WORKING WITH SELF-NEGLECTING CLIENTS

PARTICIPANT MANUAL

MODULE 10
This training was developed by the Academy for Professional Excellence, which is funded by a generous grant from the Archstone Foundation.

Curriculum Developer

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INTRODUCTION

THE ACADEMY FOR PROFESSIONAL EXCELLENCE

We are pleased to welcome you to the Working with Self-neglect Clients Training developed by Project MASTER, a program of the Academy for Professional Excellence and the product of the National APS Training Partnership.

The Academy for Professional Excellence was established in 1996 and provides training, technical assistance, organizational development, research, and evaluation to public and private health and human service agencies and professionals.

The Academy is a project of San Diego State University School of Social Work (founded in 1963), which offers both a bachelor’s and master’s degree in Social Work. The School of Social Work at San Diego State University was founded in 1963 and has been continuously accredited by the Council of Social Work Education since 1966.

The Academy has extensive experience in providing specialized services, including:

- multi-disciplinary competency-based trainings
- curriculum development
- needs assessment
- research
- evaluation
- meeting facilitation
- organizational development consultation services

MASTER is an Archstone Foundation funded program of the Academy for Professional Excellence which has the overarching goal is to develop standardized core curricula for new APS social workers and to share these trainings on a national scale. Professional training opportunities are a critical step toward ensuring APS social workers have the appropriate tools to serve their victims. MASTER has worked extensively with state and national partner agencies in the development of this curriculum.

Our partners include:
- National Adult Protective Services Association Education Committee (NAPSA)
- The Statewide APS Training Project of the Bay Area Training Academy
- California Department of Social Services, Adult Services Branch
- California State University Sacramento IHSS Training Project
- Protective Services Operations Committee of the California Welfare Director’s Association (PSOC)
- California Social Work Education Center Aging Initiative (CalSWEC)
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ACKNOWLEDGMENTS

This training is the product of the National APS Training Partnership and is the result of a collaborative effort between Adult Protective Services administrators, supervisors, staff development officers and workers across the state and the nation; professional educators; and the Academy for Professional Excellence staff members. Project MASTER would like to thank the following individuals and agencies:

**Agencies**
- Bay Area Academy, Statewide APS Training Project
- California Department of Social Services, Adult Services Branch
- California Social Work Education Center Aging Initiative
- Imperial County Department of Social Services
- Orange County Social Services Agency
- Riverside County Department of Public Social Services
- San Bernardino County Department of Aging and Adult Services
- San Diego County Aging and Independence Services

**Regional Curriculum Advisory Committee**
- Carol Mitchel, APS Manager and PSOC Representative, Orange County
- Beverly Johnson, LCSW, Staff Development Officer, Riverside County
- Carol Castillon, APS Supervisor, San Bernardino County
- Carol Kubota, LCSW, Staff Development Officer, Orange County
- LaTanya Baylis, Staff Development Officer, San Bernardino County
- Zachery Roman, Staff Development Officer, Los Angeles County

**Committees**
- Project MASTER Steering Committee
- APS Core Curriculum Committee
- National Adult Protective Services Association Education Committee
- Protective Services Operations Committee of the California Welfare Directors’ Association

**Curriculum Developer/ Consultant**
- Susan Castaño, Consultant

**Evaluation Consultant**
- James Coloma, Evaluation Consultant
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**MODULE 10** -7- 6/2/2015

Version 1.1
# WORKING WITH SELF-NEGLECTING CLIENTS - PARTICIPANT MANUAL

## COURSE OUTLINE

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<tr>
<th>Time (minutes)</th>
<th>Training Topics</th>
<th>Materials/Activities</th>
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<tbody>
<tr>
<td>15 minutes (9:00 – 9:15)</td>
<td>Welcome and Introductions: Review student learning outcomes</td>
<td>Handouts 1-3 Slides 2-6</td>
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<td>25 minutes (9:15 – 9:40)</td>
<td>Introduction to Self -Neglect • Definitions • Prevalence • Profiles of self-neglecting adults • Indicators of self-neglect • Impact • Ethics</td>
<td>Handout 4 Slides 7-15</td>
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<td>10 minutes (9:40- 9:50)</td>
<td>Causes of self-neglect</td>
<td>Handout 5 Slide 16</td>
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<td>30 minutes (9:50-10:20)</td>
<td>Assessing Self-Neglect in five domains • Physical/Medical • Psychological/Mental Health • Living Environment • Financial • Social/Cultural</td>
<td>Jeopardy Game Slides 17-19 <em>(Note: the 50 slides for the Jeopardy Game are not included in the slide count)</em></td>
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<td>10:20-10:35</td>
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<td>Assessing severity and urgency in self-neglect</td>
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<td>Special issues in Self-Neglect • Compulsive Hoarding • Self-Neglect as a Caregiving Issue • Health Literacy</td>
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<td>Lunch</td>
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<td>10 minute 1:00-1:10</td>
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<td>Intervening with self-neglecting clients • Neglect and self-neglect through the &quot;caregiving lens&quot; (Dubin). • Working with “resistant” Clients • Motivational Interviewing • Substance abuse treatment (including harm</td>
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<td>2:40-2:55</td>
<td>Break</td>
<td></td>
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<td>2:55-3:15</td>
<td>Working the Self-Neglect Case</td>
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<td>Slide 56</td>
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<td>3:30-3:40</td>
<td>Community Partners</td>
<td>Handout 14</td>
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<td>Slide 57</td>
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<tr>
<td>3:40-4:00</td>
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By the end of this training, participants will be able to:

