INTRODUCTION

THE ACADEMY FOR PROFESSIONAL EXCELLENCE

We are pleased to welcome you to the Working with Self-neglecting Clients Training developed by Project MASTER, a program of the Academy for Professional Excellence.

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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This training 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
- 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
- Ralph Pascaul, 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**
- Susan Castano

**Evaluation Consultants**
- James Coloma, Evaluation Consultant
- Jane Berdie, Evaluation Consultant
- Cynthia Parry, Evaluation Consultant
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HOW TO UTILIZE THIS TRAINING MANUAL

The course outline, provided in the next section of this manual, is the class schedule used during the piloting of this training. It can be used to help you determine how much time you might need to present each section. However, times will vary based on the experience and engagement of your audience.

Customizing the Power Point:
Once you decided on how you want to divide up your time in presenting this material, you may want to customize your Power Point. The Microsoft Office Power Point software allows you to hide any slides you don’t want to use.

Hide a slide instructions

1. On the Slides tab in normal view, select the slide you want to hide.
2. On the Slide Show menu, click Hide Slide.

The hidden slide icon appears with the slide number inside, next to the slide you have hidden.

Note: The slide remains in your file, even though it is hidden when you run the presentation.

Please note that this manual is set up so that the trainer script/ background material is on the same page as the accompanying Power Point slide making it easy to also customize your manual to match the slides you have decided to use, Just remove the unneeded pages.
## COURSE OUTLINE

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<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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| 25 minutes (9:15 – 9:40) | Introduction to Self -Neglect  
• Definitions  
• Prevalence  
• Profiles of self-neglecting adults  
• Indicators of self-neglect  
• Impact  
• Ethics | Handout 4 Slides 7-15 |
| 10 minutes (9:40- 9:50) | Causes of self-neglect | Handout 5 Slide 16 |
| 30 minutes (9:50-10:20) | Assessing Self-Neglect in five domains  
• Physical/Medical  
• Psychological/Mental Health  
• Living Environment  
• Financial  
• Social/Cultural | Jeopardy Game Slides 17-19  
(Note: the 50 slides for the Jeopardy Game are not included in the slide count) |
| 10:20-10:35 | Break | |
| 20 minutes 10:35-10:55 | Assessing severity and urgency in self-neglect | Small group activity Flip chart Slide 20 |
| 35 minutes 11:25-12:00 | Special issues in Self-Neglect  
• Compulsive Hoarding  
• Self-Neglect as a Caregiving Issue  
• Health Literacy | Slides 26-34  
• “Who’s Normal Anyway?” video  
• AMA video on health literacy |
| 12:00-1:00 | Lunch | |
| 10 minute 1:00-1:10 | Tools used in assessing self-neglect | Handout 9 Slide 35 |
| 90 minutes 1:10-2:40 | Intervening with self-neglecting clients  
• Neglect and self-neglect through the “caregiving lens” (Dubin).  
• Working with “resistant” Clients  
• Motivational Interviewing  
• Substance abuse treatment (including harm reduction)  
• Compulsive Hoarding | Handout 10 Slides 36-48  
• Video on harm reduction  
• Motivational Interviewing video |
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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
### Teaching Strategies

The following instructional strategies are used:

- Lecture segments
- Interactive exercises (e.g., Table Top Activities, experiential exercises, role plays)
- Question/answer periods
- Slides
- Participant guide (encourages self-questioning and interaction with the content information)
- Evaluation to assess training process
- Transfer of Learning activity

### Materials and Equipment

The following materials are provided and/or recommended:

- Computer with LCD (digital projector)
- CD-ROM or other storage device with the slide presentations
- Easel/Flip chart paper/markers
- Trainer’s Guide: This guide includes the course overview, introductory and instructional activities, and an appendix with reference materials.
- Participant Guides: This guide includes a table of contents, course introduction, all training activities/handouts, and transfer of learning materials.
- Evaluation Guide: contains all post training and transfer of learning evaluation tools.
- Name tags/names tents.
- Water access/snacks/restroom access/lunch plans

**NOTE:** Segments written in blue indicate areas where you will need to do research about the policies and procedures specific to your agency or jurisdiction.
COURSE OUTLINE

9:00  Welcome and Introductions
9:15  Introduction to Self-Neglect
9:40  Causes of self-neglect
9:50  Assessing Self-Neglect in Five Domains
10:00 BREAK
10:35 Assessing Severity and Urgency in Self-neglect
10:55 Assessing Capacity in Self-Neglect Cases
11:25 Special Issues in Self-Neglect
12:00 LUNCH
1:00 Tools Used in Assessing Self-neglect
1:10 Intervening with Self-neglecting Clients
2:40 BREAK
2:55 Working the Self-Neglect Case
3:15 Documenting Self-neglect
3:30 Community Partners
3:40 Q and A, Evaluation and closing
EXECUTIVE SUMMARY

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
SLIDE #2

This training was funded by:

The Archstone Foundation is the only private foundation which provides funding for elder abuse projects.

TOPIC: Thanks you to Archstone
**TOPIC: Housekeeping**

**WELCOME** the participants and introduce yourself by name, job title, organization, and qualifications as Trainer.

**NOTE:** If you wish, you can individualize the PowerPoint slides by adding information in the “notes” section of each slide.

**Review Housekeeping Items**

- There will be two 15-minute breaks and an hour for lunch today: 12-1 pm in…
- Use the restrooms whenever you need to do so. The restrooms are located at…
- Please turn off your cell phones for the duration of the training. If you must make or receive a call, please leave the training room and return as quickly as possible. Check the course outline to see what you have missed.

Ask participants to introduce themselves and say what agency they work for if multiple agencies have been invited to the training. Ask them to tell you whether they have ever worked with self-neglecting clients and what they found to be challenging.
**TOPIC:** Introducing participants to the evaluation process

For this training, you will be completing a training satisfaction survey, an evaluation regarding question typology (completed in class) and a post training transfer of learning exercise (to be turned in next week). All of these materials can be found in the Evaluation Manual, and are intended to allow you to practice what you have learned and measure whether the training was effective. We want APS training to become an evidenced based practice that truly provides the knowledge and skills we believe it provides. The purpose of the evaluation process is more fully explained in your “Letter to Participants”.

**HANDOUT #2: Participant Letter of Consent**

- Academy for Professional Excellence at San Diego State University School of Social Work, MASTER (Multi-disciplinary Adult Services Training & Evaluation for Results) begun a process of evaluating training delivered to Adult Protective Service workers.
- At certain points during this training series, in addition to the usual workshop evaluation forms, you will be asked to complete various training evaluation activities.
- These training evaluation activities aim to: (1) improve trainings’ effectiveness and relevance to your needs, and help you better serve adults and their families; and (2) see if the training has been effective in getting its points across.
- If you agree to participate, you will fill out a questionnaire administered before and after the training.
- The questionnaires will be coded with a unique identifier system and all responses will be confidential.
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 various training evaluation activities.

These training evaluation activities have 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 questionnaire 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.

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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San Diego, CA 92120
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jcoloma@projects.sdsu.edu
TOPIC: Developing an ID code

We are NOT evaluating you and no one from your agency will see your individual responses. To keep your responses confidential, we are going to develop your personal ID code. Follow along with your ID Assignment Handout and write in your ID code on the Handout:

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: S M I. 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: A L I. 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?
**HANDOUT #3: MASTER Identification Code Assignment**

- In order to track each of your evaluation responses while maintaining your anonymity, we need to assign you an identification 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.
- The questionnaires will be coded with a unique identifier system and all responses will be confidential. Only you will know your ID code refers to you.
- Aggregate data may be used for future research to improve training for Adult Protective Service workers.
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:

4. 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: **S M I**. 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.
   __ __ __

5. 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: **A L I**. 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.
   __ __ __

6. What are the numerals for the DAY you were born?
   Example: If you were born on November 29, 1970, the numerals would be **2 9**. If your birth date is the 1st through the 9th, please put 0 (zero) in front of the numeral (example **0 9**).
   __ __

Combine these parts to create your own identification code (example: **S M I A L I 2 9**). 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

TOPIC: Learning Objectives

Review the Learning Objectives with the class.
Introduction to Self-Neglect

TIME ALLOCATED: 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”

[Dyer, Goodwin, Pickens-Pace, Burnett, & Kelly (2007)]

Topic: Self-neglect defined

Explain that disagreement exists, even among experts, about what self-neglect is. It’s important to understand how your state and agency define self-neglect.

