

## WORKING WITH CLIENTS WHO SELF-NEGLECT

# TRAINER MANUAL



## MODULE 10



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

Curriculum Developer  
Version 1  
Lisa Nerenberg



Curriculum revisions (version 2.0) was developed by the San Diego State University School of Social Work, Academy for Professional Excellence with funding from the California Department of Social Services, Adult Programs Division.

Curriculum Revision 2018  
Version 2  
Kevin Bigelow

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## INTRODUCTION

### THE ACADEMY FOR PROFESSIONAL EXCELLENCE

We are pleased to welcome you to the Adult Protective Services (APS) *Working with Clients Who Self-Neglect* Trainer Manual, developed by APSWI, a program of the Academy for Professional Excellence under a grant from the California Department of Social Services, Adult Programs Division.

The Academy for Professional Excellence, a project of San Diego State University School of Social Work, was established in 1996 to provide exceptional workforce development and organizational support to the health and human services community by providing training, technical assistance, organizational development, research, and evaluation. Serving over 20,000 people annually, the Academy continues to grow with new programs and a diversity of training focused on serving the health and human services community in Southern California and beyond.

The Academy is a project of San Diego State University School of Social Work founded in 1963 and continuously accredited by the Council of Social Work Education since 1966. The School of Social Work at San Diego State University offers both a bachelor's and master's degree in Social Work.

Adult Protective Services Workforce Innovations (APSWI) is a program of the Academy for Professional Excellence. APSWI is designed to provide competency-based, multidisciplinary training to Adult Protective Services professionals and their partners. APSWI's overarching goal is the professionalization of Adult Protective Services professionals to ensure that abused and vulnerable older adults and adults with disabilities receive high quality and effective interventions and services. In partnership with state and national organizations, APSWI has developed a nationally recognized Core Competency Training Curriculum for Adult Protective Services professionals. This curriculum is reviewed and approved by experts in the elder and dependent adult abuse fields.

APSWI's partners include:

- National Adult Protective Services Association (NAPSA) Education Committee
- California Department of Social Services (CDSS), Adult Programs Division
- County Welfare Directors Association of California (CWDA), Protective Services Operations Committee (PSOC)

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## ACKNOWLEDGEMENTS

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

### **Agencies**

California Department of Social Services, Adult Programs Division  
County of Los Angeles Workforce Development, Aging and Community Services  
Orange County Social Services Agency  
Riverside County Department of Public Social Services  
San Bernardino County Department of Aging and Adult Services  
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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 determine how much time is needed to present each section. However, times will vary based on the experience and engagement of the audience.

Customizing the Power Point:

This manual is set up so that the trainer script/ background material is on the same page as the accompanying Power Point slide.

### **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 slide number will have line through it to show you have hidden it.

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

*\*For this particular PowerPoint there are hidden slides that are part of a game/activity included in this manual so any re-structuring of slides will cause the game slides not to work. See **Assessing Self-Neglect in the Five Domains** on page 35.*

**Use of language:** Throughout the manual, client is used most to describe the individual at the center of the APS investigation. However, if concept or material was directly quoted from copyrighted material, the term victim is used. Also, alleged perpetrator is used to describe the person alleged to have committed the abuse or neglect. However, if concept or material was directly quoted from copyrighted material, the term abuser is used.

He and she has been replaced with the gender-neutral they throughout this manual, unless quoted from copyrighted material. This should not be thought of as plural persons, but rather a gender-neutral term describing all humans.

## Course Outline

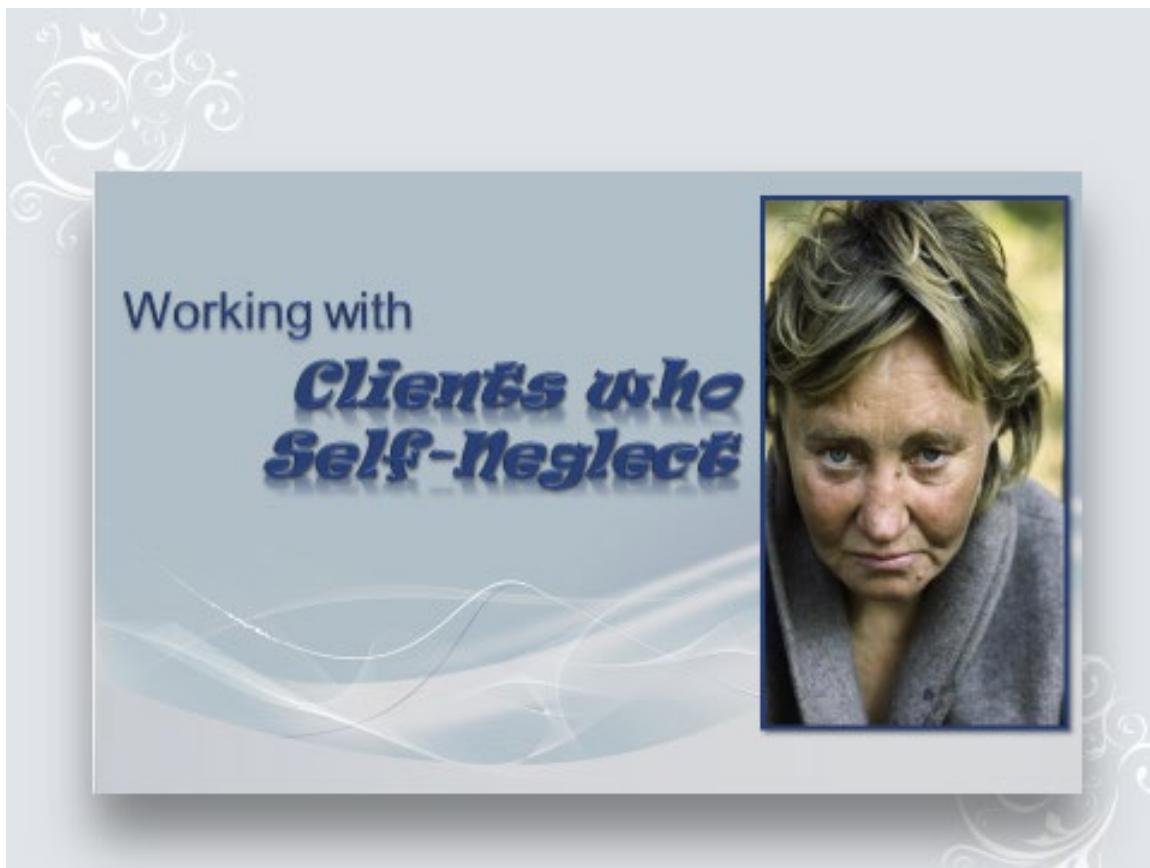
<b><u>CONTENT</u></b>	<b><u>MATERIALS</u></b>	<b><u>TIME</u></b>
<b>WELCOME, INTRODUCTIONS, COURSE OVERVIEW</b>	Flip-Chart	<b>TOTAL: 15 minutes</b>
<b>INTRODUCTION TO SELF-NEGLECT</b>		<b>TOTAL: 25 minutes</b>
<i>Activity #1- The Diverse Spectrum (Table groups)</i>	<i>Maria and John fillable scenarios</i>	<b>15 minutes</b>
<i>Ethical Principles</i>	<i>Handout #1: NAPSA Ethical Principles</i>	
<b>CAUSES OF SELF-NEGLECT</b>		<b>TOTAL: 15 minutes</b>
<i>Absence or Breakdown of Caregiving System</i>	<i>Handout #2: Neglect and Self-Neglect as the Absence or Breakdown of Caregiving System</i>	
<b>ASSESSING SELF-NEGLECT IN THE FIVE DOMAINS</b>		<b>TOTAL: 30 minutes</b>
<i>Activity #2- Five Domains Game (Large group)</i>	<i>Printed copies of PowerPoint Slides</i>	<b>20 minutes</b>
<b>ASESSING SEVERITY AND URGENCY</b>		<b>TOTAL: 25 minutes</b>
<i>Activity #3- Round Robin Assessment (Table groups)</i>	<i>Flipcharts (pre-labeled)</i>	<b>15 minutes</b>
<b>BREAK</b>		<b>15 minutes</b>
<b>SCREENING CAPACITY</b>		<b>TOTAL: 30 minutes</b>
<i>Capacity</i>	<i>Handouts #3 &amp; #4</i>	<b>3 minutes</b>
<i>Activity #4- Mrs. Green: Assessing Capacity (Class divided in half)</i>	<i>Handout #5</i>	<b>25 minutes</b>
<b>SPECIAL ISSUES</b>		<b>TOTAL: 30 minutes</b>