1) Define self-neglect, its prevalence, risk factors, and indicators
2) Assess self-neglect in the 5 domains
3) Describe risk assessment tools used for evaluating self-neglect
4) Describe promising methods for working with self-neglecting adults, including
   - Motivational interviewing
   - Harm reduction
   - Hoarding treatment
5) Develop safety and risk reduction interventions for self-neglecting adults
6) Elements to document in self-neglect cases
7) Identify community partners in self-neglect cases
Course Title: Working with Self-neglecting Clients

Outline of Training:
In this interactive and thought provoking introductory training, new APS workers and their allied partners will learn the definition of self neglect, how prevalent it is in our society and the risk factors and indicators to watch for when assessing a case. They will learn how to access self neglect across five domains (medical, psychological, environmental, financial and social). They will be exposed to tools used to evaluate self neglect cases and learn about promising methods to work with self neglecting adult. They will learn how to develop interventions, how to document a self neglect case and what agencies they might want to partner with to work these cases.

The following instructional strategies are used: lecture segments; interactive activities/exercises (e.g. small group discussion, case studies); question/answer periods; PowerPoint slides; participant guide (encourages self-questioning and interaction with the content information); embedded evaluation to assess training content and process; and transfer of learning activity to access knowledge and skill acquisition and how these translate into practice in the field.

Course Requirements:
Please note that training participants are expected to participate in a variety of in-class and post-training evaluation activities. These activities are designed to enhance the learning experience and reinforce the skill acquisition of training participants as well as determine the overall effectiveness of the trainings.
An executive summary of each training and directions for post-training evaluation activities will be provided to training participants and their supervisors. Certificates of course completion will be awarded upon completion of ALL course activities.

Target Audience:
This course is designed for new APS social workers as well as Vulnerable Adult Abuse partners (e.g. conservatorship investigators, workers in the aging and disability networks, law enforcement). This training is also appropriate for senior staff that require knowledge and/or skills review.

Outcome Objectives for Participants:
Learning goals – Upon completion of this training session, participants will be able to:

1. Define self-neglect, its prevalence, risk factors, and indicators
2. Assess self-neglect in the 5 domains
3. Describe risk assessment tools used for evaluating self-neglect
4. Describe promising methods for working with self-neglecting adults, including
   a. Motivational interviewing
   b. Harm reduction
c. Hoarding treatment
5. Develop safety and risk reduction interventions for self-neglecting adults
6. Elements to document in self-neglect cases
7. Identify community partners in self-neglect cases

Transfer of Learning: *Ways supervisors can support the transfer of learning from the training room to on the job.*

**BEFORE the training**
Supervisors can encourage line staff to attend the training and help them identify particular strengths and/or challenges that they have had in developing safety plans for victims in the past. Training participants can share these experiences during training.

**AFTER the training**
Supervisors can read the training executive summary and instructions for out-of-class transfer of learning activity. Supervisor and training participant will then schedule a time to complete the activity together – at this point the trainees can share what specific skills they obtained from the training. If further staff involvement is available, trainees may present an overview of what was learned to other staff members to encourage collaboration and a culture of learning.
PRESENTATION
WELCOME AND INTRODUCTIONS

TIME ALLOTTED: 15 minutes

Slide 2
This training was funded by:

Slide 3
Housekeeping and Introductions

- Schedule for the day
- CEU instructions
- Location of restrooms
- Set cell phones to vibrate
- Introductions
Slide 4

Evaluation Process

- Transfer of Learning Activity
- Satisfaction Survey
- Embedded Evaluation

Slide 5

Developing an ID Code

- What are the first three letters of your mother’s maiden name? Alice Smith
- What are the first three letters of your mother’s first name? Alice Smith
- What are the numerals for the day you were born? Nov 29th

Trainee ID Code: SMIAL129
Dear Training Participant,

As a training program for the Academy for Professional Excellence at San Diego State University School of Social Work, MASTER (Multi-disciplinary Adult Services Training & Evaluation for Results) has begun a process of evaluating training delivered to Adult Protective Service workers. As part of this evaluation, we need your help.

At certain points during this training series, in addition to the usual workshop evaluation forms, you will be asked to complete an embedded skills evaluation within the training day. This embedded skills evaluation will take about 15 minutes. You will be asked to determine what types of questions are being asked in a written interview. This evaluation has two main purposes:

1. To improve trainings’ effectiveness and relevance to your needs, and help you better serve adults and their families; and
2. To see if the training has been effective in getting its points across.

Our goal is to evaluate training, NOT the individuals participating in the training.

In order to evaluate how well the training is working, we need to link each person’s assessment data using a code. You will generate the code number using the first three letters of your mother’s maiden name, the first three letters of your mother’s first name, and the numerals for the day you were born. Please put this 8-digit ID code on each of your assessment forms, exactly the same way each time. ID code information will only be used to link demographic data to test data to ensure that the training is working equally well for all participants. Once this linking is done, we will only be looking at class aggregate scores, rather than individual scores.

Only you will know your ID code refers to you. All individual responses to evaluation exercises are confidential and will only be seen by the Academy’s training program and
evaluation staff. Only group averages and percentages will be reported. Individual results will not be reported to your employer. Aggregate data may be used for future research to improve training for Adult Protective Service workers.

If you agree to participate, you will fill out a questionnaires administered before and after the training. The questionnaire will be coded with a unique identifier system and all responses will be confidential.

There are no foreseeable risks to you from participating. There is also no direct benefit to you. Your responses will contribute to the development of a series of evaluation tools that will be able to accurately assess the effectiveness of adult protective service training. It is hoped that these tools will assist the Academy for Professional Excellence in improving training for adult protective service workers and therefore improve services to adults and families in California.

