herein. The department may declare housing that is dilapidated, unsafe or unsanitary to be a human health hazard.”

For our definition the concerns addressed were “Does the home have running water and a working sewer system?” The City of Madison goes one step further and also requires a working furnace. Along with the county’s Corporation Counsel, the subgroup reviewed the ordinances and decided that the best remedy may not be to change them, but educate the county about them instead. It would be beneficial to meet with local city, town and village boards to make them aware of concerns and educate them on whom to call.

This may be the most effective way to deal with the hoarding situations. We also discussed the potential of increasing the fines for not complying with court orders. The group acknowledged that often hoarders do not see anything wrong with the condition they are living in and so the consequences are almost meaningless. Fines may mean nothing but the possessions in the home mean everything. We concluded that education and a team approach with local municipalities are the keys to successfully managing these hoarding situations.

Application of pertinent statutes as discussed in a Wisconsin State Journal article, dated 7/31/01:

Hoarders come to the attention of public officials when neighbors complain about odors or debris piling up outside, when utilities report that water, heat or electricity has been cut off or when a concerned relative or friend asks for help. Public health and building inspection departments then work together to resolve the problem, using city ordinance violations to prod the hoarder to clean up. Often they call in Dane County mental health workers and, as the typical hoarder is elderly, work with senior citizen organizations that provide support for the hoarder. They may call in adult protective services workers or county investigators of elder abuse and neglect. Animal control officers are used as needed. Over the years, an informal "special response team" has developed to work with the hoarder.

"There's a definite pattern for these people," Tommye Schneider, Madison Health Department's Director of Environmental Health, said. "They reach the point where they don't cook anymore or clean anymore. They go out and pick food up and come back home and the containers are just left. They might want to clean it up, but they can't make a decision about what can be thrown away and so nothing is thrown away." Officials rely on ordinances that require occupants of a residence to keep the premises in "a clean, proper and sanitary condition." They also rely on the city housing code, which requires two exits, three-foot pathways, access to all rooms and electrical outlets, clear heat ducts and at least 150 square feet of living space for the resident.

Officials first send the hoarder a letter, asking them to contact officials. If the hoarder refuses to let anyone in, officials with probable cause can obtain an "inspection warrant" from a magistrate or judge, allowing them to go inside. They try to be gentle, Grubb said. "We've never had to use a locksmith or break down a door." Health and building officials also try to respect homeowner's or renter's rights. "People have a right to do a lot of things in their own home," Schneider said. Not long ago, for example, the fire department notified the health department about a suspected hoarder. "We went in and it was just 'stuff.' Newspapers and piles of clothes. There was no rotten food or animal feces," she said. "People can live that way if they want to and are free to do so, so we closed the case."

Officials intervene "when you have feces or rotting food that attracts rodents. Some people end up not paying their utility bills. It's very unhealthy situations, and yet when you see them on the street, they look like the healthiest people around. They're obviously ill in some way, but they're out, driving around, shopping," she said. Schneider said she'd worked with several retired professional women, "who are very bright to talk with. When you go into their houses, it's overwhelming. I'm pretty convinced they can't smell anymore, because they don't realize it. By the time we get to them, they've been living that way for 20 or 30 years. To go in and turn their world upside down in a couple of days is pretty overwhelming."

The health or building department issues cleanup orders, then makes repeat inspections until conditions are remedied. It is the homeowner's or renter's responsibility to hire a cleaning company. "There are certain cleaning companies that specialize in these heavy-duty jobs," Schneider said. Often, building inspectors designate the property "no occupancy," meaning it's unfit to live. "Sometimes the threat of a citation or court gets the person moving on cleanup. If they don't comply, we prosecute them in municipal court for violating ordinances," the building department's Grubb said. "It's very real pressure that won't go away."

The worst cases can drag on for months or even years, Grubb said. "The success stories are when the person is returned to a clean situation, may get some medication or end up with some kind of supervision and are able to live without sliding back into this," she said.