This definition assumes that self-neglecting clients have impairments in Activities of Daily Living (ADLs)--medical care, assistance with bathing, dressing, home cleaning, laundry, and obtaining food)

AND

- Lack needed support
- Fail to recognize danger
- Refuse help
- Lose capacity for self-protection
- Cannot complete tasks necessary to obtain available services

CONTINUED
Explain that self-neglecting elders have impairments in ADLs, but that's also true of 38% of elderly persons in the US. So what differentiates elders who self-neglect from those who don't? (Research is needed to answer this question).
Topic: Conditions that can be mistaken for self-neglect

It's important that we don't mistake self-neglect for other conditions or impose our own (or others') values on clients. What first appears to be self-neglect may actually be a reflection of poverty, eccentricity, unconventional lifestyles, trauma, neglect by others or 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)

**Topic: Prevalence of Self-neglect**

Self-neglect cases account for the majority of substantiated Adult Protective Services reports. Therefore the skills to deal with these clients are essential to effective job performance. This class will just get you started on the road to learning how to deal with this diverse population.
**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

**Topic:** Profile of Self-neglecting elders

A study by Dyer, Goodwin, Pickens-Pace, Burnett, & Kelly (2007) found that self-neglecting elders has this profile:

Note: This slide is animated so you will need to click to get each factor to appear on the screen.

- Average age is 75.6 years
- Women account for 70%
- 50% had abnormal Mini Mental State Examination scores
- 15% had abnormal Geriatric Depression Scale scores
- 76.3% had abnormal physical performance test scores
- 95% had moderate-to-poor social support (per the Duke Social Support Index)
- Although elders had a range of illnesses, 46.4% were taking no medications.
TOPIC: Indicators of Self-neglect

Explain:

These are the red flags or indicators that we usually associate with self-neglect. Many are the same for neglect by others.
Self-neglect cases encompass a wide range of situations. Here are some examples:

As you read each case example, ask how it connects back to the definition of abuse.

“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”

- Mr. Saunders is alert and oriented but suffers from short-term memory loss. He has neglected to pay his bills.

- Mrs. Anderson suffers from alcohol related dementia, which is mild when she is sober and extreme when she is intoxicated. She knows she has heart problems but denies the seriousness of her condition and refuses to go to a doctor.

- Mr. and Mrs. Hubbard both suffer from dementia. Both are disheveled, thin, and dirty. They are refusing APS.
• Mrs. Jone’s phone, gas, and electricity have been turned off because she hasn’t been paying her bills. She has become increasingly isolated. She smokes and sometimes forgets that she’s left a cigarette burning in the ashtray.

• Robert Stevens is 53 years old and suffers from a dementia due to a brain injury. He also has cancer. He is not able to follow instructions or cook for himself. He recently was hospitalized for dehydration. The discharge planner did not want to let him go home alone without help, but he refused services.

• Mrs. Graves lives with her schizophrenic, substance-abusing son. He refuses to allow visitors into the home and has had the phone disconnected. Mrs. Graves is afraid of her son but refuses help because she feels that he is her responsibility.
Impact

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

Explain:

- The consequences of self-neglect can be devastating. It can lead to premature death, institutionalization, homelessness (due to evictions), and dependency.
- It can also have negative consequences on family members, neighbors, and society in general.

Ask: Can you give examples of how others, besides the self-neglecting adult, are affected? Answers may include:

- When a self-neglecting adult lets their home deteriorate, it can endanger neighbors.
- Failure to provide self-care can result in a need for expensive treatment, hospitalization, or placement, the costs of which may be borne by taxpayers.
Before we dive into assessment, we need to consider the ethical principles that should guide your assessment and intervention with self-neglecting clients. APS workers are guided by their professional orientation and values. Although there are no universally accepted ethical principles, many subscribe to those developed by the National Adult Protective Services Association.

Direct students to **Handout #4 Ethical Principles** in the Participants Manual
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.

Explain:

- Clients’ right to exercise freedom and autonomy may come into conflict with workers’ commitment to protect clients and ensure their safety.
- As long as clients understand risks and make choices voluntarily, their wishes must be respected.
- When victims do not understand the risks they are taking or are operating under coercion AND the threat is substantial, we may be obligated to take actions.

Ask: Can you give an example of when a self-neglecting person’s behavior constitutes a crime? Answers may include:

- When an animal hoarder endangers animals
- When the self-neglecting person refuses to leave a condemned home
- When a self-neglecting person refused to cut (or allow to be cut) grass that is a fire hazard
- When a hoarder refuses to follow orders to clean up a home which is a fire hazard or pest infestation
Causes of Self-Neglect

TIME ALLOTTED: 10 minutes

SLIDE #16

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

HANDOUT #5: Neglect and Self-Neglect as the Absence or Breakdown of Caregiving Systems (Part 1)

TOPIC: Neglect and Self-Neglect As the Absence or Breakdown of Caregiving Systems

Explain:

It isn’t always easy to differentiate self-neglect from neglect by others. Researcher Tina Dubin looked at both types of cases handled by APS workers in Texas. Her work suggests relationships between the two. Later, we’ll be looking at the interventions that APS workers tried in cases and what the results were.

Review the categories in Neglect and Self-Neglect as the Absence or Breakdown of Caregiving Systems (Part 1) with the participants. Note that understanding the underlying cause of the neglect is important in later determining an appropriate intervention.

CONTINUED
Ask: Can you give an example of a situation that may appear to be self-neglect but is actually something else? Answers may include:

- The client is not receiving needed care because caregivers are in conflict
- Clients are not aware of available services
HANDOUT #5

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

A. Overwhelmed Caregiving System.
   • 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

CONTINUED
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.

- 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

Assessment in self-neglect involves the same considerations and techniques used in other APS referrals.

Let’s review the five domains that APS workers consider as they apply to self-neglect. To do this, let’s play a game of Jeopardy!

**Trainer’s note:**
Divide the class in half down the middle. Ask for one person to be the score keeper. Explain that each team will get a turn to select a category representing one of the domains and a point value (e.g. “I’ll take Physical and Medical for 400 please”). Individuals should raise their hand to volunteer to answer for their team. Answers are supposed to be given in the form of a question (e.g. “What is …”) You can decide whether or not to enforce this rule in order to give points. If one team can’t answer, the other team gets to try and answer. Explain that the game is a fun platform for the
lecture on assessment. The participants are not required to already know the material. They should give their best guess. Pages 45-46 provides the questions and answers for the jeopardy game. As the participants uncover answers, use the notes below to add to their understanding. (In other words, insert the training points into the game).

**Domain 1: Physical/Medical Factors:**

- Dehydration
- Congestive heart failure
- Chronic lung disease
- Urinary tract infection
- Diabetes
- Strokes
- Transient ischemic accidents (min-strokes)
- Vitamin D deficiency

**Question for 500 points:**

**DISCUSS:** These are some of the common conditions that affect seniors’ ability to manage independently. However, assessing these factors may present a “chicken vs. egg” dilemma (e.g. the research suggests a link between Vitamin D deficiency and self-neglect, but we don’t know if the deficiency predisposes people to self-neglect or if the deficiency is a consequence of self-neglect.

**Domain 2: Psychological/Mental Health**

- Mental illnesses
- Substance abuse
- Trauma
- Dementias and pseudo-dementias
- Depression
- Diminished mental capacity
- Anxiety
- Obsessive Compulsive Disorders (associated with hoarding)

We know that there’s a strong link between self-neglect and psychological or mental health factors. These are some of the common psychological or mental health problems that affect seniors’ ability to manage.
Question for 300 points:

DISCUSS: Causes of “Pseudo-dementia”

Causes include:

- Problems with medications, including overdoses or interactions between medications
- Infections (including urinary tract infections)
- Substance abuse
- Depression
- “Hospital psychosis” refers to the fact that persons who are hospitalized sometimes experience delusions and severe agitation. Although the cause is unknown, some believe that sleep deprivation or medication interactions may play a role.

Explain:

- Some cognitive impairments result from conditions or situations that are treatable and reversible.
- These treatable or reversible conditions that are often mistaken for dementias are sometimes called “Pseudo-dementias.” They include delirium and depression.
- Refer to chart Comparing dementia, depression and delirium in Participants Manual.

Domain 3: Environmental

Self-neglecting elders and dependent adults may live in homes that are unsafe and unhealthy. Or, they may pose a threat to others (e.g. someone who is forgetful may leave stoves burning or forget they have left a cigarette burning).

Domain 4: Financial

Clients’ inability to manage their finances, or disinterest in doing so, are often the reasons that self-neglect cases come to light.