Your participation is voluntary and you may withdraw your consent and participation at any time. Participation or non-participation will have no effect on your completion of this training series.

By completing and submitting the questionnaire, you agree to participate. You further agree to permit us to use your anonymous responses in written reports about the questionnaires.

Your help with this evaluation process is greatly appreciated. Your feedback will be instrumental in helping to improve adult protective service training for future participants. If you have any questions about the evaluation or how the data you provide will be used, please contact:

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Training & Evaluation Specialist
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San Diego State University – School of Social Work
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San Diego, CA 92120
(619) 594-3219
jcoloma@projects.sdsu.edu
Handout 3

**MASTER IDENTIFICATION CODE ASSIGNMENT**

**YOUR IDENTIFICATION CODE:**

In order for us to track your evaluation responses while maintaining your anonymity, we need to assign you an identification code. We would like you to create your own identification code by answering the following questions:

1. What are the first three letters of your mother’s maiden name?
   
   Example: If your mother’s maiden name was Alice Smith, the first three letters would be: **SMI**. If the name has less than three letters, fill in the letters from the left and add 0 (zero) in the remaining space(s) on the right.
   
   _____ _____

2. What are the first three letters of your mother’s First name?
   
   Example: If your mother’s maiden name was Alice Smith, the first three letters would be: **AIL**. If the name has less than three letters, fill in the letters from the left and add 0 (zero) in the remaining space(s) on the right.
   
   _____ _____

3. What are the numerals for the DAY you were born?
   
   Example: If you were born on November 29, 1970, the numerals would be **29**. If your birth date is the 1st through the 9th, please put 0 (zero) in front of the numeral (example **09**).
   
   _____ _____

Combine these parts to create your own identification code (example: **SMIAL129**). Please write your identification code in the space at the top right corner of all evaluation materials you receive.

*Remember your identification code and write it at the top of every evaluation form provided to you throughout this training.*
Learning Objectives

- Define self-neglect, its prevalence, risk factors, and indicators
- Assess self-neglect in the 5 domains
- Describe risk assessment tools used for evaluating self-neglect
- Describe promising methods for working with self-neglecting adults, including
- Develop safety and risk reduction interventions for self-neglecting adults
- Elements to document in self-neglect cases
- Identify community partners in self-neglect cases
Introduction to Self-Neglect

TIME ALLOTTED: 25 minutes

Slide #7

Self Neglect defined:

“The inability or refusal to perform activities of daily living, which is manifested by some combination of poor hygiene, squalor in and outside their dwellings, a lack of utilities, an excess numbers of pets, and inadequate food stores”

(Oyer, Goodwin, Pickens-Pace, Burnett, & Kelly (2007))

Slide #8

Conditions mistaken for self-neglect:

Poverty
Eccentricity
Unconventional lifestyles
Trauma
Neglect by others
Low health literacy
Prevalence of Self-neglect

A national study indicates that self-neglect is the most common category of substantiated APS reports (37.2% in 2004).

(Teaster, Dugar, Mendiondo, & Otto, 2005)

Profile of self-neglecting elders

- 75.6 years old
- 70% female
- 50% had abnormal MMSE score
- 15% were depressed
- 76.3% had abnormal physical performance
- 95% had moderate-to-poor social support
- 46.4% were taking no medications

Indicators of self-neglect

- Reluctance to leave their homes to visit a doctor's office, clinic, or hospital
- Lack of medical care for a prolonged period of time
- Inability or refusal to see physicians
- Possible underdiagnosis, overmedication, or inadequate care
- Pressure ulcers
- Debilitated homes
- Filth
- Signs of malnutrition
- General decline
Case Examples

<table>
<thead>
<tr>
<th>Mr. Saunders</th>
<th>Mrs. Anderson</th>
<th>Mr. and Mrs. Hubbard</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mrs. Jones</td>
<td>Robert Stevens</td>
<td>Mrs. Graves</td>
</tr>
</tbody>
</table>

Impact

- Higher than expected mortality rates (Dong, et al; Badr, Hossain, & Iqbal, 2005).
- Hospitalization
- Long-term care placements
- Environmental and safety hazards
- Homelessness

Ethical issues in Self-neglect

- Autonomy and self-determination
- Least restrictive alternatives
- Beneficence
- Nonmaleficence
- Privacy
Ethical Principles

**Autonomy:** People living in free societies have the right to make decisions for themselves that are voluntary and free from interference by others. The closely related concept of self-determination refers to people's ability to manage their own affairs, make their own judgments, and provide for themselves. Applying these principles to elder abuse prevention requires workers to abide by clients’ wishes with respect to intervening or not intervening, and their choices with respect to services. Workers can help enhance their clients’ autonomy by providing them with tools, information, and assistance and removing threats to autonomy and self-determination such as coercion, duress, and undue influence.

**Least Restrictive Alternatives:** APS workers and others also operate on the principle that priority should be given to interventions that least restrict clients’ autonomy, independence, and freedom of choice.

**Beneficence:** The obligation to do good and assist others further their interests.

**Justice:** The fair and equitable distribution of benefits and burdens. For protective and social service workers, it entails an obligation to ensure that their clients have equitable access to service resources.

**Nonmaleficence:** It is morally wrong to harm others. Because helping others often consists in the infliction of a lesser harm in order to avoid a major imminent harm, nonmaleficence is generally taken to mean “Do not cause other persons to die, suffer pain or disability, or deprive them of their most important interests, unless you have a good reason.”

**Privacy:** The right of individuals to keep their lives and personal affairs out of public view, or to control information about themselves.
Safety versus Self-determination

When these interests compete, clients’ right to exercise self-determination outweighs their safety. People have a right to take risks.