CASE STUDIES FROM DANE COUNTY, WISCONSIN

The following two case studies are examples of how the Hoarding Task Force solidified a community response to the problem of hoarding. It is expected in the future that the Dane County Elder Abuse & Neglect Multi-Disciplinary Team will provide the consultation and identification of services needed to resolve newly identified hoarding cases.

▪ "JANE," AN ANIMAL HOARDER

On November 19, 2000 the Elder Abuse Office (EAO) received a phone call from the Dane County Sheriff's Department in regards to two friends, "Jane" and "Frances." Frances had been staying with Jane since being evicted from her home. Jane called the police because she was concerned about Frances making suicidal statements due to her recent circumstances. Another referral was made from the Village Board of Supervisor's Chairperson. She was aware of the eviction and concerned about the living conditions and that Frances had moved her horse to Jane's property, which was zoned as residential; therefore horses were prohibited.

Information was collected from the local senior services agency (focal point), as well as other public officials that had been involved. The County Public Health Department had been called but refused to do a home inspection based on what the reported condition of the home was thought to be. The Public Health Department asked the Elder Abuse Office to assess the situation. It was decided that one of the EAO social workers would accompany "Sara" (the focal point case manager) on a home visit to assess the situation.

We were greeted by several dogs on chains, the horse that was penned in, and a woman who looked like she had been in the same clothes all fall. It was evident Jane's hygiene was being neglected. Her hands, nails, feet and clothing were very dirty. The porch looked like it had actually sunk into the ground because of the weight it was holding. There were boxes, newspapers and clothes all piled up, filling the tiny space. There was food stored outside; there was no room for it in the house, according to Jane. A closer look revealed jugs of milk that had passed their expiration dates. There was a refrigerator and other indiscernible objects in the front yard, which was covered in dog feces. Cats lined up in the windows to get a look at us.

We talked with Jane about her situation. She told us about Frances being evicted for nonpayment and because of the condition of the home. She had been renting from a family member of Jane's. Frances did not have any money and Jane was paying for food for the animals, as well as utilities and all other costs incurred. We asked Jane about the condition of her home. Of course she told us that everything was fine. It did not look fine. We met Frances, who initially came across as being depressed. She was looking for a place where she could live with all her animals; a few dogs, cats, and a horse. We later found out she had over 15 dogs, 5 cats, a few birds and a horse. This did not include the animals Jane owned. We continued to visit and offered assistance with cleaning up, alternate housing and mental health needs, but were always turned down when we offered assistance. Any questions about the house were deflected.

We were at a standstill. The local case manager and elder abuse investigator discussed getting all involved agencies together to meet and discuss options. We had two competent women living in a house that was full and dilapidated. At least one of the women had mental health issues. We were concerned about the care the animals were receiving. The village was concerned about what to do with the horse.

We held a meeting in October with the family member of Jane's who had evicted Frances. The Sheriff's Department, Village Chair, Humane Society, County Public Health Inspector, Community Action Coalition (for alternate housing options), Sara and I met to discuss and address our concerns. Jane's family member stated he was aware there was no running water and therefore no working sewer system. He felt Frances was dependent on Jane not only for a place to live but also for money. It was later determined that Frances was financially taking advantage of Jane by receiving Social Security/Disability yet denying any income when she talked to Jane. Jane's other bills were being neglected due to these new responsibilities, causing more problems for her.

From October 2000 until February 2001, all the agencies listed above made efforts to provide assistance to the two women. The Public Health Department attempted three visits to inspect the house but was denied every time. They worked to get an inspection warrant. The need for a Representative Payee for both women was being considered. This would protect and ensure that bills would be paid on Jane's behalf and take some of the decision-making issues away from Frances if someone else was finding her a place to live. Meanwhile, five animals were taken into custody by the Humane Society.