<i>Activity #5- Hoarding Video and Reflection</i>	<i>Bob and Shirley Hoarding Video Clip</i>	<b>20 minutes</b>
<b>ASSESSMENT TOOLS</b>	<i>Handout #6</i>	<b>TOTAL: 10 minutes</b>
<b>LUNCH</b>		<b>60 minutes</b>
<b>INTERVENTIONS</b>		<b>TOTAL: 90 minutes</b>
<i>Results of Dubin Study</i>	<i>Handout #7</i>	<b>30-40 minutes</b>
<i>Shout-Out: Decisional Worksheet (Large group)</i> <b>Or</b> <i>Activity #6: Self-Neglect Home Visit (Individual)</i>	<i>Self-Neglect Home Visit Video Clip</i>	<b>10 minutes</b> <b>Or</b> <b>20 minutes</b>
<i>Activity #7: Understanding Harm Reduction (Large group)</i>	<i>Handout #8</i>	<b>5 minutes</b>
<b>BREAK</b>		<b>15 minutes</b>
<b>DETERMINING APPROPRIATE INTERVENTIONS</b>		<b>TOTAL: 60 minutes</b>
<i>Types of Interventions</i>	<i>Handout #9</i>	
<i>Activity #8: Working the Self-Neglect Case (Small groups)</i>	<i>Handout #10</i>	<b>30 minutes</b>
<b>DOCUMENTATION</b>		<b>TOTAL: 15 minutes</b>
<i>Activity #9: Case Scenarios</i>	<i>Handout #10 and #11</i>	<b>5 minutes</b>
<b>PARTNERS IN SELF-NEGLECT</b>	<i>Handout #12</i>	<b>TOTAL: 10 hours</b>
<b>LESSONS LEARNED AND EVALUATIONS</b>		<b>15 minutes</b>
<b><u>TOTAL (INCLUDING LUNCH AND BREAKS)</u></b>		<b>7 hours</b>

## TRAINER GUIDELINES

<b>Teaching Strategies</b>	<p>The following instructional strategies are used:</p> <ul style="list-style-type: none"> <li>• Lecture segments</li> <li>• Interactive exercises (e.g. table top activities, experiential exercises, role plays)</li> <li>• Question/answer periods</li> <li>• Slides</li> <li>• Participant guide (encourages self-questioning and interaction with the content information)</li> <li>• Evaluation to assess training process</li> <li>• Transfer of Learning activity</li> </ul>
<b>Materials &amp; Equipment</b>	<p>The following materials are provided and/or recommended:</p> <ul style="list-style-type: none"> <li>• Computer with LCD (digital projector)</li> <li>• CD-ROM or other storage device with the slide presentations</li> <li>• Easel/Flip Chart paper/markers</li> <li>• Trainer Manual: This manual includes the course overview, introductory and instructional activities, and reference materials</li> <li>• Participant Manual: This manual includes a table of contents, course introduction, and all training activities/handouts</li> <li>• Printed copy of Five Domains Game (if PowerPoint game board doesn't work)</li> <li>• Video clips downloaded:           <ul style="list-style-type: none"> <li>*Bob and Shirley Hoarding</li> <li>*Self-neglect Initial Home Visit</li> </ul> </li> <li>• Name tags/tents</li> <li>• Water access/snacks/restroom access</li> </ul>

## TRAINING GOALS AND OBJECTIVES



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 five domains.
3. Identify tools for evaluating self-neglect.
4. Describe promising techniques for working with adults who are self-neglecting such as, "Harm Reduction" and "Hoarding Treatment".
5. Identify safety and risk reduction interventions for adults who are self-neglecting.
6. Demonstrate an understanding of the elements to document in self-neglect cases.
7. Identify community partners to work with in self-neglect cases.

## Executive Summary

**Course Title:** *Working with Clients Who Self-Neglect*

### Outline of Training:

In this interactive and thought provoking introductory training, new APS professionals 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 assess 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 adults. 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. This is the Instructor Led Training for Core Curriculum Module 10.

The following instructional strategies are used: lecture segments; interactive activities/exercises (e.g. small group discussion and case studies); question/answer periods; PowerPoint slides; participant guide (encourages self-questioning and interaction with the content); embedded evaluation to assess training content and process; and transfer of learning activity to assess 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 training. 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 professionals as well as Vulnerable Adult Abuse partners (e.g. conservatorship investigators, workers in the aging and disability networks, and law enforcement). This training is also appropriate for senior staff that require knowledge and/or skills review.

### Learning Objectives:

1. Define self-neglect, its prevalence, risk factors, and indicators.
2. Assess self-neglect in the five domains.
3. Identify tools for evaluating self-neglect.
4. Describe promising techniques for working with adults who are self-neglecting such as, "Harm Reduction" and "Hoarding Treatment".
5. Identify safety and risk reduction interventions for adults who are self-neglecting.
6. Demonstrate an understanding of the elements to document in self-neglect cases.
7. Identify community partners to work with in self-neglect cases.