There are two exceptions:
- When clients do not understand risks AND the risks or dangers are substantial, involuntary measures may be warranted.
- Criminal acts may be pursued without the consent of victims.
Causes of Self-Neglect

TIME ALLOTTED: 10 minutes

Slide #16
Neglect and Self-Neglect As the Absence or Breakdown of Caregiving Systems

- Overwhelmed Caregiving Systems
- The Dysfunctional Caregiving System
- The Self Interested Caregiver
- The Elder Alone
- Elders Who Refuse Care
HANDOUT #5

Neglect and Self-Neglect as the Absence or Breakdown of Caregiving Systems* 
(Part 1)

A. Overwhelmed Caregiving Systems.
   • Definition: The older person has family, friends, or paid caregivers who are actively involved in providing care but are not doing everything that’s necessary.
   • Examples:
     • The caregiving system was adequate at one time - but then there were changes, a gradual deterioration or an abrupt incident - a stroke for example - which rendered the care inadequate.
     • The caregiver is trying to balance caregiving with a job or other responsibilities.
     • The elder really should be in nursing home - they need extensive care - but they’re refusing to go
     • The family cannot afford nursing home care or support services

B. The Dysfunctional Caregiving System
   • Definition: A caregiving system is in place but the dynamics between caregivers, or between caregivers and older person are characterized by dysfunction.
   • Examples:
     • The older person is difficult and alienates others - choreworkers quit or the older person fires them
     • Family members are estranged
     • Feuding families. You may have sibling feuding with each other or with the older person.
     • Alcoholic families

C. The Self Interested Caregiver
   • Definition: Someone has responsibility for providing but the care is inadequate because the caregiver is really just in it for the money.
   • Examples:
     • Caregiver is being paid or stands to inherit.
     • Caregiver is concerned or preoccupation with their own interests.
   • Accounted for the fewest number of cases

D. The Elder Alone
   • Definition: Elders who have no one to provide care. Since the neglect in these situations can not be attributed to anyone other than the elders themselves, these cases are often referred to as self neglect.

continued on the next page…
• Examples:
  • Elder recently lost close friends or relatives, or spouses who were providing care and alternative arrangements haven’t been made.
  • Elders who have chosen to be alone or to live with animals.
  • Debilitated couples where neither member is capable of providing care to the other.

E. Elders who Refuse Care
• Definition: Same as above but senior has refused help.
• Examples:
  • Senior is depressed. May be close to death and wants to die
  • Senior doesn’t want to have their affairs scrutinized
  • Senior is committing slow form of suicide.

Assessing Self-Neglect in the Five Domains

TIME ALLOTTED: 30 minutes

Slide #17

Assessing Self-Neglect in 5 Domains

Slide # 19

Is it Neglect or Self-neglect?
Assessing Severity and Urgency in Self-Neglect

TIME ALLOTTED: 20 minutes

Slide #20
Screening Capacity in Self-Neglect Cases

Assessing Capacity in Self-Neglect Cases

- Capacity is the ability to perform specific functions or tasks
- Always need to ask "Capacity to do what?"

Does the client have the ability to:

- Live alone safely
- Provide self care (e.g. eating, bathing, taking medications)
- Make informed decisions about whether or not to accept medical treatment, health care, or services
- Manage finances
Dimensions of Capacity

- **Understanding**: Ability to comprehend information and to demonstrate that comprehension.

- **Appreciation**: The ability to determine the significance of a decision relative to one's own situation, focusing on beliefs about the actual situation and the possibility that outcome of the decision would be beneficial; involves insight, judgment, and foresight.

- **Reasoning**: The process of comparing alternatives in light of consequences by integrating, analyzing, and manipulating information. It involves the ability to:
  - Provide rational reasons for a decision,
  - Manipulate information rationally
  - Generate consequences of decisions for one's life
  - Compare those consequences in light of one's values

- **Expressing a choice**: The ability and willingness to make and communicate decisions.
## Capacity for Medical treatment

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<thead>
<tr>
<th>Dimensions of capacity</th>
<th>Definition</th>
<th>Questions used to demonstrate this dimension</th>
</tr>
</thead>
</table>
| Understanding          | The ability to comprehend diagnostic and treatment-related information and to demonstrate that comprehension. | • Can you tell me the purpose of the treatment?  
• What will this procedure accomplish? |
| Appreciation           | The ability to determine the significance of treatment information relative to one's own situation, focusing on beliefs about the actual presence of the diagnosis and the possibility that treatment would be beneficial; involves insight, judgment, and foresight. | • How would you prepare for (surgery)?  
• What do you see your life being like if you have surgery?  
• What do you see your life being like if you don’t have surgery? |
| Reasoning              | The process of comparing alternatives in light of consequences by integrating, analyzing, and manipulating information. It involves the ability to:  
• Provide rational reasons for a treatment decision,  
• Manipulate information rationally  
• Generate consequences of treatments for one’s life  
• Compare those consequences in light of one’s values | • How did you reach the decision?  
• What factors did you consider?  
• If you don’t have this procedure, what will you do instead (e.g. are there other treatments that can offer relief?) |
| Expressing a choice    | The ability and willingness to make and communicate decisions about treatment | • Can you explain to me what you’ve decided and why?  
• How did you reach this decision? |
Executive Function

Higher-level cognitive skills such as judgment, insight, the ability to plan for the future, and “mental flexibility” (the ability to switch from one mental task to another).