Domain 5: Social and Cultural

- Lack of caregivers
- Caregivers fail to provide care
- Clients forego necessities or care for the sake of others (e.g. a grandmother with diabetes fails to follow the diet her doctor recommends because she buys food for other family members).
Question for 200 points:
Explain that social support is a critical determinant in self-neglect. And, someone with severe impairments may manage well if they have a strong support network. In contrast, a mild or moderate impairment may have significant consequences for someone who lacks support.

Questions for 400 points: Cultural factors contributing to self-neglect include feeling a sense of shame which may be heightened within cultures that have high expectations for children taking care of parents. In other cultures, fatalistic religious or philosophical views may believe that efforts to change one’s fate are not desirable or likely to be successful. And, some cultures have a fear of the government and may fear deportation (e.g. undocumented or persons with restricted documentation, institutionalization. Other people may just lack an understanding of treatment.
## FIVE DOMAINS JEOPARDY GAME

<table>
<thead>
<tr>
<th>Physical and Medical</th>
<th>Psychological and Mental Health</th>
<th>Environmental</th>
<th>Financial</th>
<th>Social</th>
</tr>
</thead>
</table>
| Q. Some individuals become self-neglecting when their heart can’t pump blood effectively because of this medical condition.  
A. *What is Congestive Heart Failure?* | Q. This mental illness, characterized by persistent sad mood, feelings of worthlessness, and the inability to feel pleasure, can be associated with self-neglect.  
A. *What is Depression?* | Q. Besides neglecting themselves, self-neglecting individuals may also fail to clean or repair this.  
A. *What is their home?* | Q. Self-neglect issues often come to the attention of APS when clients fail to do this financial task.  
A. *What is paying their bills?* | Q. Self-neglecting clients often lack a person to take this disability related role in their life.  
A. *What is a caregiver?* |
| Q. Some self-neglectors have a condition in which their glucose level gets too high.  
A. *What is Diabetes?* | Q. Individuals with mental illness may also have this co-occurring problem.  
A. *What is substance abuse?* | Q. Often the easiest way to determine whether self-neglect is caused by alcoholism is to check this aspect of the client’s environment.  
A. *What is their trash?* | Daily Double means double points!  
Q. What wealthy New York heiress was financially exploited by her son?  
A. *Who is Brooke Astor?* | Q. Clients may manage well, even with severe impairments, if their social network is …  
A. *What is strong and supportive?*  
*Explain how social support interacts with impairment* |
| Q. Self-neglect is a medical emergency when fluid intake gets too low causing this medical condition.  
A. *What is dehydration?* | Q. This is a descriptive term for a collection of symptoms that can be caused by a number of disorders that affect the brain. It includes a memory deficit plus a deficit in at least one other cognitive domain  
A. *What is dementia?*  
*Discuss causes of “Pseudo-dementia” here* | Q. When dealing with extreme animal hoarding cases, APS should partner with this agency.  
A. *What is animal control?* (or the Humane Society) | Q. When a self-neglecting client gives his money away to a person he trusts, against his own best interest, you may be dealing with this type of financial abuse.  
A. *What is undue influence?* | Q. Neighbors generally characterize self-neglecting clients as a problem because they do this.  
A. *What is 1. Bring down property values, 2. Pose a nuisance, 3. Reduce quality of life or, 4. Endanger their safety?* |
### Q. A common cause of confusion found is self-neglecting clients is this infection.
A. *Urinary Tract Infections*

### Q. In legal terms, individuals who are unable to make informed decisions about their medical care are said to have this.
A. *What is Diminished Capacity?*

### Q. The biggest dilemma when dealing with self-neglecting clients is balancing safety against this.
A. *What is self determination?*

### Q. When the client is unable to manage his own finances, you may want him to consider this type of service.
A. *What is daily money management or a Representative Payee Program?*

### Q. Cognitively intact self-neglecting clients may refuse help for this reason.
A. *What is:*
1. Shame that children aren’t caring for them.
2. A philosophical view that they should handle their own affairs or,
3. Fear of institutionalization, deportation or other government response?

### Q. Deficiency in this vitamin has been linked by research to self-neglect.
A. *What is Vitamin D?*

* Discuss cause and effect issues

### Q. Clients who agonize about making the right decisions due to Obsessive Compulsive Disorders may demonstrate this type of self-neglecting behavior.
A. *What is Hoarding? (Note: Hoarding is more often related to executing functioning problems)*

### Q. APS should intervene against a client’s wishes (when the client appears to be otherwise competent) when the client’s environment is this.
A. *What is a source of immediate danger to the client’s life?*

### Q. The most extreme intervention for clients who are financially self-neglecting is to refer them for this service.
A. *What is a guardianship or conservatorship? (In some jurisdictions it would be a guardianship of the estate)*

### Q. Self-neglect makes up approximately this percentage of an average APS caseload.
A. *What is 37%?*
Is it neglect or self-neglect?

**TOPIC:** Neglect vs. Self-neglect

**Explain:**

- Sometimes, what appears to be self-neglect may, in fact, be caregivers’ failure to provide care.

**Ask:** What are some examples of situations where neglect may be mistaken for self-neglect? Answers may include:

- Not clear who is responsible or who has a “duty” to provide care (duty may arise from contract, family relationship, or agreement)
- Caregiver fails to provide duties but claims the client is refusing care
- Elder has fired a caregiver or has alienated caregiver.
Assessing Severity and Urgency in Self-Neglect

**TOPIC:** Severity and Urgency

**Explain:**

Self-neglect cases vary widely in terms of severity and urgency. Clients’ self-neglecting behaviors may result in gradual decline to life threatening emergencies.

**Activity:** Assessing severity and urgency in self-neglect

1. Post 5 sheets of flip chart paper around the room. Label each sheet with the name of a domain:
   a. Physical and Medical
   b. Psychological/Mental Health
   c. Environmental

**TIME ALLOTTED:** 20 minutes
d. Financial
   e. Social and Cultural

2. Assign each table group to a “domain” to start.

3. Explain: “For this activity, you’re going to work in groups to explore the impact of self-neglect in 5 domains.” Provide one of the examples from the list at the bottom of the page to get them started in each domain.

4. Given the groups 3 minutes to list as many examples as they can of in which clients (or others) are at risk in their domain. They should list them on the flip chart paper.

5. After 3 minutes, ask the groups to move clockwise to the next “domain” and give them 3 minutes to add to that list. Continue having the groups move around the room until each group has had a chance to add to each domain list.

6. Then, have each group take their original “domain” flip chart back to their table and rank (from least severe/least urgent to most severe/most urgent) the examples according to the level of urgency and severity, giving reasons for each decision. Write the situations, in rank order, on the flip chart paper. (*They can just number the examples on their current flip chart paper or have a new paper to re-write the examples in rank order depending on their preference.*) Explain that the rank order of the situations will be a matter of opinion and there will not be a “correct” answer. The reasons they provide for the order is the important teaching point.

7. Have each group report out their list and their reasons for putting the situations in the order they selected.

Below is a list of possible examples, in rank order:

1. Physical/Medical
   - Failure to eat properly may result in failure to thrive, vitamin deficiency, gradual weight loss
   - Failure to manage blood pressure medication may result in heightened risk of stroke
   - Failure to manage diabetes diet or medications can lead to blindness, loss of limbs
   - Failure to seek medical treatment for acute problems (e.g. gangrene) may result in amputation, sepsis, or death

2. Mental health status and capacity
   - Inability to remember to take medications may lead to pseudo dementia
   - Depression may result in client becoming isolated

3. Financial
   -...
• Obsessive compulsive disorder may result in hoarding
• Adult is gravely disabled

3. Living environment
• Failure to maintain property may decrease the value of the home or neighborhood
• Failure to clean home may lead to isolation
• Failure to maintain home may raise the risk of falls, fire
• Failure to maintain animals may place pets in jeopardy result in animal cruelty

4. Financial
• Failure to monitor finances may raise the risk of exploitation
• Failure to pay taxes may lead to debt,
• Failure to pay bills may lead to loss of utilities, eviction

5. Social (risk posed by others, including caretakers and family members)
• Adult is unwilling to hire or accept needed care
• Caregivers lack the skills or ability to provide needed care
• Caregivers are withholding needed care
• Caregivers are abandoned client
Screening Capacity in Self-Neglect Cases

TIME ALLOTTED: 30 minutes

TOPIC: Screening Capacity in Self-neglect Cases

Explain:

• Screening for capacity problems is extremely important in self-neglect cases because many clients have impairments.
• In screening capacity in self-neglect cases, what skills are important to assess?

Asking participants for 4 or 5 examples of why screening for capacity problems is important in self-neglect cases before showing the next slide.
**TOPIC: Assessment**

Explain that we want to know if the person is capable of managing on his or her own. These are some of the activities and decisions that we need to assess.