1 of 2

**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 clients in the past. Training participants can share these experiences during training.

**AFTER the training**

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

# PRESENTATION



# WELCOME & INTRODUCTIONS

TIME ALLOTTED: 15 minutes

SLIDE #2



TOPIC: Funding Sources

Version 1 was funded by The Archstone Foundation, the only private foundation that provides funding for elder abuse projects.

Version 2 was made possible by California Department of Social Services.

SLIDE #3

## Housekeeping and Introductions

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



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 1 hour for lunch today.
- Use the restrooms as needed. The restrooms are located...
- Please turn off your cell phones for the duration of the training. If you must make or receive a call, please step outside the training room and return as quickly as possible. Check the course outline to see what you missed.

**Ask** participants to introduce themselves by name and agency (if multiple agencies are participating). **Ask** if anyone has ever worked with clients who self-neglect and what they found to be challenging.

## SLIDE #4

## Learning Objectives

- Define self-neglect, its prevalence, risk factors, and indicators
- Assess self-neglect in the 5 domains
- Identify tools used for evaluating self-neglect
- Describe promising techniques for working with adults who are self-neglecting, such as 'Harm Reduction', and 'Hoarding Treatment'
- Identify safety and risk reduction interventions for adults who are self-neglecting
- Demonstrate an understanding of the elements to document in self-neglect cases
- Identify community partners to work with in self-neglect cases

### TOPIC: Learning Objectives

**Review** the Learning Objectives with the class.

**Ask** if there are any specific skills or information they are hoping will be covered in this module.

# INTRODUCTION TO SELF-NEGLECT

TIME ALLOTTED: 25 minutes

SLIDE #5

## Self Neglect defined:

"An adult's inability, due to physical or mental impairment or diminished capacity, to perform essential self-care tasks including-

- (A) Obtaining essential food, clothing, shelter, and medical care;
- (B) Obtaining goods and services necessary to maintain physical health, mental health, or general safety; or
- (C) Managing one's own financial affairs"

(The Elder Justice Act of 2009)

## TOPIC: Self-Neglect Defined

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

This definition, from the Elder Justice Act of 2009, assumes that clients who are self-neglecting have impairments with essential self-care tasks—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

**Explain** that older adults who are self-neglecting have impairments in Activities of Daily Living or self-care tasks, but that is also true of 38% of older adults in the U.S. So what differentiates older adults and dependent adults who self-neglect from those who do not? (Research is needed to answer this question.)

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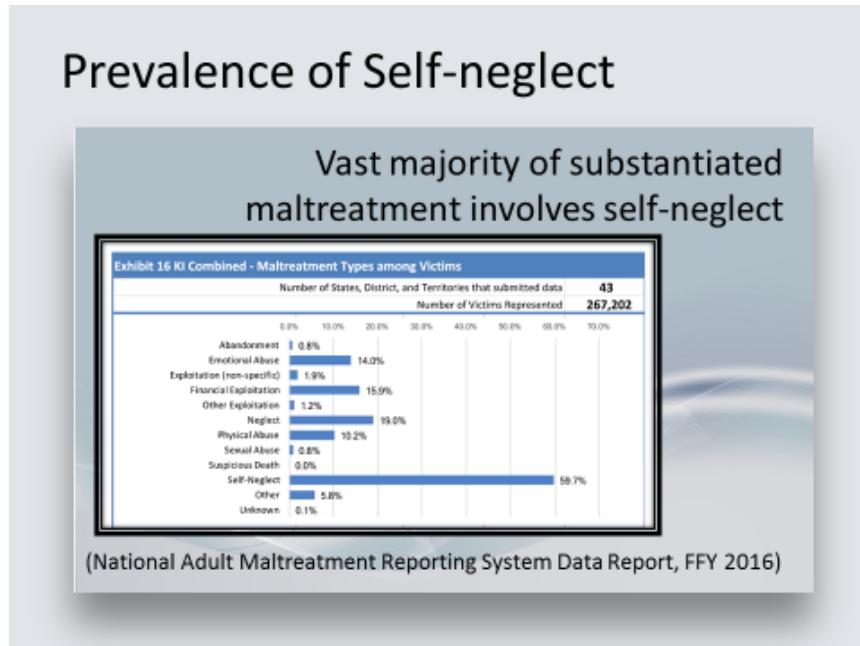
## SLIDE #6



## TOPIC: Conditions That Can Be Mistaken for Self-Neglect

It is important that we do not 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.

## SLIDE #7



## TOPIC: Prevalence of Self-Neglect

**TRAINER NOTE:** In NAMRS, a “client” is considered a “victim” if at least one maltreatment allegation within an investigation has the disposition “substantiated.” This chart displays Maltreatment Types among “victims”.

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.

## SLIDE #8



## TOPIC: Self-Neglect Spectrum

Activity #1: The Diverse Spectrum (15 minutes)

Instructions:

1. **Divide** class into groups of 4-6 (or do as individual table exercise).
2. **Provide** each table with either John or Maria scenario (they will be used more than once.)
3. **Inform** the group they have approximately 10 minutes to complete the activity and decide on a spokesperson who will report out to the larger group.
4. **Ask** each group to fill in the blanks, giving a description based on what they think it will be or based on their past experience in the field. There are hints on some more difficult blanks.
5. Once completed, **ask** one group to read the first couple of sentences for their description.
6. **Capture** the descriptions on flip chart paper, labeled in 2 columns: John (1) and Maria (2).
7. After the first blank has been read, ask for the other groups with the same scenario to share their descriptors. (E.g. Group One says John lives in a mobile home, but Group Two wrote boat and Group Three wrote ranch style home).
8. **Continue** this until each group has shared.

**TRAINER NOTE:** This activity acts as an icebreaker on the topic of self-neglect and sets the stage for this module's content. It allows veteran staff to share some of their experiences with self-neglect reports. It also allows newer staff to discuss their fears, pre-conceived notions, and initial gut feelings on what it might be like. Ultimately, it will demonstrate the spectrum of clients APS serves, environments and causes of self-neglect for all participants.

Continued

**Activity #1**

John is 76 years old and is described by his neighbors as a “hoarder.” John lives in a \_\_\_\_\_ (place of living). You can tell that it is John’s place because when you approach, you \_\_\_\_\_ (see/hear/smell). John lives \_\_\_\_\_ (with/what). When you talk with John, he is friendly but adamant that he cannot \_\_\_\_\_ (something to do with hoarding). When you ask to see what John has been eating, you see \_\_\_\_\_. When discussing his living situation, John seems \_\_\_\_\_ (emotion/behavior). In an effort to evaluate John and his situation, you \_\_\_\_\_ (assessment tool). As you leave, you are thinking that John may suffer from \_\_\_\_\_ (mental illness diagnosis).