A warrant was issued in February and the Public Health Inspectors, the local building inspector, and the Humane Society inspected the house. It was found to be uninhabitable because of structural damage and internal plumbing problems. The house was condemned and residents given notice to have all wanted belongings out in 30 days. The Village will most likely have to demolish the property. The Elder Abuse Office and focal point worked to find Frances another home (an apartment) and she surrendered all but two of her animals to the Humane Society. Jane moved to another property she owned.

The local case manager continued to visit with Jane to make sure her needs were being met and she was safe. There are concerns about the new place she moved to, but the family is now involved and monitoring the situation.

“VIRGINIA” & ALL HER STUFF

In June of 1998, our office received a phone call from a local focal point. The call was in regards to a woman “Virginia,” who was 76 years old. She had health concerns, mostly related to her heart. She had trouble breathing at times and was having difficulty getting around. This was due partly to her health and partly to the “stuff” that was taking over her home.

“Stuff” had spewed off the kitchen counters onto the floor. Stuff had oozed out of every room and even into the bathtub. The home was so full there was only a small path left to walk through the house. The stuff consisted mostly of furniture, clothing, old mail, empty pill bottles and containers ranging from Rubbermaid gallon containers (that were going to be used to put the stuff in someday, according to her) to small, previously used food containers. There was a layer of dust about an inch thick covering everything. The dust reminded me of a blanket that was there to protect something. From the smell, it was evident that food was being allowed to ferment into something other than its normal state. With the home looking and smelling so unkempt, I expected to meet an owner that looked and smelled quite the same.

To my surprise, I met a woman who was quite interested in her appearance. At least as much as she could be, given that the mirror in the bathroom had stuff piled up in front of it and the bathtub was full of clothes that “were going to be taken to the cleaners someday.” The bathroom floor was so worn and rotting from water damage that if I looked close enough I could almost see through to the basement. Virginia was sleeping on her couch because she could not make enough room on her bed; the stuff had already claimed ownership. All three bedrooms were full, making it difficult to open or close any of the doors completely.

Our office was asked to “encourage” her to clean up her home; it was in her best interest and for her safety. She did not feel the same. After taking the time to build a relationship with her, she eventually allowed a housekeeper in to help uncover a lost dining room. This person was hired to help her go through and discard belongings. At first things seemed to be going well, but eventually Virginia accused the person of wanting to steal her possessions and dismissed her. The encouragement continued and ultimately another attempt was made.

In June of 1999, Virginia agreed to meet with a cleaning agency. It was going to cost \$300 just to remove debris and clean the living room. Financial assistance was offered by the Elder Abuse Office; however, she refused the money and the cleaning. Things had started to fall down around her. In September of 1999, the utility companies got involved. She was alerted to the fact that she was several thousand dollars behind in bills. She also owned three homes that she owed back-taxes on. Her attorney was persuading her to make some decisions and changes. He was feeling frustrated. We were all feeling frustrated. Several meetings took place with and without Virginia to determine if there was anything that could be done to improve her situation.

Virginia continuously reported thefts to the police. One report noted that the house was too cluttered to determine if anything had been stolen. Meanwhile, her health was failing. One private case manager had the police force their way into the home when Virginia would not answer the door. The case manager knew something was wrong because Virginia’s dog would come to the door and then run to the back of the house. When the police entered, they found she had tripped over some stuff in the bathroom and fallen into the tub, unable to get out on her own. She was hospitalized and her cognitive status was evaluated; the doctors felt that she was competent. Virginia finally agreed to work with the Elder Abuse Office. In August of 2000, a conservatorship was arranged. Working with Virginia, the conservator paid her debts and hired people to clean up, restore and maintain the home.

There was a significant improvement in the home and it became a safer place for her to live. However, this was not the only change. Friends and neighbors that had stopped coming over because of the mess eventually started visiting again. Her health was improving because she was allowing services to come into the home. Her mood was also improving because a door had opened for her friends that in the past was barricaded shut with piles of stuff. It took two years and much effort from neighbors, friends, the police, the focal point, and the Elder Abuse Office to secure a safer place for Virginia.