Enhancing Capacity

- Determine if there are times of day when a client performs at his or her best.
- Make sure that the client is using assistive devices to optimize communication.
- Get medical work-up
Sample Case 1. Mrs. Green

An APS worker receives a call from a neighbor, who is concerned because she has not seen Mrs. Green in more than a week. The worker receives another call the next day from Mrs. Green’s son, who lives out of state, who had been alerted by the same neighbor. He reports that he called his mother and she “doesn’t sound right.”

Bruce, an experienced worker, makes a visit. Mrs. Green welcomes him into the house and insists that she is fine and doesn’t need anything. In the kitchen, Bruce finds a sink filled with unwashed dishes and the odor of rotting garbage. He looks in the refrigerator, and finds only an old container of milk, the “use by” date three weeks ago, some slices of moldy cheese and a few eggs. They talk for a while and Mrs. Green continues to insist that she doesn’t need anything. She adds that she usually does her own grocery shopping, but occasionally doesn’t feel up to going out. Although Mrs. Green’s is neglecting many household tasks, during the interview her memory appeared to be intact. Mrs. Green tells him that she thinks her medications are making her sick so she doesn’t take them and mentions that she has blacked out a few times. When Bruce asks to see the medication bottles, Mrs. Green gets very angry and insists that she has thrown them all out. She then tells Bruce that “this conversation is over.”

The next week, Bruce receives another call from Mrs. Green’s son. He has received a call from a collections agency reporting that his mother has not paid her bills. When he called Mrs. Green, she got angry. She has always paid her bills on time.
Special Issues in Self-neglect

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Special Issues in Self-Neglect

- Compulsive Hoarding
- Health Literacy

Slide #27

Hoarding defined:

“The acquisition of, and failure to discard a large number of possessions that appear to be useless or of limited value including newspapers, magazines, old clothes, bags, storage containers, books, mail, boxes, notes and lists and memorabilia.”

- Compulsive Hoarding (Stellettre, G. & Frost, R., 2003)
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Compulsive hoarding affects over 3 million Americans

City building inspector Lauren Mosley photographs the kitchen at a home in the 1500 block of East 69th Street. An elderly couple was found buried under mounds of trash in the building on Monday night. (Alex Garcia, Chicago Tribune / May 25, 2010)

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Impact of Compulsive Hoarding

- Significant distress or impairment in functioning
- Reclusiveness
- Death
- Homelessness
- Shame and depression

Slide #30

“Who's Normal Anyway?”

http://www.youtube.com/watch?v=CMEWT1AWhq0
Slide #31

Health Literacy Defined:

- The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.

- The ability to read and comprehend prescription bottles, appointment slips, and other essential health-related materials required to successfully function as a patient. (AMA Council of Scientific Affairs, 2000)

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Clients with low literacy:

- Make more medication or treatment errors.
- Are less able to comply with treatments.
- Lack the skills needed to successfully negotiate the health care system.
- Are at a higher risk for hospitalization (Villaire, M., 2009)

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Clients may try to hide illiteracy/lack of understanding:

- “I forgot my glasses.”
- “I don’t need to read this now; I’ll read it after you leave.”
- “I’d like to discuss this with my family.”
- Nodding (Believe they understand but don’t.)
Health Literacy Video

AMA Video on Health Literacy available at
http://classes.kumc.edu/general/amaliteracy/AMA_NEW3.swf
Assessment Tools

TIME ALLOTTED: 10 minutes

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Self-neglect Related Assessment Tools

- Functional Assessment Tools:
  - Activities of Daily Living (ADL) scales
  - Instrumental Activities of Daily Living (IADL) scales
- Cognitive Assessments:
  - Mini-Mental State ©
  - "Clock drawing test"
  - Montreal Cognitive Assessment (MoCA©)
- CREST Self Neglect Severity Scale
- Kohlman Evaluation of Living Skills (KELS)
- Duke Social Support Index
- Home or Environmental Safety Assessments
- Health literacy evaluation
- Hoarding scales
Functional Assessment Tools

Functional assessment tools measure people’s ability to meet their own needs. Among the most commonly used are the Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) scales. The ADL scale measures people’s ability to perform a variety of personal care tasks such as bathing, eating, dressing, getting in and out of bed and chairs, using the toilet, and walking. The IADL scale measures more complicated tasks like the ability to balance checkbooks, perform housework, go grocery shopping, prepare meals, arrange for outside services, drive or take public transportation, manage finances, and take medications.

Cognitive Assessments

A variety of tools exist to measure mental capacity. The most common, the Mini-Mental State Exam, is no longer available as the result of a lawsuit. Because the research on self-neglect suggests that executive dysfunction is correlated with self-neglect, instruments that measure this dimension of capacity are most useful. They include the “clock drawing test” and the Montreal Cognitive Assessment (MoCA©), a cognitive screening test designed to assist in detecting mild cognitive impairment.

CREST Self Neglect Severity Scale

An instrument developed using survey data and consultation with experts in the field to provide a common language for describing cases of self-neglect. It uses observer ratings, interview responses, and assesses subjects’ physical and environmental domains. It also assesses functional status as it relates to health and safety issues.

http://www.bcm.edu/crest/?PMID=5668

Kohlman Evaluation of Living Skills (KELS)

This instrument, which is associated with substantiated cases of elder self-neglect, provides clinicians with an objective measure of an individual’s capacity and performance with everyday life-supporting tasks. It assesses 18 basic living skills. These 18 skills are distributed into five evaluation categories. The categories and skills are as follows (Bruce & Borg, 1993):
Duke Social Support Index

This instrument, developed by Dan Blazer, et al, 1990, is a 35-item instrument that measures multiple dimensions of social support. It is used to measure social support of the elderly. An 11-item version have been used for the chronically ill and frail elderly. It is available through the Psychiatry Department of Duke University.