Maria is 82 years old and her neighbors describe her as “unable to care for herself.” When you make your home visit, Maria seems \_\_\_\_\_ (behavior/emotion). She invites you to come in and your first impression of her home is \_\_\_\_\_ (adjective). While you try and interview her, Maria continually \_\_\_\_\_ (behavior). When you ask about her diet, she says that \_\_\_\_\_ (behavior/feeling). You notice Maria has a couple of cats that do not look well cared for and when you ask about them, she says \_\_\_\_\_. During the interview you noticed a strong odor and you eventually concluded it was \_\_\_\_\_. The interview concluded when Maria \_\_\_\_\_.

## SLIDE #9

### Profile of Elders who are self-neglecting



- 75.6 years old
- 70% female
- 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

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

A study by Dyer, Goodwin, Pickens-Pace, Burnett, & Kelly (2007) found that older adults who self-neglect have this profile:

- Average age is 75.6 years
- Women account for 70%
- 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 48.4% were taking no medications

## SLIDE #10

## Indicators of self-neglect



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

## 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.

## SLIDE #11

**Case Examples**

Inability, due to physical or mental impairment or diminished capacity, to **perform essential self-care tasks**- food, clothing, shelter, medical care, obtaining goods and services necessary to maintain physical/mental health, or safety; or managing one's own financial affairs

<b>Mr. Nguyen</b> 	<b>Mrs. Anderson</b> 	<b>Mr. and Mrs. Hubbard</b> 
<b>Mrs. Jones</b> 	<b>Robert Stevens</b> 	<b>Mrs. Sanchez</b> 

**Explain:**

Self-neglect cases encompass a wide range of situations.

**Read** the scenarios for the corresponding picture as each picture pops up. **Ask** if it meets the definition of self-neglect and if so, ask participants to identify which parts of the definition it meets.

"An adult's inability, due to physical or mental impairment or diminished capacity, to perform essential self-care tasks including (A) obtaining essential food, clothing, shelter, and medical care; (B) obtaining goods and services necessary to maintain physical health, mental health, or general safety; or (C) managing one's own financial affairs."

- **Mr. Nguyen** is alert and oriented but suffers from short-term memory loss. He has neglected to pay his bills.  
**Answer:** Mr. Nguyen may be self-neglecting in that his short-term memory loss may prevent him from managing his finances.
- **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.  
**Answer:** Mrs. Anderson is making a choice to abuse alcohol however, her diminished capacity to make decisions and denial about the seriousness of her condition may place her at risk of health crises.

Continued

- **Mr. and Mrs. Hubbard** both suffer from dementia. Both are disheveled, thin, and wearing clothes they have not washed in 5 days. They are refusing APS services.  
**Answer:** Mr. and Mrs. Hubbard may be self-neglecting in that their hygiene may result in health or other problems and their “thin” appearance may reflect inadequate nutrition which may cause health problems.
- **Mrs. Jones'** phone, gas, and electricity have been turned off because she has not been paying her bills. She has become increasingly isolated. She smokes and sometimes forgets that she has left a cigarette burning in the ashtray.  
**Answer:** Mrs. Jones is self-neglecting and may be in danger due to her careless behavior with cigarettes. An APS investigation will have to examine the reasons for her doing (or not doing) these things to see if offering resources may help solve these problems or not.
- **Robert Stevens** is 53 years old and suffers from 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.  
**Answer:** Mr. Stevens’s cancer and dementia from his brain injury make him more vulnerable than most other people. His inability to cook for himself or perform other functions increase that risk and his recent hospitalization for dehydration will have to be assessed during the APS investigation to see if he can live on his own safely.
- **Mrs. Sanchez** lives with her son who is living with schizophrenia and has a substance use disorder. He refuses to allow visitors into the home and he has had the phone disconnected. Mrs. Sanchez is afraid of her son but refuses help because she feels that he is her responsibility.  
**Answer:** Mrs. Sanchez may be at risk due to the behavior of her son and his substance use disorder as well as his mental health issues. Mrs. Sanchez may be at risk due to physical or mental abuse; however, her own ability to make decisions, care for herself, and to have the mental capacity to understand the dangers her son represents will have to be assessed. This case may have a self-neglect component in addition to other risk factors.

## SLIDE #12

## 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), financial debt, 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 adult who self-neglects, are affected?

Answers may include:

- When an adult who is self-neglecting 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.

SLIDE #13

## Ethical issues in Self-neglect

- Avoid imposing personal values
- Informed consent
- Least restrictive services

Rights of Adults:

- \*Safety
- \*Civil Rights
- \*Decision Making
- \*Right to Refuse



**HANDOUT #1**  
**Ethical Principles**

**Explain:** Before we dive into assessment, we need to consider the ethical principles that should guide your assessment and intervention with clients who are self-neglecting. APS professionals are guided by their professional orientation and values. Although there are not universally accepted ethical principles, many subscribe to those developed by the National Adult Protective Services Association.

Direct students to **HANDOUT #1 Ethical Principles** in the Participant Manual.



## Ethical Principles and Best Practice Guidelines

*Dedicated to the memory of Rosalie Wolf ©NAPSA 2018*

HANDOUT #1

**Adult Protective Services** programs and staff promote safety, independence and quality-of-life for older persons and persons with disabilities who are being mistreated or in danger of being mistreated, and who are unable to protect themselves.

**Guiding Value:** Every action taken by Adult Protective Services must balance the duty to protect the safety of the vulnerable adult with the adult's right to self-determination.

**Secondary Value:** Older persons and persons with disabilities who are victims of mistreatment should be treated with honesty, caring and respect.

### Principles

- Adults have the right to be safe
- Adults retain all their civil and constitutional rights unless a court adjudicates otherwise
- Adults have the right to make decisions that do not conform with societal norms as long as these decisions do not harm others
- Adults have the right to accept or refuse services

### Practice Guidelines

- Recognize that the interests of the adult are the first concern of any intervention
- Avoid imposing personal values on others
- Seek informed consent from the adult before providing services
- Respect the adult's right to keep personal information confidential
- Recognize individual differences such as cultural, historical and personal values
- Honor the right of adults to receive information about their choices and options in a form or manner that they can understand
- To the best of one's ability, involve the adult as much as possible in developing the service plan
- Focus on case planning that maximizes the vulnerable adult's independence and choice to the extent possible based on the adult's capacity
- Use the least restrictive services first whenever possible-community-based services rather than institutionally-based services
- Use family and informal support systems first as long as this is in the best interest of the adult
- Maintain clear and appropriate professional boundaries
- In the absence of an adult's expressed wishes, support casework actions that are in the adult's best interest
- Use substituted judgment in case planning when historical knowledge of the adult's values is available
- Do no harm. Inadequate or inappropriate intervention may be worse than no intervention

## SLIDE #14

## 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 clients 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 the behaviors of a person who is self-neglecting constitutes a crime?