- Live alone safety
- 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
TOPIC: Screening for Capacity

Explain that in evaluating capacity, we want to know “Can the person understand and appreciate decisions? Can he or she use reasoning and express choices?

So, for example, in making medical decisions:

Does the person:
- Understand his or her options? Does the person know what medical treatments are available?
- Appreciate the benefits and drawbacks of their actions or decisions? Does the person know what will happen if he refuses medical treatment? Does he understand how the treatment will benefit him?

Can he or she:
- Use reasoning to analyze pertinent information?
- Express choices

- Review Dimensions of Capacity handout with participants.
- Review the chart Capacity for Medical Treatment, which provides sample questions that can be used to assess clients’ ability to make informed medical or treatment decisions.

Tell the participants: In a few minutes, you’re going to have a chance to apply this scheme to other kinds of capacity.
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

<table>
<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).

**TOPIC: Executive Function**

Explain to the participants that executive functioning can be thought of as the activities that we associate with business executives: planning, scheduling, organizing tasks, evaluating options, making complex decisions, predicting outcomes, etc.

Recent studies suggest that there’s a strong relationship between “executive dysfunction” and impairment of activities of daily living. For that reason, executive dysfunction is an important consideration in self-neglect.

Ask the participants, “How would you know that the client’s executive functioning was impaired?”

Possible answers might include:

The client may have problems with bill paying, driving, managing medications, and missing doctor’s appointments.
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

**TOPIC: Enhancing Capacity**

Sometimes clients’ capacity to understand can be improved through simple measures. Physicians and psychologists may be able to conduct analyses that can identify treatable problems.

trainer’s note: It’s important to determine your agency’s policy for referring clients to other professionals for capacity assessments so that you can provide that information to participants if questions arise.

Now, let’s practice screening client capacity. This exercise will give you practice in framing questions to help you assess clients’ capacity to perform important tasks.

Activity: Assessing Capacity in Self-Neglect Cases

1. Direct the participants to go to HANDOUT 8, Sample Case 1: Mrs. Green.
2. Have them read the case.
3. Ask each group to assign a Note-taker and reporter.
4. Have each group develop a list of questions to determine if Mrs. Green has capacity to make decisions.
   - Have half the groups develop questions to assess Mrs. Green’s ability to provide self-care.
   - Have the other half the groups develop questions to assess Mrs. Green’s ability to manage her finances.
Below are:

Examples of questions about Mrs. Green's ability to provide self care:

- Can you tell me what these medications are for? (Understanding)
- What makes you think that your medications are making you sick? How did you reach that decision? What factors did you consider? (Reasoning)
- What will happen if you don’t take them? (Appreciation)
- On those days that you aren’t able to go grocery shopping, how can you continue to eat properly? (Appreciation)
- If you needed to call a friend, a cab, or other transportation to take you to the store, how would you do that? (Reasoning)
- If you had someone give you your medications, how would that affect your everyday life? (Appreciation)

Examples of questions about Mrs. Green’s ability to manage her money:

- Show Mrs. Green the letters from the collection agency and ask: Do you know what these are and why you've received it? (Understanding)
- What will happen if you don’t respond? (Appreciation)
- How could asking [cite individual] to help you with paying your bills be better than managing your monthly income and paying bills by yourself? (Reasoning)
- Are there any reasons why asking (caregiver, family member, or agency) to manage your income might not help or might make things worse for you? (Reasoning).
- Can you explain to me what you’ve decided and why? (Expressing a choice).
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

What we call self-neglect actually includes different types of behavior. For the next 20 minutes, we're going to focus in on a few of the various forms of self neglect.
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 (Steketee, G. & Frost, R., 2003)

TOPIC: Hoarding Defined

A simpler definition is:
“Living or workspaces are sufficiently cluttered so as to preclude activities for which these spaces are designed.”

Compulsive hoarding is considered by many to be a form of self-neglect because it typically interferes with a peoples’ ability to care for themselves. Hoarders may only come to someone’s attention when public officials are notified because of a dangerous situation such as a structure fire or other problem such as excessive rodents, toilets that have become unusable, debris spilling out of a residence, or sagging roofs.
Compulsive hoarding affects over 3 million Americans

Although the problem has always existed, it has become the focus of attention in recent years, with many communities developing programs and services. We don’t know the causes of compulsive hoarding, but many hoarders show signs of obsessive-compulsive disorder. Some suggest that past trauma may be a contributing factor.

Part of the text of the newspaper article:

“For what may have been three weeks, a husband and wife in their mid-70s — a retired zoologist and retired schoolteacher — were trapped in their own junk and squalor.

The police described them as hoarders.

It may be tempting to think of hoarders as people who are just extra sloppy or lazy, in need of a scolding and a subscription to "Real Simple" magazine.

But compulsive hoarders aren’t typical clutterers. They’re not normal collectors. They struggle with a psychiatric disturbance that, though related to obsessive-compulsive disorder, is not well understood.
Impact of Compulsive Hoarding

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

TOPIC: Impact of Compulsive Hoarding

A lot of people make jokes about hoarding, but the consequences of compulsive hoarding can be very severe. It can result in death if the home poses a fire hazard or homelessness if the person is evicted. Many hoarders experience intense shame and depression.
"Who's Normal Anyway?"

Available at: http://www.youtube.com/watch?v=CMEWT1AWhq0

Explain:

This video, which features Dr. Randy Frost, a leading expert in hoarding, is part of a BBC series. It profiles:

- Bob, who has lived in New York all his life, but for the past 30 years nobody has been allowed into his apartment. Like one in two million Americans, Bob has a hoarding disorder; whatever comes into his apartment never leaves it. Is he beyond help?
- Shirley, also a hoarder, might be Bob's saving grace. She is part of a 'mentoring' scheme that puts hoarders in contact with each other in order to offer support and encouragement. Will she be able to help Bob start the huge task of throwing things out
Following the video:

Ask: What characteristics do Bob and Shirley have common in terms of their backgrounds and how they view their situations? Answers may include:
  - Both have experienced trauma
  - Both experience intrusive, fearful thoughts
  - They feel “protected” by their possessions

How does Dr. Frost describe the compulsive hoarding? Answers may include:
As a form of Obsessive, Compulsive Disorder (OCD) as characterized by intrusive, fearful thoughts.
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)

**TOPIC: Health Literacy**

Many adults lack the literacy skills necessary to manage their own health, which may contribute to, or be mistaken for, self-neglect.

The statistics below suggest that those working with self-neglecting clients need to pay attention to health literacy:

- The average American reads at the 8th to 9th grade level.
- Most health care materials are written about the 10th grade level.
- More than 66% of adults age 60 and over have either inadequate or marginal literacy skills. (The Partnership for Clear Health Communication at the National Patient Safety Foundation, www.npsf.org/pchc).
- According to the Center for Health Care Strategies, a disproportionate number of minorities and immigrants are estimated to have literacy problems:
  - 50% of Hispanics
  - 40% of Blacks
  - 33% of Asians
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)

**TOPIC:** Clients with low literacy make these mistakes

Does it seem likely that some self-neglecting adults may not understand how to provide appropriate self-care? How might these same limitations affect your service planning?

Ask the participants if they (given their advanced education) have ever had problems navigating the health care system? (e.g. Do they understand the “bills” (that are really statements of what has been paid) that the insurance company sends them? Have they ever had trouble figuring out where to go for a test or procedure? Or whether the doctor wants to see them again after the test? What kind of problems have they had getting in to see a specialist?) Then ask them to imagine how difficult this would be if English as their second language, they got easily confused or were very shy about asking for information?
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.)

**TOPIC: Hiding Illiteracy**

Many people are too embarrassed to admit they have trouble reading and understanding.

Ask: What are some ways to make clients more comfortable talking about literacy?

Explain that one of the best ways to determine whether a client understands your directions or information is to ask the client to “teach it back” to you. It’s a best practice in health literacy to always ask the patient/client to explain (or demonstrate) what you are asking them to do. So if, for example, you just helped the client sign up for Meals on Wheels you might ask, “Explain to me how the Meals on Wheels program works so that I know you understand what is going to happen next.”
TOPIC: AMA Health Literacy video

If time allows, show the class the AMA Health Literacy video which demonstrates many of the points we have discusses. If time is tight, this video may be skipped.

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

TIME ALLOTTED: 10 minutes

TOPIC: Self-neglect Related Assessment Tools

There are a lot of tools available for measuring people’s ability to manage. Some of these tools are proprietary (notably the Mini Mental State Exam). They are available for purchase. Let the workers know that these tools are being developed and are being used in research.

Review Handout #9 with the participants.