Home or Environmental Safety Assessments

Safety assessments identify hazards in the homes or environments of people with functional limitations. They are often used, for example, when seniors choose to live independently at home. Many focus on reducing the risk of falls, fires, and crime. An example is the Cougar Home Safety Assessment for Older Persons, Version 1.0.

Hoarding Scale

The National Study Group on Chronic Disorganization (NSGCD), an association of professional organizers (professional organizers receive remuneration for assisting clients with compulsive hoarding behaviors and their families) developed the NSGCD Clutter-Hoarding Scale to assist members and related professionals identify health and safety risks and respond appropriately.

http://www.nsgcd.org/resources/clutterhoardingscale/nsgcd_clutterhoardingscale.pdf
Interventions with Self-Neglecting Clients

TIME ALLOTTED: 90 minutes

Results of the Dubin Study

- Overwhelmed Caregiving Systems
- The Dysfunctional Caregiving System
- The Self Interested Caregiver
- The Elder Alone
- Elders Who Refuse Care
1) Overwhelmed Caregiving Systems.
   - Definition: The older person has family, friends, or paid caregivers who are actively involved in providing care but are not doing everything that's necessary.
   - Examples:
     - The caregiving system was adequate at one time - but then there were changes, a gradual deterioration or an abrupt incident - a stroke for example - which rendered the care inadequate.
     - The caregiver is trying to balance caregiving with a job or other responsibilities.
     - The elder really should be in nursing home - they need extensive care - but they're refusing to go
     - The family cannot afford nursing home care or support services
   - Prognosis: highest rates of success because there is a system in place, the senior is willing to accept help, and people are willing to provide care.
   - Promising Approaches: Because caregivers are exhausted, they are unwilling to agree to interventions that require them to do more. If caregivers are offered help that takes burden off, the situations can be improved.

2) The Dysfunctional Caregiving System
   - Definition: A caregiving system is in place but the dynamics between caregivers, or between caregivers and older person are characterized by dysfunction.
   - Examples:
     - The older person is difficult and alienates others - choreworkers quit or the older person fires them
     - Family members are estranged
     - Feuding families. You may have sibling feuding with each other or with the older person.
     - Alcoholic families
   - Prognosis: Not good unless “tolerant outsiders” (people who are not involved in the conflict) can be found.
   - Promising Approaches: The likelihood of success improves if feuding family members are kept involved (so that they won’t sabotage treatment plans), but are not in control. Guardianship can be very helpful to shift responsibility away from people who are enmeshed in the conflict.
3) The Self Interested Caregiver
   - Definition: Someone has responsibility for providing but the care is inadequate because the caregiver is really just in it for the money.
   - Examples:
     - Caregiver is being paid or stands to inherit.
     - Caregiver is concerned or preoccupation with their own interests.
   - Accounted for the fewest number of cases
   - Prognosis: Interventions are relatively simple if caregivers were removed as responsible parties.
   - Promising Approaches: Guardianship. Money management.

4) The Elder Alone
   - Definition: Elders who have no one to provide care. Since the neglect in these situations can not be attributed to anyone other than the elders themselves, these cases are often referred to as self neglect.
   - Examples:
     - Elder recently lost close friends or relatives, or spouses who were providing care and alternative arrangements haven’t been made.
     - Elders who have chosen to be alone or to live with animals.
     - Debilitated couples where neither member is capable of providing care to the other.
   - Prognosis: Depends on the reason that the older person or couple is alone. Many older people and their families don’t know about services. Some may agree to services when they hear about them.
   - Promising Approaches: Educate seniors and their families about services.

5) Elders who Refuse Care
   - Definition: Same as above but senior has refused help.
   - Examples:
     - Senior is depressed. May be close to die and wants to die
     - Senior doesn’t want to have their affairs scrutinized
     - Senior is committing slow form of suicide.
   - Prognosis: Poor but depends on reasons that clients are refusing help. If they really want to die, there may be little that can be done.
   - Promising approaches: If judgment is shaded by depression, it may be treatable. Bringing services in to home. Crisis may precipitate change.

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Working with “Resistant” Clients

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Reasons People Refuse Help

- Dementia
- Anxiety
- Grief
- Depression
- Lack of insight
- Personality problems
- Shame
- Distrust
- Fatigue
- Fear
- Pain
- Anger

Slide #39

Motivational Interviewing

“Motivational interviewing is a directive, client centered counseling style for eliciting behavior change by helping clients to explore and resolve ambivalence.”

Core Concepts of MI

- Express empathy
- Avoid arguing
- Roll with resistance
- Support self efficacy
- Develop discrepancy

Stages of Change

1. Pre-contemplation (Not even considering change/denial.)
2. Contemplation (Ambivalent about change)
3. Preparation (Preparing or making small changes)
4. Action (Making changes)
5. Maintenance (Incorporating new behavior into lifestyle)

Change Talk

- Listen for:
  - Desire statements (I'd like..., I wish..., I want...)
  - Ability statements (I could..., I might...)
  - Reason statements
  - Need statements
- Reflect them back and ask for elaboration
- Listen for a commitment verb
  - (I will..., I'm planning to..., I am going to...)
Decisional Balance Worksheet

<table>
<thead>
<tr>
<th>Good things about behavior:</th>
<th>Good things about changing behavior:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not so good things about behavior:</td>
<td>Not so good things about changing behavior:</td>
</tr>
</tbody>
</table>

Case Example: Responding To Resistance

Substance Abuse Treatment

- Hospital Detox
- Medication and Therapy
- Counseling
- Self Help groups
Slide #46

“For seniors, hitting bottom can mean death. Or, it may mean becoming so incapacitated that they’re institutionalized. And the “helping hand” may not be there for them.”