Answers may include:

- When a person who hoards endangers animals
- When the person who is self-neglecting refuses to leave a condemned home
- When a person who is self-neglecting refused to cut (or allow to be cut) grass that is a fire hazard
- When a person identified as 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: 15 minutes

SLIDE #15

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

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

## HANDOUT #2

### 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 is not always easy to differentiate self-neglect from neglect by others. Researcher Tina Dubin (1986) looked at both types of cases handled by APS professionals in Texas. Her work suggests relationships between the two. Later, we will be looking at the interventions that APS professionals tried in cases and what the results were.

Review the categories in **HANDOUT #2 Neglect and Self-Neglect as the Absence or Breakdown of Caregiving Systems (Part 1)** with the participants.

**Explain** that understanding the underlying cause of the neglect is important in later determining an appropriate intervention.

**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 resources
-

**HANDOUT #2****Neglect and Self-Neglect as the Absence or Breakdown of Caregiving Systems<sup>^</sup>  
(Part 1)****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

**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 – house workers/caregivers 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.
  - Families with substance use disorders

**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)

**1 of 2**

## Neglect and Self-Neglect as the Absence or Breakdown of Caregiving Systems<sup>^</sup> (Part 1)

### 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.

### 5. 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

2 of 2

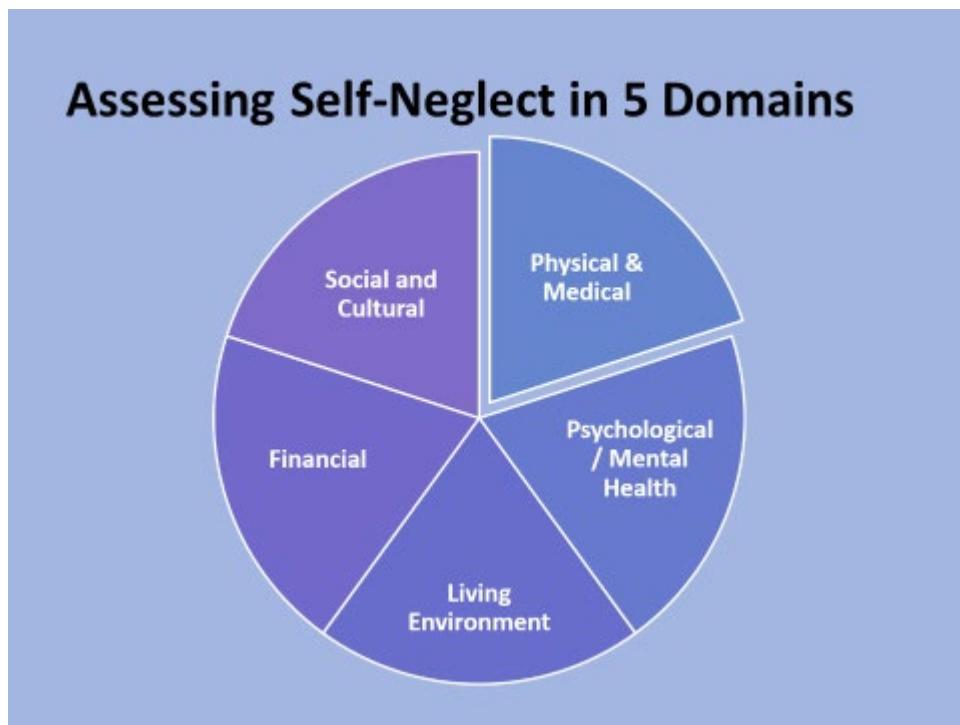
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<sup>^</sup> Dubin, T., Garcia, R., Lelong, J., & Mowesian, R. (1986). Family neglect and self-neglect of the elderly: Normative characteristics and a design for intervention. Austin, TX: Hogg Foundation for Mental Health, Family Eldercare, Inc.

# Assessing Self-Neglect in the Five Domains

TIME ALLOTTED: 30 minutes

SLIDE #16



TOPIC: Assessing Self-Neglect in 5 Domains

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

**Discuss** the five domains and some of the causes or manifestations of each domain of self-neglect:

## Domain 1: Physical/Medical Factors

- Physical factors could include limitations to the client's functioning such as a limp, the inability to walk, or some type of developmental disability impacting the client's function.
- Medical factors may be conditions that impact the client's ability to care for them or place them as significant risk such as, diabetes or kidney failure requiring dialysis.

## Domain 2: Psychological/Mental Health

We know that there is a strong link between self-neglect and psychological or mental health factors. These are some of the common psychological or mental health issues that affect someone's ability to manage.

Continued

- Mental illness
- Substance use disorder
- Trauma
- Dementia and pseudo-dementia
- Depression
- Diminished mental capacity
- Anxiety
- Obsessive Compulsive Disorders (associated with hoarding)

### **Domain 3: Environmental**

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

### **Domain 4: Financial**

- Client's 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
- Clients forgo 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).

## SLIDE #17

Physical & Medical	Psychological & Mental Health	Environmental	Financial	Social
100pts	100 pts	100 pts	100 pts	100 pts Continue Class
200 pts	200 pts	200 pts	200 pts	200 pts
300 pts	300 pts	300 pts	300 pts	300 pts
400 pts	400 pts	400 pts	400 pts	400 pts
500 pts	500 pts	500 pts	500 pts	500 pts

Activity #2: Five Domains Game (20 min)

Let us review the five domains that APS professionals consider as they apply to self-neglect. To do this, let us play the Five Domains game!

**Instructions:**

1. If you do not have a Training Assistant, **ask** for one participant to be the score keeper.
2. **Divide** the class in half down the middle.
3. **Explain** that each team will get a turn to select a category representing one of the domains and a point value (i.e., “I’ll take Physical and Medical for 400 please.”)
4. **Explain** that individuals should raise their hand to volunteer to answer for their team.
5. **Remind** participants that answers are supposed to be given in the form of a question (i.e., “What is...”). You can decide whether or not to enforce this rule in order to give points.
6. If one team cannot answer, the other team gets to try and answer.
7. **Explain** that the game is a fun platform for the lecture on assessment. They are NOT required or expected to already know the material in the game, but should give their best guess.
8. Page 39 provides the questions and answers for you as the Trainer.
9. As the participants uncover answers, **use** the notes below to add to their understanding. (In other words, insert the TRAINING POINTS into the game.)