Trainer Note: Some of the tools are included in the trainer’s manual for your review. They are NOT in the participant manual. For copyright reasons, copies of the other tools are not included. However, trainers are encouraged to download copies/additional information from the internet to review in anticipation of possible questions from the participants.
Tools for Assessing Self Neglect

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 has 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
**WORKING WITH SELF-NEGLECTING CLIENTS: TRAINER’S MANUAL**

**UNIVERSITY OF NEBRASKA MEDICAL CENTER**
**UNIVERSITY HOSPITAL & UNIVERSITY MEDICAL ASSOCIATES**
**GERIATRIC ASSESSMENT CENTER**
**SCALE FOR INSTRUMENTAL ACTIVITIES OF DAILY LIVING**

Visit: 1st  2nd  3rd  
(Circle one)

**Instructions:** Write in the appropriate value number on the score lines provided to the right of the responses. Add the value numbers to obtain total score.

1. **ABILITY TO USE TELEPHONE**
   - 3 Operates telephone on own initiative; looks up and dials numbers, etc.  
   - 2 Dials a few well known numbers  
   - 1 Answers telephone but does not dial  
   - 0 Does not use telephone at all

2. **SHOPPING**
   - 3 Takes care of all shopping needs independently  
   - 2 Shops independently for small purchases  
   - 1 Needs to be accompanied on any shopping trip  
   - 0 Needs to have meals prepared and served

3. **FOOD PREPARATION**
   - 3 Plans, prepares and serves adequate meals independently  
   - 2 Prepares adequate meals if supplied with ingredients  
   - 1 Heats and serves prepared meals, or prepares meals but does not maintain adequate diet  
   - 0 Needs to have meals prepared and served

4. **HOUSEKEEPING**
   - 4 Maintains house alone or with occasional assistance (e.g., heavy-work domestic help)  
   - 3 Performs light daily tasks such as dish-washing and bed-making  
   - 2 Performs light daily tasks but cannot maintain acceptable level of cleanliness  
   - 1 Needs help with all home maintenance tasks  
   - 0 Does not participate in any housekeeping tasks

5. **LAUNDRY**
   - 2 Does personal laundry completely  
   - 1 Launders small items; rinses socks, stockings, etc.  
   - 0 All laundry must be done by others

6. **MODE OF TRANSPORTATION**
   - 4 Travels independently on public transportation or drives own car  
   - 3 Arranges own travel via taxi, but does not otherwise use public transportation  
   - 2 Travels on public transportation when assisted or accompanied by another  
   - 1 Travel limited to taxi or automobile, with assistance of another  
   - 0 Does not travel at all

7. **RESPONSIBILITY FOR OWN MEDICATION**
   - 2 Is responsible for taking medication in correct dosages at correct time  
   - 1 Takes responsibility if medication is prepared in advance in separate dosages  
   - 0 Is not capable of dispensing own medication

8. **ABILITY TO HANDLE FINANCES**
   - 2 Manages financial matters independently (budgets, write checks, pays rent and bills, goes to Bank) collects and keeps track of income  
   - 1 Manages day-to-day purchases, but needs help with banking, major purchases, etc.  
   - 0 Incapable of handling money

**TOTAL SCORE**

**Interviewer Signature**

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**MODULE 10**  
Version 1.1  
6/2/2015
**WORKING WITH SELF-NEGLECTING CLIENTS: TRAINER’S MANUAL**

**UNIVERSITY OF NEBRASKA MEDICAL CENTER**
**UNIVERSITY HOSPITAL & UNIVERSITY MEDICAL ASSOCIATES**
**GERIATRIC ASSESSMENT CENTER**
**ACTIVITIES OF DAILY LIVING**
**PHYSICAL SELF-MAINTENANCE SCALE**

Visit: 1\(^{st}\) 2\(^{nd}\) 3\(^{rd}\) (Circle one)

**Instructions:** Write in the appropriate value number on the score lines provided to the right of the responses. Add the value numbers to obtain total score.

<table>
<thead>
<tr>
<th>1. TOILET</th>
<th>Value No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. Cares for self at toilet completely, no incontinence</td>
<td></td>
</tr>
<tr>
<td>3. Needs to be reminded, or needs help in cleaning self, or has rare (weekly at most) accidents</td>
<td></td>
</tr>
<tr>
<td>2. Soiling or wetting while asleep, more than once a week</td>
<td></td>
</tr>
<tr>
<td>1. Soiling or wetting while awake, more than once a week</td>
<td></td>
</tr>
<tr>
<td>0. No control of bowels or bladder</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2. FEEDING</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>4. Eats without assistance</td>
<td></td>
</tr>
<tr>
<td>3. Eats with minor assistance at meal times, with help preparing food or with help in cleaning up after meals</td>
<td></td>
</tr>
<tr>
<td>2. Feeds self with moderate assistance and is untidy</td>
<td></td>
</tr>
<tr>
<td>1. Requires extensive assistance for all meals</td>
<td></td>
</tr>
<tr>
<td>0. Does not feed self at all and resists efforts of others to feed him</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3. DRESSING</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>4. Dresses, undressed and selects clothes from own wardrobe</td>
<td></td>
</tr>
<tr>
<td>3. Dresses and undresses self, with minor assistance</td>
<td></td>
</tr>
<tr>
<td>2. Needs moderate assistance in dressing or selection of clothes</td>
<td></td>
</tr>
<tr>
<td>1. Needs major assistance in dressing but cooperated with efforts of other to help</td>
<td></td>
</tr>
<tr>
<td>0. Completely unable to dress self and resists efforts of others to help</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4. GROOMING (neatness, hair, nails, hands, face, clothing)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>4. Always neatly dressed and well-groomed, without assistance</td>
<td></td>
</tr>
<tr>
<td>3. Grooms self adequately, with occasional minor assistance, e.g., in shaving</td>
<td></td>
</tr>
<tr>
<td>2. Needs moderate and regular assistance or supervision in grooming</td>
<td></td>
</tr>
<tr>
<td>1. Needs major assistance in dressing but cooperates with efforts of others to help</td>
<td></td>
</tr>
<tr>
<td>0. Actively negates all efforts to others to maintain grooming</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5. PHYSICAL AMBULATION</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>4. Goes about grounds or city</td>
<td></td>
</tr>
<tr>
<td>3. Ambulates within residence or about one block distant</td>
<td></td>
</tr>
<tr>
<td>2. Ambulates with assistance of (check one): _____ another person, _____ railing, _____ cane, _____ walker, or _____ wheelchair; _____ gets in and out without help _____ needs help in getting in and out</td>
<td></td>
</tr>
<tr>
<td>1. Sits unsupported in chair or wheelchair, but cannot propel self without help</td>
<td></td>
</tr>
<tr>
<td>0. Bedridden more than half the time</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>6. BATHING</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>4. Bathes self (tub, shower, sponge bath) without help</td>
<td></td>
</tr>
<tr>
<td>3. Bathes self, with help in getting in and out of tub</td>
<td></td>
</tr>
<tr>
<td>2. Washes face and hands only, but cannot bathe rest of body</td>
<td></td>
</tr>
<tr>
<td>1. Does not wash self but is cooperative with those who bathe him</td>
<td></td>
</tr>
<tr>
<td>0. Does not travel at all</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>7. RESPONSIBILITY FOR OWN MEDICATION</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Is responsible for taking medication in correct dosages at correct time</td>
<td></td>
</tr>
<tr>
<td>1. Takes responsibility if medication is prepared in advance in separate dosages</td>
<td></td>
</tr>
<tr>
<td>0. Does not try to wash self, and resists efforts to keep him clean</td>
<td></td>
</tr>
</tbody>
</table>

**TOTAL SCORE**

**1\(^{st}\) Check**

**2\(^{nd}\) Check**

**Interviewer Signature**


**MODULE 10**

-75-  

6/2/2015

Version 1.1
MONTREAL COGNITIVE ASSESSMENT (MOCA)

VISUOSPATIAL / EXECUTIVE

Copy cube

Draw CLOCK (Ten past eleven) (3 points)

NAME:
Education:
Sex:
Date of birth:
DATE:

POINTS

CONTOUR

NUMBERS

HANDS

NAMING

MEMORY

Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.

F A C E
V E L V E T
C H U R C H
D A I S Y
R E D

1st trial

2nd trial

No points

ATTENTION

Read list of digits (1 digit/sec.). Subject has to repeat them in the forward order

Subject has to repeat them in the backward order

Read list of letters. The subject must tap with his hand at each letter. No points if > 2 errors


Serial 7 subtraction starting at 100

4 or 5 correct subtractions

3 pts. 2 or 3 correct: 2 pts. 1 correct: 1 pt. 0 correct: 0 pt

LANGUAGE

Fluency / Name maximum number of words in one minute that begin with the letter F

The cat always hid under the couch when dogs were in the room.