Charmaine Spencer, Simon Fraser University

Slide #47

Video available at: http://www.youtube.com/watch?v=Swxdf17vFz4&NR=1

Slide #48

Treatment for Hoarding

• Simply cleaning up doesn’t work
• Support/treatment groups
Working the Self-Neglect Case

TIME ALLOTTED: 10 minutes

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What factors determining appropriate interventions?

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Types of Intervention

Support Services  Mental Health Treatment  Involuntary Interventions

Monitoring
Services to victims or caregivers to prevent self-neglect

- **Attendant Care.** Attendants assist vulnerable people with their daily activities, including bathing, shopping, and preparing meals.

- **Caregiver Support Services** reduce the stress and strain on caregivers that may cause them to abandon or neglect elders and dependent adults. They include:
  - **Support groups** address the emotional demands and stresses of providing care. They also provide instruction and guidance in meeting the older person's needs and handling difficult behaviors. They may relieve the tensions, resentments and stresses that give rise to abuse and neglect.
  - **Respite Care** offers relief to caregivers by giving them a break. Respite can be provided in many ways. Attendants, professionals or volunteers may come to the vulnerable person’s home to relieve a caregiver for a few hours, or the older person may be brought to an agency or day center. Some communities offer extended respite care in residential care or skilled nursing facilities.

- **Case Management.** A way of providing care for people who have multiple and changing needs. Case managers may work for public programs like MSSP and Linkages or in private practice. Case managers conduct comprehensive assessments of clients' abilities and what they need help with. They then arrange for services and monitor them, responding to problems. Specifically, they:
  - Conduct comprehensive assessments of the older person’s general health, mental capacity and ability to manage in the home and community
  - Develop “care plans,” often in consultation with other professionals from several disciplines, for meeting clients’ service needs
  - Arrange for needed services
  - Respond to problems or emergencies
  - Conduct routine re-assessments to detect changes in the person’s health or ability to manage, and anticipate problems before they occur

- **Conservatorship.** A mechanism by which a court appoints a person to handle the financial and/or personal affairs of individuals who are unable to protect themselves as the result of disability. This is also called a guardianship in some states. States differ in whether they compartmentalize the duties of a conservator but they are often divided as follows:
  - **Conservatorship of person** refers to the handling of an individual's personal needs through the provision of medical care, food, clothing and shelter
  - **Conservatorship of estate** refers to the management of financial resources and assets
  - **Counseling** may be needed to alleviate the immediate and long term traumatic stress associated with abuse. Some groups address such issues as co-dependency depression and diminished self-esteem.
• **Daily Money Management (DMM).** Financial abuse frequently may occur when an older person has lost the ability to manage his or her finances. Arranging for trustworthy people to help can reduce this risk. The help may be informal, where the money manager simply helps the elder with simple tasks like paying bills, or it may involve formal transfers of authority, including representative payeeship, power of attorney, or guardianship.

• **Emergency funds** may be needed for temporary caregivers, housing, food, rent, mortgage payments, shelter, transitional housing, transportation, utilities, new locks to secure victims’ homes, attorney’s fees, court filing fees, repairs, relocation costs, security deposits, respite care, and home modification. In cases of serious neglect, a one-time “deep cleaning service” may be needed to make the victim’s home habitable, thus preventing placement in a more restrictive environment.

• **Home delivered meal programs.** Programs deliver nutritious meals to seniors in their homes. Also called meals on wheels.

• **Mental health assessments** are often needed to determine if an older person is capable of meeting his or her own basic needs, making decisions about services, offering testimony, and protecting him or herself against abuse. Assessments of alleged abusers’ mental status are sometimes needed to determine if they pose a danger to others and are in need of treatment. Assessments range from simple “mini-mental status exams,” a test that can be performed quickly by persons with minimal training to geriatric assessments, which involve multiple professionals performing a comprehensive battery of tests.

• **Respite Care** offers relief to caregivers by giving them a break. Respite can be provided in many ways. Attendants, professionals or volunteers may come to the vulnerable person’s home to relieve a caregiver for a few hours, or the older person may be brought to an agency or day center. Some communities offer extended respite care in residential care or skilled nursing facilities.

• **Regional Centers** are nonprofit private corporations that contract with the Department of Developmental Services to provide or coordinate services and supports for individuals with developmental disabilities. They have offices throughout California to provide a local resource to help find and access the many services available to individuals and their families.

• **Shelter.** Elderly victims may need shelter when they have been evicted from their homes or apartments as a result of the abuse; when caregivers have abandoned them, or been terminated or arrested; or when their homes are unsafe or unhealthy. Shelter options may include beds or rooms in senior apartment houses or board and care homes, to free-standing elder shelters.

• **Telephone reassurance programs** can make routine “check in” calls to isolated seniors or provide telephone counseling to seniors who are in emotional distress.
Supportive Services

- Friendly visitors
- Telephone Reassurance
- Lifeline
- Support for caregivers
- Daily money management
- Caregiver services

Mental Health Treatment

- Crisis intervention
- Individual or group counseling for anxiety, depression, substance abuse, traumatic stress, hoarding, co-dependency
- Medications

Mental Health Treatment

- Involuntary assessments or hospitalizations
- Protective Custody
- Appointment of Surrogates
- Probate guardianship or conservatorship of person and/or finances
- Mental health guardianship or conservatorship of person and/or estate
- Appointment of a representative payee
- "Triggering" of advance directives
- Removal of animals by Animal Care and Control Workers
- Health and Safety regulations
Slide #54

Monitoring

• APS worker checks on client
• Arrange for formal / informal monitors to check in and report changes.