**TRAINER NOTE:** Ensure you have checked the slides prior to training. The “clue slide” (e.g. “Individuals with mental health conditions may also have this co-occurring issue”) is hyperlinked to each point amount. After the clue is read and you are ready to click on the “question slide” (e.g. “What is Substance Use Disorder?”) just click on the slide. After that question is complete, you can click on the home icon to get back to the board. Each point is hyperlinked to a hidden slide within the PowerPoint. If you restructure any slides, the hyperlink will NOT work. When the game is finished, you can click on the “Continue Class” at the top left of the board.

If the slides do not work, print out the PowerPoint slides and tape them up to a whiteboard or wall. You can then remove each “clue card” as participants pick a category.

**TRAINING POINTS for Physical/Medical Factors Domain****Question for 400 points:**

**DISCUSS:** These are some of the common conditions that affect older adults' 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 do not know if the deficiency predisposes people to self-neglect or if the deficiency is a consequence of self-neglect.)

**TRAINING POINTS for Psychological/Mental Health Domain****Question for 400 points:**

**DISCUSS:** Causes of "Pseudo-dementia"

Causes include:

- Problems with medications, including overdose or interactions between medications
- Infections (including urinary tract infection)
- Substance use disorder
- 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.

**TRAINING POINTS for Social Cultural Domain****Question for 200 points:**

**Explain** that social support is a critical determinant in self-neglect. 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.

**Question 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 unlikely to be successful. Some cultures have a fear of the government and may fear deportation (e.g. undocumented or persons with restricted documentation or institutionalization.) Other people may just lack an understanding of treatment.

## FIVE DOMAINS GAME

Physical and Medical	Psychological and Mental Health	Environmental	Financial	Social
Q. Self-neglect is a medical emergency when fluid intake gets too low causing this medical condition. <i>A. What is dehydration?</i>	Q. This mental health condition, characterized by persistent sad mood, feelings of worthlessness, and the inability to feel pleasure, can be associated with self-neglect. <i>A. What is Depression?</i>	Q. Besides neglecting themselves, individuals who self-neglect may also fail to clean or repair this. <i>A. What is their home?</i>	Q. Self-neglect issues often come to the attention of APS when clients fail to do this financial task. <i>A. What is pay their bills?</i>	Q. Clients who are self-neglecting often lack a person to take this support role in their life. <i>A. What is a caregiver?</i>
Q. Some persons who self-neglect have a condition in which their glucose level gets too high. <i>A. What is Diabetes?</i>	Q. Individuals with mental illness may also have this co-occurring problem. <i>A. What is substance abuse?</i>	Q. Often the easiest way to determine whether alcohol use may be an issue is to check this aspect of the client's environment. <i>A. What is their trash, refrigerator or cabinets?</i>	Daily Double Q. When a client is suddenly sending large amounts of money to a new "girlfriend" he may be a victim of.... <i>A. What is a "sweetheart" scam?</i>	Q. People who self-neglect by letting their yards overgrow with weeds often get reported by neighbors because their yard poses this threat. <i>A. What is a fire hazard.</i>
Q. A common cause of confusion found in clients who are self-neglecting is this infection. <i>A. What is a Urinary Tract Infection?</i>	Q. Clients who have persistent difficulty with discarding possessions, regardless of their actual value demonstrate this type of self-neglecting behavior. <i>A. What is Hoarding?</i> (Note: Hoarding is more often related to executing functioning problems)	Q. When dealing with extreme animal hoarding cases, APS should partner with this agency. <i>A. What is animal control?</i> (or the Humane Society)	Q. When the client is unable to manage his own finances, you may want him to consider this type of service. <i>A. What is daily money management or a Representative Payee Program?</i>	Q. Clients may manage well, even with severe impairments, if their social network is ... <i>A. What is strong and supportive?</i> *Explain how social support interacts with impairment
Q. Deficiency in this vitamin has been linked by research to self-neglect. <i>A. What is Vitamin D?</i> * Discuss cause and effect issues	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 <i>A. What is dementia?</i> * Discuss causes of "Pseudo-dementia"	Q. The biggest dilemma when dealing with clients who are self-neglecting is balancing safety against this. <i>A. What is self determination?</i>	Q. The most extreme intervention for clients who are financially self-neglecting is to refer them for this service. <i>A. What is a guardianship or conservatorship?</i> (In some jurisdictions it would be a guardianship of the estate)	Q. Cognitively intact clients who are self-neglecting and have adult children may refuse help for this reason. <i>A. What is:</i> <i>Do not want to be a burden on their families.</i> *Discuss other fears such as fear of institutionalization, etc may also play a role.
Q. Some individuals become self-neglecting when their heart can't pump blood effectively because of this medical condition. <i>A. What is Congestive Heart Failure?</i>	Q. In legal terms, individuals who are unable to make informed decisions about their medical care are said to have this. <i>A. What is Diminished Capacity?</i>	Q. APS should intervene against a client's wishes (when the client appears to be otherwise competent) when the client's environment is this. <i>A. What is a source of immediate danger to the client's life?</i>	Q. When a client who is self-neglecting gives his money away to a person he trusts, against his own best interest, you may be dealing with this type of financial abuse. <i>A. What is undue influence?</i>	Q. Self-neglect cases make up approximately this percentage of an average APS caseload. <i>A. What is 52.9%?</i>

## SLIDE #18



## 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?

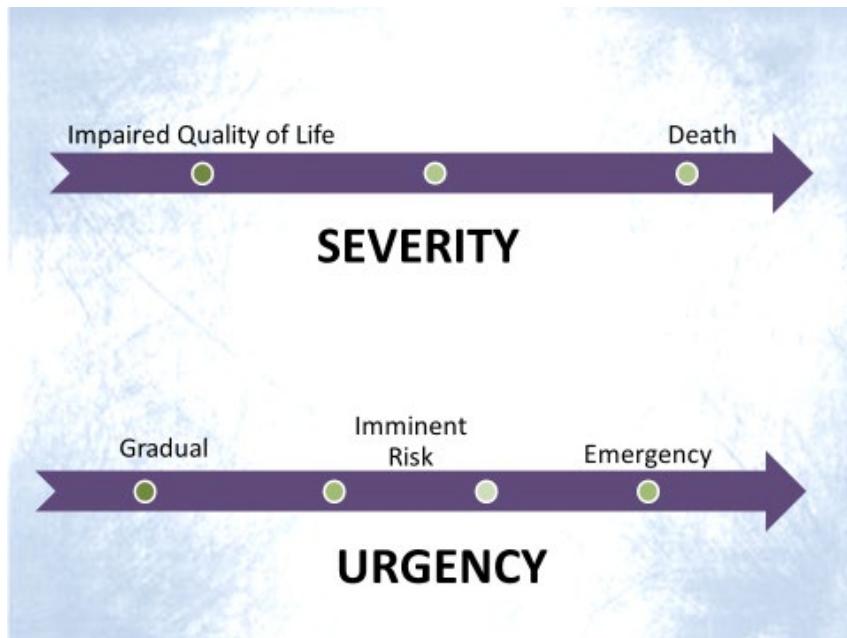
Answers may include:

- 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.
- Older or dependent adult has fired a caregiver or has alienated a caregiver.