LOCAL MEDIA:

“HOARDING CAN BE SERIOUS MENTAL DISORDER”

CAPITAL TIMES

July 18, 2000

By Barbara Quirk, RN and Columnist

A former neighbor, a widow who lived alone in a four-bedroom, two story house with a full basement, had to put an addition on to hold all of her “stuff.” Other neighbors and I just laughed about it, not realizing that this poor lady’s inability to throw things away could be a sign of a serious mental disturbance. Since then I have been in several homes and apartments where there is barely a path through the accumulated clutter, and every stick of furniture is piled high. Today, hoarding is recognized as a significant problem that can threaten health and lead to falls, isolation, neglect and eviction.

“Hoarding is significant for what we don’t know about it,” explains Melanie McIntosh, program and services manager for the Area Agency on Aging of Dane County. She and Brenda Ziegler, social worker for Dane County’s Elder Abuse and Neglect program, have joined forces with other area agencies to form a Hoarding Task Force to address this growing but poorly understood problem. “Many of us are ‘pack rats,’” says McIntosh. “Clinical compulsive hoarding goes beyond this.” It is defined as:

- ◆ The acquisition of and failure to discard a large number of possessions that appear to be useless or of limited value.
- ◆ Living space cluttered so as to preclude activities for which those spaces were designed.
- ◆ Significant distress or impairment in functioning caused by the hoarding.

Hoarding represents a complex set of psychological and social factors requiring multilevel responses. “First of all, we don’t usually find these folks until there is a crisis,” says McIntosh. “So the crisis has been dealt with first. It may be an injury, or an eviction threat, or a public health issue.” “It is far more than just removing the clutter,” Ziegler adds, while describing one Madison home whose rubble filled 15 dumpsters. “If the reasons for hoarding are not addressed, the process of accumulating will simply start over. “It is so sad,” says Ziegler, describing how difficult it is for hoarders to part with things. “I’ve heard it described as their homes being as full as their lives are empty.”

Hoarding involves amassing things in no apparent order. There will be a wedding ring next to an old plastic bottle, next to a 3-year-old bagel, next to last year’s newspapers. “After a while, it is like a tossed salad, with things mixed together in no particular order,” Ziegler says. “There seems to be no rhyme nor reason for what is saved.” McIntosh describes one Dane County home where you literally had to step up three feet to get into (and onto) the pile of stuff inside the doorway. “I’ll never forget it. It was like walking on a garbage heap,” she says. “In the middle of all the trash was a lovely portrait in a beautiful gold frame. Turns out, it was a picture of this lady’s deceased daughter.”

McIntosh asks: “How much loss can people take?” Although there are some clear associations of hoarding with obsessive compulsive disorder, schizophrenia, depression and other pathology, McIntosh believes there is often a strong association to unresolved grief or loss. “So many women have lost children and may not have had the opportunity to process that loss. And when children are abused, they tend not to share or give up their possessions.” McIntosh thinks there also might be a connection there. Generally, people who hoard have done so over a lifetime and see nothing wrong with their chosen lifestyle. They tend to lack insight into the problem and resist change. They may be considered simply eccentric and do not come to anyone’s attention until, in their old age, they need services.

Hoarders tend to live alone, so their extreme behavior is not obvious. Hoarders come from all socioeconomic backgrounds. The tendency crosses class, education, income and cultures. More women than men hoard. They

are generally mentally competent, although a certain number of people with dementia can be called hoarders. The prevalence is unknown, but the complexity of the problem is such that it demands attention.

A nurse with the Madison Public Health Department, Nancy Odell, wrote a paper describing the “Dirty House” problem. “The ‘dirty house’ referral received in a local health department is one that is guaranteed to elicit sighs from the staff, be it nurses or sanitarians,” she writes. “These referrals tend to be multi-faceted in that there are aspects of the problem that involve several different agencies, such as building inspection, fire department, social services as well as public health.”