ABSTRACTION

Similarity between e.g. banana - orange - fruit

.train - bicycle

.watch - ruler

DELAYED RECALL

Has to recall words

WITH NO CUE

FACE
V E L V E T
C H U R C H
D A I S Y
R E D

Points for UNCLUED recall only

Optional

Category cue

Multiple choice cue

ORIENTATION

Date

Month

Year

Day

Place

City

© 2.3asredine MD Version 7.1 www.mocatest.org Normal ≥ 26 / 30

TOTAL: __/30

Add 1 point if ≤ 12 yr ed
### The NSGCD Clutter Hoarding Scale

<table>
<thead>
<tr>
<th>Level</th>
<th>Structure &amp; Zoning Issues</th>
<th>Pets &amp; Rodents</th>
<th>Household Functions</th>
<th>Sanitation &amp; Cleanliness</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>I</strong></td>
<td>All doors and stairways accessible</td>
<td>Normal household pet activity</td>
<td>Clutter not excessive</td>
<td>Normal housekeeping, safe and healthy sanitation, no odors</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1-3 spills or pet accidents evident</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Light evidence of rodents/insects</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>II</strong></td>
<td>1 exit blocked</td>
<td>Some pet odor</td>
<td>Clutter inhibits use of more than two rooms</td>
<td>Limited evidence of housekeeping, vacuuming, sweeping</td>
</tr>
<tr>
<td></td>
<td>1 major appliance or regionally appropriate heating, cooling or ventilation device not working for longer than 6 months</td>
<td>Cat spray or pet waste puddles</td>
<td>Unclear functions of living room, bedroom</td>
<td>Tolerable, but not pleasant, odors</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Light pet dander in evidence</td>
<td>Slight narrowing of household pathways</td>
<td>Overflowing garbage cans</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3 or more incidents in evidence</td>
<td></td>
<td>Light-to-medium mildew in bathroom or kitchen</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Limited fish, reptile or bird pet care</td>
<td></td>
<td>Moderately soiled food preparation surfaces</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Light-to-medium evidence of common household rodents/insects</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>III</strong></td>
<td>Visible clutter outdoors</td>
<td>Pets exceed local humane Society limits by 1-3 animals, excluding well-cared-for puppy or kitten litter less than 4 months old</td>
<td>Visible clutter outdoors</td>
<td>Excessive dust</td>
</tr>
<tr>
<td></td>
<td>Items normally stored indoors evident outside (TV, sofa)</td>
<td>Stagnant fish tank</td>
<td>Narrowed hall and stair</td>
<td>Bed linens, including pillow, show evidence of dirt, long time use</td>
</tr>
<tr>
<td></td>
<td>2 or more appliances broken or not functioning</td>
<td>Poorly maintained reptile aquarium odor and waste</td>
<td>1 bathroom or bedroom not fully usable; i.e. items in the shower</td>
<td>No evidence of any recent vacuuming or sweeping</td>
</tr>
<tr>
<td></td>
<td>Inappropriate and/or excessive use of electric and extension cords</td>
<td>Bird droppings not recently cleaned</td>
<td>Small amounts of 1-2 obviously hazardous substances, chemicals, substance spills, broken glass</td>
<td>Heavily soiled food preparation surfaces</td>
</tr>
<tr>
<td></td>
<td>Light structural damage limited to 1 part of the home, recent (less than 6 months)</td>
<td>Audible, but not visible, evidence of rodents</td>
<td></td>
<td>Obvious and irritating odor</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Light flea infection</td>
<td></td>
<td>Unused, full or odorous garbage cans</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Medium amount of spider webs inside house</td>
<td></td>
<td>Dirty or soiled laundry throughout house, exceeding 3 hamper-sized baskets per bedroom</td>
</tr>
<tr>
<td>Level</td>
<td>Structure &amp; Zoning Issues</td>
<td>Pets &amp; Rodents</td>
<td>Household Functions</td>
<td>Sanitation &amp; Cleanliness</td>
</tr>
<tr>
<td>-------</td>
<td>---------------------------</td>
<td>----------------</td>
<td>---------------------</td>
<td>-------------------------</td>
</tr>
</tbody>
</table>
| IV    | Structural damage to part of home (longer than 6 months)  
      | Mold or mildew on walls or floors  
      | Inappropriate use of appliance: storing paper in oven, storing nonfood items in refrigerator (beyond batteries, film)  
      | Evidence of damage to 2 or more sections of wall board  
      | Faulty weather protection: deteriorated or ineffective waterproofing of exterior walls, roofs, foundation or floors, including broken windows or doors; missing or damaged gutters/downspouts  
      | Hazardous electrical wiring  
      | Odor or evidence of sewage backup | Pets exceed local Humane Society limits by 4 animals (of any type)  
      | Obvious aged animal waste exceeding 2-3 recent “accidents”  
      | Pet dander on all furnishing  
      | Pet has free range with evidence of destructive behavior, clawed furnishings, chewed doors or frame  
      | Excessive spiders and webs  
      | Bats, squirrels, raccoons in attic or room  
      | Flea infestation | Designated bedroom unusable: using living area or sleeping on sofa or floor  
      | Hazardous materials stored inside of home, e.g. gasoline, aged, rusted and leaking paint or household chemical cans and bottles  
      | Excessive combustible and highly flammable packed material in living area or attached garage | Rotting food on counters  
      | 1-15 aged canned goods with buckled tops and sides  
      | No covers on beds, sleeping directly on mattresses, lice on bedding or furnishings  
      | No clean dishes or utensils locatable in kitchen |
Earlier we talked about the study of Tina Dubin and her colleagues and the various categories of self-neglecting clients they identified. Now, we’ll take a closer look at how APS workers intervened and how well they did. As you might imagine, APS workers had better results working with some clients than others.

Read the description of each type of self-neglecting client and ask for a show of hands as to whether they think that type of client has a good prognosis or a bad prognosis. For example:

CONTINUED
Overwhelmed Caregiving Systems. The older person has family, friends, or paid caregivers who are actively involved in providing care but are not doing everything that’s necessary.

Ask: How many of you think the prognosis is good in Overwhelmed caregivers cases. Give reasons.

Follow up by asking: What types of interventions would you think are effective?

Answer.

- The prognosis for these cases is good because the “essential ingredients” are present. The adult is willing to accept help. there are caregivers willing to help
- Successful interventions were giving caregivers “hands on” help.

Repeat for the remaining 4 types of Caregiving Systems

Then share the results from the study for that type of self neglecting client.

When you have covered each type, explain that for the rest of the afternoon we will be discussing how to intervene with clients who “resist” our help.
Neglect and Self-Neglect as the Absence or Breakdown of Caregiving Systems (Part 2)

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 cannot 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.

Working with “Resistant” Clients

Self-neglecting clients who refuse help are referred to by some as “resistant” or “reluctant” clients. We need to be careful not to stigmatize or blame these clients but rather, to understand their reasons for resisting help. We will spend the next portion of the training learning methods for working with these clients.
TOPIC: Reasons People Refuse Help

Research and practice suggests that people neglect their care and/or refuse help or services as a result of many factors.

Ask: What cultural factors may contribute to clients refusing help? Answers may include: Sense of shame may be heightened within cultures that have expectations for children taking care of parents, lack of knowledge about services, etc.
Motivational Interviewing

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


TOPIC: Motivational Interviewing

Motivational Interviewing is a short term counseling technique which has proven to be very effective with other “resistant” populations such as substance abusers and some mentally ill populations. The basic tenets of this interviewing technique are:

- Motivation to change is elicited from the client (not imposed upon the client).
- The client must resolve his own ambivalence.
- Direct persuasion doesn’t work!
- Your style must be quiet and eliciting while helping the client examines and resolve the ambivalence.
- Readiness to change is the product of the interpersonal interaction.
- You are a partner, not “the expert”.

 MODULE 10 -85- 6/2/2015

Version 1.1
Core Concepts of MI

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

TOPIC: Core Concepts of Motivational Interviewing

There are four general principles behind Motivational Interviewing.

Express Empathy

Empathy involves seeing the world through the client's eyes, thinking about things as the client thinks about them, feeling things as the client feels them, sharing in the client's experiences. Expression of empathy is critical to the MI approach. When clients feel that they are understood, they are more able to open up to their own experiences and share those experiences with others. Having clients share their experiences with you in depth allows you to assess when and where they need support, and what potential pitfalls may need focused on in the change planning process. Importantly, when clients perceive empathy on a counselor's part, they become more open to gentle challenges by the counselor about lifestyle issues and beliefs about substance use. Clients become more comfortable fully examining their ambivalence about change and less likely to defend ideas like their denial of problems, reducing use vs. abstaining, etc. In short, the counselor's accurate understanding of the client's experience facilitates change.