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Working the Self Neglect Case
Case 1. John Sumner

Robert, an APS worker, receives a call from Sara, who is the manager of a senior apartment building Sara, a landlord, is concerned about a tenant in her apartment building, 80 year-old John Sumner. John has not left his apartment for the past two weeks and yells, “Go away!” whenever Sara knocks on the door. John has not paid his rent for the last two months, nor has he picked up his mail. His neighbors have complained about the smells coming from his apartment. Sara can hear the sound of many cats when she comes to John’s door. She doubts that John or the cats have sufficient food and wonders if John is caring for himself. Robert makes a home visit and finds John to be willing to talk to Robert.

What should Robert do (e.g. what should he do next, what additional information should he gather, what should he consider)?
Case 2. Mrs. Albertson

Mrs. Albertson called the fire department about a kitchen fire. When the firefighters arrived, they found Mrs. Albertson confused and paranoid and made a report to APS. Trudy, an APS worker, was assigned to the case. During their initial interview, Mrs. Albertson told Trudy that strangers were always breaking into her apartment, moving her belongings around and turning on the stove. She found this disturbing and wanted them to go away. With Mrs. Albertson’s permission, Trudy contacted Mrs. Albertson’s physician who informed her that he’d prescribed medications for Mrs. Albertson’s hyperthyroidism and moderate dementia with psychosis. When Trudy asked Mrs. Albertson about the medication, she responded that she didn’t need them.

What should Trudy do (e.g. what should she do next, what additional information should she gather, what should she consider)?
Documenting Self-Neglect

Importance of Good Documentation

- Continuity of care
- Provides a baseline for detecting gradual changes
- May be needed in legal proceedings
Documentation in Self Neglect

Physical signs and symptoms

- Bruises and other injuries (photographs, descriptions and body maps, which are drawings of the front, sides, and back of a human figure, can be used to describe injuries)
- Pressure ulcers
- Weight loss
- Dental problems
- Deteriorated or dilapidated living conditions, filth, pest infestations
- Signs of hoarding and cluttering
- Adequacy of facilities. Are there hazards or dangers, adequate heating, etc.
- Evidence of medication mismanagement, non compliance, etc.
- Adequate clothing and assistance devices
- Evidence of alcohol or substance abuse

Behavioral Signs and Symptoms

- Lethargy
- Depression
- Signs of post-traumatic stress disorder (PTSD) including withdrawal, hyper-vigilance and fear
- Patient’s demeanor (the patient is crying, shaking, angry, agitated, upset, calm, or happy.
- Sexual “acting out” (may be a sign of sexual assault).
- Fearfulness, distrust
- Hallucinations
- Alertness
- Flat affect
- Agitation and anxiety

Indicators of capacity and consent, including:

- Changes over time. Has there been a gradual or rapid decline?
- Statements that indicate that clients do not realize how dangerous or serious their situations are
- Client’s judgment is impaired
- What services were offered and refused?
- Number of times offered and refused
- Clients’ stated reasons for refusing services
- How well is the clients “tracking,” or following what is being said
Indicators of Clients’ Preferences, Values and Lifestyles

Indicators of preferences, values and lifestyles can be documented by recording clients’ (or others’) statements about:

- Their treatment and service preferences
- Their wishes and preferences as told to others or as indicated in advance directives
- Values
- Life-style

Workers’ Actions

- Actions taken by workers
- Reasons for actions not taken
- Indicators that workers followed agency chain of command, such as consulting with supervisors, following rules concerning documentation, etc.
Partners in Self-Neglect

TIME ALLOTTED: 10 minutes

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Partners in Self Neglect

With whom should you partner?

_______________________________

_______________________________

_______________________________

_______________________________
### Community Partners in Self-Neglect Cases

<table>
<thead>
<tr>
<th>Professional, entity or group</th>
<th>Role in self-neglect cases</th>
</tr>
</thead>
</table>
| Mental health professionals, including county geriatric mental health program personnel or professionals in private practice (geriatric psychologists, psychiatrics, etc.) | - Can assess clients’ mental status  
- Can arrange for psychiatric hospitalizations under W& I Code §5150.  
- Can diagnose and treat depression and other mental conditions |
| Geriatric physicians and nurses | - Can diagnose, assess and treat medical conditions  
- Can complete medical declarations (doctors) for conservatorship  
- Can review medical records, and distinguishing injuries from effects of aging and disease |
| Conservators, including private professionals | - Can file for and provide conservatorship services |
| Public Guardians | - Can file for and provide conservatorship services |
| Clergy | - Can provide emotional and spiritual support to clients  
- Can provide or arrange for informal support services |
| Local law enforcement, including police and sheriffs | - Can assist with well-being checks, psychiatric hospitalizations, protective custody, freezing assets |
| Animal Welfare Organizations (municipal animal care and control agencies, humane societies and SPCAs, and rescue organizations) | - Can provide information and assist with finding homes for animals.  
- Can make home visits to check on the welfare of the animals in the home. |
<table>
<thead>
<tr>
<th>Ethics Committees (most are convened by hospitals and nursing homes)</th>
<th>Can identify and address ethical issues raised in self-neglect cases</th>
</tr>
</thead>
</table>
| Multidisciplinary teams, including elder abuse multidisciplinary teams and death review teams. | Can provide suggestions for interventions  
Provides a “checks and balances” to ensure that all multiple options and points of view are considered.  
Can ensure that workers’ actions reflect community standards of practice |
REFERENCES