Odell points out the crux of the issue: “These complaints also cross into an area of tension in the law between citizens’ right to privacy and threats to public health and safety.” “If we had the time and resources, the process of intervening in a hoarder’s way of life could be much more positive and humane,” says McIntosh. “That is why we have formed a task force.” If you believe someone needs assistance with hoarding or other aging issues, call the Senior Hotline to Help at (608) 266-9007.

Barbara Quirk is a geriatric nurse practitioner.

BACKDROP FOR THE TASK FORCE: DANE COUNTY’S ELDER ABUSE & NEGLECT COORDINATED COMMUNITY RESPONSE PROJECT

In 1998, Dane County Department of Human Services competed for a state grant to help fund the development of a community response system for elder abuse and neglect prevention and intervention. The grant allowed DCDHS to develop a small community organization team comprised of case managers from the local senior services network as well as to provide direct service to at-risk older people.

During the first year of the grant, the Area Agency on Aging of Dane County (AAA) was opened and the elder abuse and neglect program transferred to that unit of DCDHS. Led by AAA staff, the community organizing team developed a steering committee. With their guidance, the team conducted a study of the adult protective services and elder abuse and neglect systems in the county. The study report was presented to the steering committee, the Area Agency on Aging Board, and disseminated around the county.

During the second year of the grant, the study report was analyzed and a list of issues was created as a blueprint for action. In January 2000, the AAA Board and the Commission on Sensitive Crimes jointly created a coordinating committee to oversee the substantial changes planned during the previous year. The Chairs of both appointed the Joint Coordinating Committee on Elder Abuse and Neglect.

Soon after their appointment, the Joint Coordinating Committee launched some new projects. First, they organized a Hoarding Task Force to develop knowledge, coordination and services for older people who are challenged by severe problems with hoarding. Next, they convened a Fiduciary Abuse Specialist Team (FAST) based on a model of a similar team in Los Angeles, California. The FAST project focuses local expertise on a coordinated approach to preventing and intervening with cases of material or financial abuse of elders. Third, the existing Multi-disciplinary Team was reevaluated and changes made in some of its logistics and meeting process in light of the community study findings. Fourth, numerous training needs existed and the JCC to focus on law enforcement training in 2001.

In addition to conducting elder abuse investigations and crisis interventions, AAA staff develops, and in partnership with other agencies, coordinates community response systems for elder abuse and neglect prevention and intervention. Currently, the four community groups are:

The Joint Coordinating Committee on Elder Abuse and Neglect (JCC)

Appointed by the Commission on Aging/AAA Board of Directors and the Commission on Sensitive Crimes, they are charged with providing leadership for the county in public education, policy development, system coordination, and enhancements. The JCC conducted research this past year and reported on the need for system changes for improving community protection and services to older adults.

The Fiduciary Abuse Specialist Team (FAST)

Membership includes attorneys from the district attorney's office, the Department of Justice and private firms, local bank officials, financial counselors, social workers, and law enforcement officers. FAST focuses on prevention, public education, system development/coordination, and case consultation.

The Hoarding Task Force (HTF)

Membership includes representatives of public health, mental health and human service agencies, as well as a local public utilities company, the county board, and building inspection departments. The Task Force is concerned with older people who have severe problems hoarding materials and/or animals. They work to improve community response by cross training, coordinating efforts and public education.

The Multi-Disciplinary Team for Elders and Vulnerable Adults (M-Team)

Provides a monthly forum for all human service, health care and law enforcement agencies to present cases anonymously about abused, neglected, exploited or at-risk adults and have the M-Team help identify additional intervention options.