Support Self-Efficacy

As noted above, a client's belief that change is possible is an important motivator to succeeding in making a change. As clients are held responsible for choosing and carrying out actions to change in the MI approach, counselors focus their efforts on
helping the clients stay motivated, and supporting clients' sense of self-efficacy is a great way to do that. One source of hope for clients using the MI approach is that there is no "right way" to change, and if a given plan for change does not work, clients are only limited by their own creativity as to the number of other plans that might be tried.

The client can be helped to develop a belief that he or she can make a change. For example, the clinician might inquire about other healthy changes the client has made in their life, highlighting skills the client already has. Sharing brief clinical examples of other, similar clients' successes at changing the same habit or problem can sometimes be helpful. In a group setting, the power of having other people who have changed a variety of behaviors during their lifetime gives the clinician enormous assistance in showing that people can change.

**Roll with Resistance**

In MI, the counselor does not fight client resistance, but "rolls with it." Statements demonstrating resistance are not challenged. Instead the counselor uses the client's "momentum" to further explore the client's views. Using this approach, resistance tends to be decreased rather than increased, as clients are not reinforced for becoming argumentative and playing "devil's advocate" to the counselor's suggestions. MI encourages clients to develop their own solutions to the problems that they themselves have defined. Thus, there is no real hierarchy in the client-counselor relationship for the client to fight against. In exploring client concerns, counselors may invite clients to examine new perspectives, but counselors do not impose new ways of thinking on clients.

**Develop Discrepancy**

"Motivation for change occurs when people perceive a discrepancy between where they are and where they want to be" (Miller, Zweben, DiClemente, & Rychtarik, 1992, p. 8). MI counselors work to develop this situation through helping clients examine the discrepancies between their current behavior and future goals. When clients perceive that their current behaviors are not leading toward some important future goal, they become more motivated to make important life changes. Of course, MI counselors do not develop discrepancy at the expense of the other MI principles, but gently and gradually help clients to see how some of their current ways of being may lead them away from, rather than toward, their eventual goals.

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)*

**TOPIC: Stages of Change**

Motivational Interviewing theory states that people will only change when they are ready to change. This slide shows the various stages of change. It’s the social worker’s job to determine the client’s readiness to change and accept help.
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...)

**TOPIC:** Change Talk

In order to determine the client’s willingness to change, the social workers needs to listen for indications that the client is ready/willing to change. The slide provides examples of statements that the client might make indicating he is ready to change.

If the client is not ready to change, how can you motivate him to change? (Remember that direct persuasion doesn’t work!)
**TOPIC: Decisional Balance Worksheet**

To move clients through the stages of change, motivational interviewing asks the client to consider the good and bad things about both changing and not changing. The social worker needs to ask the client for the good and not so good things about their current behavior and about changing their behavior. Ask the class to shout out examples of the good and not so good things about hoarding in order to complete a decisional balance sheet.

The result might look like this:

<table>
<thead>
<tr>
<th>Good things about behavior:</th>
<th>Good things about changing behavior:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don’t need to change/do anything different</td>
<td>My home would be more comfortable</td>
</tr>
<tr>
<td>I get to keep my things</td>
<td>I could have company</td>
</tr>
<tr>
<td>Don’t need to buy things that I already own</td>
<td>My neighbors would stop bugging me</td>
</tr>
<tr>
<td>I have keepsakes/memories/documents</td>
<td>My home would be safer</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Not so good things about behavior:</th>
<th>Not so good things about changing behavior:</th>
</tr>
</thead>
<tbody>
<tr>
<td>The neighbors complain</td>
<td>Important papers might get thrown out</td>
</tr>
<tr>
<td>I can’t use some of my rooms/appliances</td>
<td>My anxiety level would be high</td>
</tr>
<tr>
<td>I can’t always find things</td>
<td>It’s a lot of work</td>
</tr>
<tr>
<td>I’m embarrassed to have company</td>
<td>I might fail and let everyone down</td>
</tr>
</tbody>
</table>
TOPIC: Video

The following video shows a therapist interviewing a gentleman who is reluctant to seek treatment for his alcoholism.

Ask the class to notice the length of time it takes her to move the client from total refusal to acceptance of help (less than 20 minutes!)

Ask the class to note how the therapist uses the core concepts of Motivational Interviewing: Expressing empathy, avoiding arguing, rolling with resistance, supporting self efficacy and developing discrepancy

Explain to the class that Motivational Interviewing is easy in theory but takes a lot of practice to execute well. Recommend that workers take advantage of any available training on the subject.
TOPIC: Substance Abuse Treatment

For some, self-neglect is associated with substance abuse. These treatments may be effective with elders and dependent adults who abuse substances.

- Provided in hospitals, therapeutic communities, or outpatient programs, and generally begins with detoxification in controlled settings.
- May use medications to control drug cravings and relieve severe symptoms of withdrawal.
- Combination of medication and individual or group therapy has been found to be most effective.
- Counseling to:
  - Help people understand their behavior and motivations
  - Develop higher self-esteem
  - Cope with stress
  - Gain insight into how alcohol and drugs have affected their lives and those of others.
- Self-help groups to provide support and reinforce messages learned in treatment (Alcoholics Anonymous)
Ask: Are there reasons that these services and interventions may not be as effective with elderly or dependent adults? Answers may include:
  o Clients may lack transportation to meetings
  o They may not be comfortable in group settings, especially with younger members.
  o May have communication barriers.
“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

TOPIC: Introduction into Harm Reduction

Traditional substance abuse programs typically assume that persons must be highly motivated to engage in the treatment process. For some, that may mean “hitting bottom” before they are ready to accept help. Traditional programs also typically require total abstinence.

Some experts question the appropriateness of traditional substance abuse prevention programs for elders who are frail.

Spencer and others suggest that “harm reduction,” may be a more appropriate approach for elders.
TOPIC: Harm Reduction Video

This interview with Allan Clear, executive director of the New York based Harm Reduction Coalition.

- Ask: How do harm reduction techniques differ from other common forms of treatment for substance abuse? Answers may include:
  - Does not require total abstinence.
  - Does not make moral judgment. Judgment free and neutral
  - Try to be neutral and value free
- Ask: Can you think of other behaviors affecting elders that may be mitigated using harm reduction techniques? Answers may include:
  - Hoarding
  - Compulsive gambling
  - Sweepstakes

The video is available for download at:
http://www.youtube.com/watch?v=Swxdf17vFz4&NR=1
Treatment for Hoarding

• Simply cleaning up doesn’t work
• Support/treatment groups

TOPIC: Treatment for Hoarding

Explain:

Refer back to “Who’s Normal Anyway” video with Dr. Randy Frost.

Ask “What interventions might work with hoarders?” Answers may include:

**Pharmacotherapy**- Hoarding and saving compulsions have been strongly associated with poor response to SRIs (Black et al., 1998; Winsberg et al., 1999; Mataix-Cols et al., 1999).

**Cognitive-Behavioral therapy**- In a controlled trial of CBT for patients who have OCD, high hoarding symptom scores predicted premature dropout and poor response to treatment (Mataix-Cols et al., 2002). CBT for compulsive hoarding is directed toward decreasing clutter, improving decision-making and organizational skills, and strengthening resistance to urges to save. Treatment includes ERP, excavation of saved material, decision-making training, and cognitive restructuring.

CONTINUED
Intensive Multimodal Treatment - Intensive treatment (at the UCLA OCD Partial Hospitalization Program) begins with a thorough assessment of the patient's amount of clutter; beliefs about possessions; information-processing, decision-making and organizational skills; avoidance behaviors; daily functioning; level of insight; motivation for treatment; social and occupational functioning; level of support from friends and family; and medication compliance. Before treatment begins, patients must provide baseline photographs of their cluttered areas.

Education and ERP are major components of treatment. Patients learn to conceptualize their hoarding in terms of problems with anxiety, avoidance, and information processing. Patients then gradually expose themselves to situations that cause them anxiety (e.g., being required to throw something away or make a decision about what to do with a specific object). They rate their subjective level of distress at regular intervals, using a Subjective Units of Distress Scale (SUDS). They are then supported and instructed to resist the urge to save or avoid until their SUDS level diminishes by at least 50%. With repeated practice, ERP extinguishes the fear of losing something important, thereby reducing the strength of the patient's urges to save. Intensive CBT for compulsive hoarding focuses on four main areas: discarding, organizing, preventing incoming clutter, and introducing alternative behaviors.