# Assessing Severity and Urgency in Self-Neglect

TIME ALLOTTED: 30 minutes

SLIDE #19



TOPIC: Severity and Urgency

**Explain:**

Cases of clients who are self-neglecting vary widely in terms of severity and urgency. Clients' self-neglecting behavior may result in gradual decline to life threatening emergencies.

Activity #3: Round Robin Assessment (15 min)

Instructions:

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
  - 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.

Continued

4. **Give** the groups 2 minutes to list as many examples as they can in which clients (or others) are at risk in their domain. They should list them on the corresponding flip chart paper.
5. After 2 minutes, **ask** the groups to move clockwise to the next domain and give them 1 minute 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. **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.

### **Activity #3**

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. Psychological/Mental Health
  - Inability to remember to take medications may lead to pseudo dementia
  - Depression may result in client becoming isolated
  - Obsessive compulsive disorder may result in hoarding
  - Adult is gravely disabled
3. 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

SLIDE #20

## Assessing Capacity in Self-Neglect Cases



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

**TRAINER NOTE:** Slide is animated to hide the definition until after you have briefly discussed the importance of screening for capacity.

## TOPIC: Screening Capacity in Self-Neglect Cases

**Ask** by a show of hands how many have been asked during their time in the field to determine a client's mental capacity? In what other cases in addition to self-neglect have they been asked to do this?

### **Explain:**

Screening for capacity issues is extremely important in self-neglect cases because many clients have impairments.

**Remind** participants that we are not legally determining capacity, but we can indicate and document if, in our opinion, a client has mental capacity or not; but this is very different than making a medical or legal decision. In documenting our opinion on capacity, **encourage** participants to use the word “appears” and carefully document what they heard or saw that lead to that opinion.

**Ask** a participant to read the definition of capacity on slide.

### **SHOUT OUT #1:**

**Ask** participants what are some of those functions or tasks?

Possible answers: ability to problem solve, ability to manage finances.

## SLIDE #21

**Does the client have the ability to:**

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



**TRAINER NOTE:** Before clicking on this slide, complete the SHOUT OUT #2

**TOPIC: Assessment****SHOUT OUT #2:**

**Ask:** What red flags have they seen in their work that caused them to wonder about a client's capacity?

Possible answers: Client opened door without wearing pants, leaving stoves on, not taking medication.

**TRAINER NOTE:** It will be important to ensure participants have an understanding of which functions and tasks are expected of someone who has decisional capacity. Therefore, in addition to participants' answers during the SHOUT OUT, it is strongly encouraged to highlight a few.

**Examples:** Client remembers to turn off the stove, clean up animal feces, understand importance of medication and takes accordingly, able to manage a checkbook or monitor online banking, bills are paid on time.

**Explain** that APS professionals need to know if the person is capable of managing on his or her own. On the slide are some of the activities and decisions that we need to assess.

**Continued**

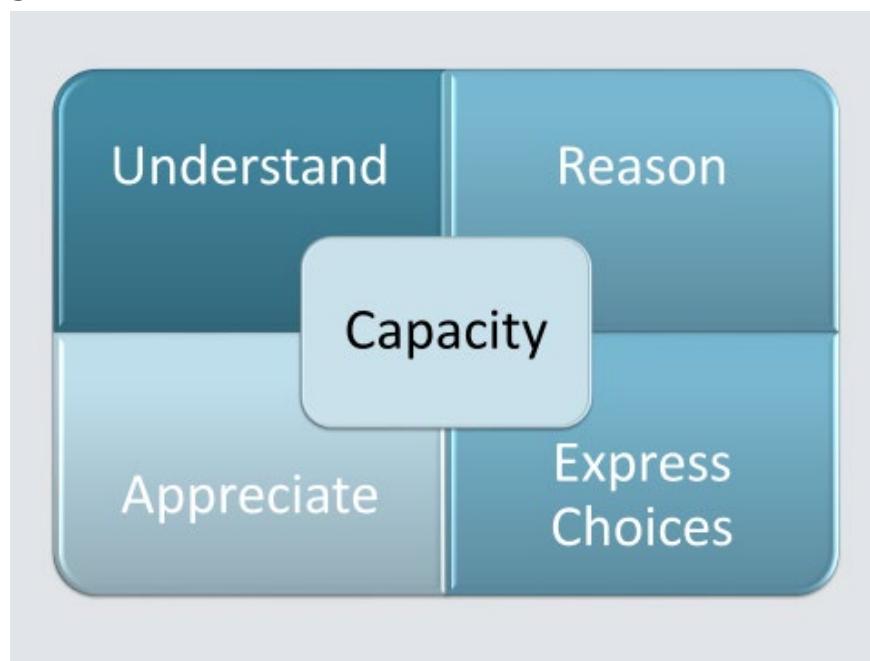
**Remind** participants that the term “capacity” is not a one-size fits all and will impact people differently. A lack of mental capacity may impact clients’ lives differently based on who they are, what the possible cause of the capacity deficit is, and how severe or far along the process or impairment is.

For example, some clients with mild cognitive impairment may function independently; at least for a while, while persons with late-stage Alzheimer’s disease will most likely be totally unable to care for themselves.

**Ask** participants for a few examples in their case work from both sides of the spectrum.

**TRAINER NOTE:** Share your own examples if participants are unable to come up with a range of examples.

## SLIDE #22

**HANDOUT #3****Dimensions of Capacity****HANDOUT #4****Capacity for Medical Treatment****TOPIC:** Screening for Capacity

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

For example, in making medical decisions:

Does the person:

- *Understand* their 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 they refuse medical treatment? Do they understand how the treatment will benefit them?

Can they:

- Use *reasoning* to analyze pertinent information?
- *Express* choices

**Review HANDBOUT #3 Dimensions of Capacity** with participants.

**Review HANDBOUT #4 Capacity for Medical Treatment**, which provides sample questions that can be used to assess clients’ ability to make informed medical or treatment decisions.