EXCERPTS FROM “CLUTTERERS ANONYMOUS: A BRIEF GUIDE”

Printed with Permission from Clutterers Anonymous, WSO Literature Committee
CLUTTERERS ANONYMOUS, PO BOX 91413, LOS ANGELES, CA 90009-1413 (310) 281-6064

PREAMBLE

Clutterers Anonymous is a fellowship of individuals who share experience, strength and hope with each other that they may solve their common problem with clutter and help others to recover. The only requirement for membership is a desire to eliminate clutter and bring order into our lives. There are no dues or fees for membership; we are self-supporting through our own contributions, neither soliciting nor accepting outside donations. Clutterers Anonymous is not affiliated with any public or private organization, political movement, ideology, or religious doctrine; we take no position on outside issues. Our primary purpose is to eliminate clutter, to establish more order in our lives, and to carry this message of recovery to clutterers who still suffer.

We believe that we can recover from cluttering and use our experience to benefit others. We believe we are entitled to surroundings of serenity and order and joyous lives. We simplify our lives, believing that when we need a fact or an item, it will be available to us. We nurture our spirit by surrounding ourselves with beauty and harmony.

HOW DO I KNOW IF I'M A CLUTTERER?

1. Do you have more possessions or items in your life than you can handle comfortably?
2. Do you find it difficult to dispose of many things, even those you haven't used in years?
3. Do you rent storage space to house items you never use?
4. Do you spend time looking for things that are hard to find because of all the clutter?
5. Do you find it easier to drop something than put it away, or to wedge an object into an overcrowded drawer or closet rather than to find a space for it?
6. Do you collect things to give to others?
7. Do you bring things into your home without establishing a place for them?

8. Is your clutter causing problems in your relationships?
9. Are you embarrassed to have visitors because your home is never presentable?
10. Do you hesitate sharing about this problem because you are ashamed of your cluttering?
11. Are you constantly doing for others while your own home is out of order?
12. Do you miss deadlines or abandon projects because you can't find the paperwork or material you need to finish the work?
13. Do you sometimes get buried in details, making projects take much longer than is really necessary?
14. Do you procrastinate about cleaning up because you believe you must do it perfectly or you won't do it at all?
15. Are you easily sidetracked, moving from one project to another without finishing any of them?
16. Do you have problems with time management and estimating how long it takes to do things?
17. Do you believe there is all the time in the world to clean your house, finish those projects, and read all those piles of old magazines?
18. Do you use distractions to escape from your clutter?
19. Have you tried to clean up from time to time but find yourself unable to stick with it?
20. Does the problem appear to be growing?

If you answered "yes" to three or more of these questions, there is a chance you are a clutterer or well on your way to becoming one.

TOOLS OF RECOVERY

ACTION is the magic word. We have found these actions helpful to create for ourselves an environment of order, beauty and serenity.

1. **MEETINGS:** We attend meetings to learn how the program works and to share our experience, strength, and hope with each other.
2. **TELEPHONE:** We use the phone to keep in touch with other members of the fellowship between meetings. We make calls before and after any critical action. Talking on the phone helps both members.
3. **DAILY ACTION:** We do something each day to further our recovery, doing what we can, no matter how small. Our goal is progress, not perfection.
4. **BUDDIES:** Buddies are CLA members and helpmates in recovery. We may call them with our daily plan or ask for help with a project.
5. **SPONSORS:** Sponsors are CLA members who are committed to recovery through the Twelve Steps and Twelve Traditions. A Step sponsor leads us through the Twelve Steps of Recovery. We choose a sponsor who has what we want. The sponsor and buddy may be the same person.
6. **LITERATURE:** We use CLA literature and that of other 12 step programs. Literature is an ever-available tool that helps us gain insight as well as strength to deal with our problem.
7. **SERVICE:** Service is giving back to the fellowship, from holding office to doing cleanup. It helps us to feel a part of the group and to solve problems cooperatively.
8. **FOCUSING:** Our goal is to do one thing at a time.
9. **STREAMLINING:** We honor what we own by setting limits on our possessions. We keep only what we use and have space for. We realize that the more we acquire, the less we enjoy what we already have.
10. **EARMARKING:** We provide a place for our possessions and return them there. We create a home for anything before bringing it in. When we add a new item, we release an old one. For accessibility, beauty and peace of mind, we keep some empty space.