From Treatment of Compulsive Hoarding by Sanjaya Saxena, and Karron M. Maidment at http://focus.psychiatryonline.org/cgi/content/full/5/3/381
What factors determining appropriate interventions?

**TOPIC: Factors Determining Appropriate Interventions**

Ask: There are multiple interventions that can be employed in self-neglect cases. Determining which ones are appropriate depends on multiple factors. What factors do you think are important to know in every self neglect case? Write their answers on a flip chart.

Possible answers include:
- What the client wants
- Is the client capable of consenting or refusing services
- Clients’ willingness to accept help
- The client’s reasons for refusing care
• Level of risk or danger
• Level of capacity

Remind participants of the ethical issues raised by self-neglect, most notably safety versus self determination.
TOPIC: Types of Interventions

A wide range of services may be helpful in helping self-neglecting adults. Refer the participants to Handout #11 Services to Victims or Caregivers to Prevent Self-neglect in the Participants Manual. The following slides refer to services referenced there.
SERVICES TO VICTIMS OR CAREGIVERS TO PREVENT SELF-NEGLECT

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, attorneys 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

**TOPIC: Supportive Services**

Support services help people who aren’t able to meet their own self-care needs. The above list is just a few of the many and varied services that may be available.
TOPIC: Mental Health Treatment

The availability of mental health services varies widely, so it’s important to stay up to date about what’s available in your community.
Involuntary interventions are only used when the client does not understand the risks they face AND the risk is high.

Appointment of surrogates may involve going to court to ask for authority (e.g. under a conservatorship) or “triggering” an “advance directive” like a durable power of attorney. The process and criteria depends on the instrument. For example, clients may have previously indicated that a durable power of attorney will come into effect when their doctor decides they decide it’s needed.

Review the list on the screen and provide the additional information provided here.

- Involuntary assessments or hospitalizations (when persons with mental illnesses pose a danger to themselves or others, or are gravely disabled).
- Protective Custody (only available in some states; used rarely in California)
- 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 (e.g. forced closure or repair of homes that pose a threat)
TOPIC: Monitoring

When clients refuse help and risk remains, workers may attempt to arrange for services to ensure that clients have to help if and access when they need it.
TOPIC: Working the Self Neglect Case

Show screen Practice Activity: Working the Self-Neglect Case

1. Divide the Class into 4 groups of six. Give each group one of the following 2 cases.
2. Allow the groups 15 minutes to read through the case and respond to the following questions:
3. Explain that there are no correct answers. The purpose of the exercise is to stimulate discussion and try new skills.
4. Reassemble the groups. Ask a representative from each group to describe the group’s discussion. Allow 15 minutes for discussion. Point out differences in how the groups working with the same client approached their clients.

Case 1. John Sumner
Robert, an APS worker, receives a call from Sara, who is the manager of a senior apartment building. Sara 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?)

Sample steps:

- Let John know that others are concerned about his well-being.
- Ask him if he needs anything.
- Ask about the rent to see if he is aware that there is a problem and, if so, what he plans to do about it.
- Check to see if there is adequate food for John and the cats.
- Offer informal services (a volunteer visitor, help cleaning his home, assistance with his finances).
- Assess John’s risk. Is he able to provide food for himself and the cats. Does he understand the consequences of failing to eat, feed the cats, pay his rent.
- If he does not seem to understand his situation, ask for his permission to call family members, his physician, or others.

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. They brought her to a hospital Emergency Room and called APS. Trudy was assigned to the case, and when she followed up with the firefighters, they told her that Mrs. Albertson is a "frequent flyer": she has similar incidents every few months. When Trudy went to the hospital ER to talk to Mrs. Albertson, she was told that she'd felt better and left. The next day Trudy visited Mrs. Albertson in her home. When she expressed concern about the incident, Mrs. Albertson insisted that it was the medication her doctor had given her that she had thrown it away. With Mrs. Albertson’s permission, Trudy contacted the physician who informed her that Mrs. Albertson was on multiple medications and that he was aware of the problems. He felt she would be better off in an assisted living facility where someone could help her but she refused. On further investigation, she discovered that Mrs. Albertson had had several falls, and on one occasion had been on the floor for several hours before the mailman heard her shouting and called the police.

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

Sample steps:

- Assess Mrs. Albertson's understanding of her medications by asking her to explain what they are for, the dosage, etc.
• If Mrs. Albertson does not seem capable of managing her medications, explore other ways to make sure she takes them such as arranging for an attendant.
• Explore options with Mrs. Albertson to make her safer at home (e.g. a “life-line” emergency response device).

HANDOUT #12

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

TIME ALLOTTED: 15 minutes
TOPIC: Importance of good documentation

While good documentation is important in all aspects of APS practice, it is particularly important in self-neglect cases.

For legal proceedings, documentation may be needed to:

- Demonstrate the need for conservatorship
- Keep an abusive or otherwise inappropriate relative from being appointed as conservator or guardian
- Provide the basis for protective orders
- May be used as evidence in criminal cases involving self-neglecting clients (e.g. client is scammed due to memory issues)
- Validation the actions of workers or their agencies when they are being sued
- When workers’ conduct is questioned by licensing boards or professional associations

Refer the class back to the cases studies in Handout 12 and ask them what they should document in each case.

Possible answers include:
Case 1. John Sumner

- Attempts made to contact Mr. Sumner
- What bills were unpaid and for how long
- Types and levels of smells coming from the apartment
- Number and condition of the cats
- Cleanliness of the home in general
- Types and amounts of food in the house (for John)
- Types and amounts of food in the house (for the cats)
- John’s explanation of why bills are unpaid
- John’s ability (financially) to pay his bills. What is his income and does it meet his needs?
- John hygiene
- Questions the worker asked and John’s response

Case 2. Mrs. Albertson

- Information from the firefighters as to size and source of the fire; and what they observed (specifically) to make them think the client was confused and paranoid.
- Mrs. Albertson’s statements about strangers in her apartment moving her things and turning on the stove.
- Mrs. Albertson’s permission to contact the doctor (in writing if possible)
- Statements from Mrs. Albertson’s doctor re: her diagnosis and medications and prognosis if she continues to refuse to take her medications
- Mrs. Albertson’s statements about her medications.
- Questions the worker asked and Mrs. Albertson’s response

Refer the participants to Handout 13 - Documentation in Self Neglect for more information on what to document.
HANDOUT # 13

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
• Memory

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.
TOPIC: Partners in Self Neglect

Self-neglect cases are among the most challenging cases APS workers face. To optimize the chances of success, workers should get to know the many community partners they call upon.

Provide the participants with an example, from your own work, when a community partner was able to resolve a difficult self neglect case. Note that example below:

CONTINUED
Ask the participants to name their community partners and to provide examples of the roles that these professionals can play. Write their answers on a flip chart. Then, click on the slide to reveal the following list and see if they missed any:

- Mental health professionals
- Geriatric physicians and nurses
- Civil attorneys
- Conservators
- Public Guardians
- Clergy
- Local law enforcement
- Animal Welfare Organizations
- Ethics Committees
- Multidisciplinary teams


Sometimes partners can help in very unusual ways. Here are a couple examples:

- Local government bought a condemned property so that self neglecting owner could afford to move into an assisted living apartment. (It was next to a school and school officials felt that it was a good investment for future school expansion).
- Case consultation at an MDT uncovered the fact that self neglecting seniors in a number of jurisdictions were being targeted by a “gypsy woman” and giving away large sums of money. (Different agencies had various pieces of the puzzle).
## 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, psychiatrists, 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 |
<p>| 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) | • Can provide information and assist with finding homes for animals. |</p>
<table>
<thead>
<tr>
<th>agencies, humane societies and SPCAs, and rescue organizations</th>
<th>• Can make home visits to check on the welfare of the animals in the home.</th>
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<tbody>
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<td>Ethics Committees (most are convened by hospitals and nursing homes)</td>
<td>• Can identify and address ethical issues raised in self-neglect cases</td>
</tr>
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</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 |
Ask the participants if they have any questions about the information that was covered in the training. Review each section of the training and ask the participants what information stood out for them. Remind them of any specific information that they fail to recall. At the end of the review, ask the participants to complete the self-assessment of learning, the trainee satisfaction survey and demographic survey located in their Evaluation Manual.

Thank them for their participation.
REFERENCES


Nerenberg, L. (2000). Elder abuse & substance abuse: Making the connection [Interview with Charmaine Spencer and Jeff Smith]. *nexus: A Publication for NCPEA Affiliates. 6*(1), 1,4-5,7.