THE TWELVE STEPS

1. We admitted we were powerless over clutter – that our lives had become unmanageable.
2. Came to believe that a Power greater than ourselves could restore us to sanity.
3. Made a decision to turn our will and our lives over to the care of God as *we understood God*.
4. Made a searching and fearless moral inventory of ourselves.
5. Admitted to God, to ourselves and to another human being the exact nature of our wrongs.
6. Were entirely ready to have God remove all these defects of character.
7. Humbly asked God to remove our shortcomings.
8. Made a list of all persons we had harmed, and became willing to make amends to them all.

9. Made direct amends to such people wherever possible, except when to do so would injure them or others.
10. Continued to take personal inventory and when we were wrong, promptly admitted it.
11. Sought through prayer and meditation to improve our conscious contract with God as *we understood God*, praying only for the knowledge of God's will for us and the power to carry that out.
12. Having had a spiritual awakening as the result of these steps, we tried to carry this message to others, and to practice these principals in all our affairs.

THE TWELVE TRADITIONS

1. Our common welfare should come first; personal recovery depends on Clutterers Anonymous unity.
2. For our group purpose there is but one ultimate authority – a loving God as expressed through our group conscience. Our leaders are but trusted servants; they do not govern.
3. The only requirement for Clutterers Anonymous membership is a desire to eliminate clutter and bring order into our lives.
4. Each group should be autonomous except in matters affecting other groups or Clutterers Anonymous as a whole.
5. Each group has but one primary purpose – to carry its message to the person who still suffers.
6. A Clutterers Anonymous group ought never endorse, finance or lend the Clutterers Anonymous name to any related facility or outside enterprise, lest problems of money, property and prestige divert us from our primary purpose.
7. Every Clutterers Anonymous should remain forever nonprofessional but our service centers may employ special workers.
8. Clutterers Anonymous, as such, ought never be organized, but we may create service boards or committees directly responsible to those they serve.
9. Clutterers Anonymous has no opinion on outside issues; hence the Clutterers Anonymous name ought never be drawn into public controversy.
10. Our public relations policy is based on attraction rather than promotion; we always maintain personal anonymity at the level of press, radio, or films.
11. Anonymity is the spiritual foundation of all our traditions, ever reminding us to place principles before personalities.

A TRAINING GUIDE ON HOARDING AND ETHICAL DILEMMAS

By Melanie McIntosh, MSW

Presented at UW Madison School of Social Work

- A. Definition of hoarding.
 - B. Show videotape of home of hoarder, interior only (with permission of owner).
 - C. Eccentricity or Self-Neglect? *
 1. Describe the concepts of self-determination and competency.
 2. Discuss the standards of dangerousness to self and or others.
 - D. Incidence – Data
 1. How much of it do we see in Dane County? *
 - E. Describe what we have learned about hoarding
-
1. Loss and control issues.
 2. Obsessive Compulsive Disorders and other research.
 3. Impact of illness, poverty, dementia, or depression or full blown OCD.
 4. Dynamics of hoarding: what is lost and what is gained?

- F. Examples:
1. Successful person – Retires – Has health problems – Begins hoarding
 2. Animal hoarder in rural Dane County.
 3. Lifelong hoarder.
- G. Whose Problem Is It?
1. The “Pain of Cleaning Up” – The meaning of things.
 2. Impact on a Community – Ethics of Interventions.
- H. Multi- Disciplinary Approach needed *
1. Describe Dane County’s community organization model.
 2. Describe what building inspectors do.
 3. Public Health perspective.
 4. Mental Health perspective.

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