**Inform** participants that in a few minutes, they’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.

**HANDOUT #4**

<b>CAPACITY FOR MEDICAL TREATMENT</b>		
<b>Dimensions of Capacity</b>	<b>Definition</b>	<b>Questions used to demonstrate this dimension</b>
Understanding	The ability to comprehend diagnostic and treatment-related information and to demonstrate that comprehension.	<ul style="list-style-type: none"> <li>• Can you tell me the purpose of the treatment?</li> <li>• What will this procedure accomplish?</li> </ul>
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.	<ul style="list-style-type: none"> <li>• How would you prepare for (surgery)?</li> <li>• What do you see your life being like if you have surgery?</li> <li>• What do you see your life being like if you don't have surgery?</li> </ul>
Reasoning	<p>The process of comparing alternatives in light of consequences by integrating, analyzing, and manipulating information. It involves the ability to:</p> <ul style="list-style-type: none"> <li>• Provide rational reasons for a treatment decision,</li> <li>• Organize information rationally</li> <li>• Generate consequences of treatments for one's life</li> <li>• Compare those consequences in light of one's values</li> </ul>	<ul style="list-style-type: none"> <li>• How did you reach the decision?</li> <li>• What factors did you consider?</li> <li>• If you don't have this procedure, what will you do instead (e.g. are there other treatments that can offer relief?)</li> </ul>
Expressing a choice	The ability and willingness to make and communicate decisions about treatment	<ul style="list-style-type: none"> <li>• Can you explain to me what you've decided and why?</li> <li>• How did you reach this decision?</li> </ul>

## SLIDE #23

## 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** 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** “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.

## SLIDE #24

## 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

### HANDOUT #5

#### CASE STUDY: Mrs. Green

## 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.

**Remind** participants that it's important to determine their agency's policy for referring clients to other professionals for capacity assessments.

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 #4: Mrs Green: Assessing Capacity (25 min with report out)

Instructions:

1. **Divide** the group into two groups.
2. **Direct** the participants to go to **HANDOUT #5 CASE STUDY: Mrs. Green**.
3. **Ask** each group to assign a note-taker and reporter.
4. **Have** them read the case.
5. **Have** each group develop a list of questions to determine if Mrs. Green has capacity to make decisions using understanding, appreciation, reasoning, and expressing a choice.
  - Have one half of the group develop questions to assess Mrs. Green's ability to provide self-care.
  - Have the other half of the group develop questions to assess Mrs. Green's ability to manage her finances.

Continued

**CASE STUDY: Mrs. Green****HANDOUT #5**

APS intake receives a call from a neighbor, who is concerned because she has not seen Mrs. Green in more than a week. APS intake 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 professional is assigned the case and 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 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 said she has always paid her bills on time.

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**Continued**

Report Out (5 min): Ask each group's reporter to share a couple of questions.

Possible answers:

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**:

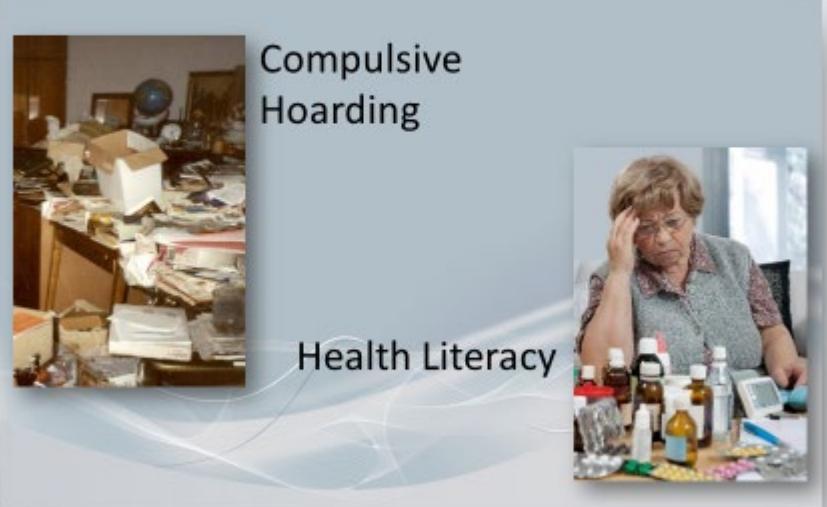
- Show Mrs. Green the letters from the collection agency and ask: Do you know what these are and why you've received it? (Understanding)
- What will happen if you don't respond? (Appreciation)
- How could asking [cite individual] to help you with paying your bills be better than managing your monthly 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).

# Special Issues in Self-Neglect

TIME ALLOTTED: 30 minutes

SLIDE #25

## Special Issues in Self-Neglect



Compulsive  
Hoarding

Health Literacy

TOPIC: 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.

## SLIDE #26

## Hoarding defined:

A persistent difficulty discarding or parting with possessions because of a perceived need to save them.

- A person with hoarding disorder experiences distress at the thought of getting rid of the items.
- Excessive accumulation of items, regardless of actual value, occurs.

– Feb. 3rd 2018- <https://www.mayoclinic.org/diseases-conditions/hoarding-disorder/symptoms-causes/syc-20356056>

## 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 persons' ability to care for themselves. A person who hoards 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.

SLIDE #27

## Impact of Compulsive Hoarding

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



### TOPIC: Impact of Compulsive Hoarding

**Explain:** 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 persons who hoard experience intense shame and depression.

## SLIDE #28

## What Causes Hoarding?



House of hoarder 'out of control';  
officials order clean up (Los Angeles  
Times, June 02, 2016)

**Explain** that 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 persons who hoard show signs of obsessive-compulsive disorder. Some suggest that past trauma may be a contributing factor.

## SLIDE #29

The image shows a video thumbnail with a dark red background. At the top, the title "Who's Normal Anyway?" is written in white. Below it, "Case 7" is in smaller white text. In the center, the subtitle "Bob and Shirley: Hoarding/Cluttering" is displayed. At the bottom, the text "Length: 10:00" is shown. At the very bottom, a small line of text reads "Source: Obsessions: Who's Normal Anyway? (BBC Motion Gallery)". Below the thumbnail, the URL <http://www.youtube.com/watch?v=CMEWT1AWhq0> is provided.

**TRAINER NOTE:** If the embedded link fails to play the video, copy the link below and paste into your browser. It is recommended that you try out the videos on the computer you will be using prior to training.

<http://www.youtube.com/watch?v=CMEWT1AWhq0>

## TOPIC: Who's Normal Anyway?

**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?

**Activity #5: Video and Reflection (20 min)**

Play the video, but **pause** the clip at 1:37 and ask participants for their initial reactions.

This is just a reflection activity, to have an honest moment about how people might feel when they are working with a person who is hoarding.

**Continue** with rest of video.

**Debrief** video (7 min)

Continued

**Ask:** What statements about their past or current situations were made by both Bob and Shirley that resonate with you and align with the definition of self-neglect?

Answers may include:

- Bob alluded that hoarding was a way to not be seen (referring back to past trauma of wanting to hide)
- Bob is creating a nest for himself.
- He feels protected but buried alive at the same time.
- Shirley started hoarding after being burglarized.
- Shirley felt if she had more stuff, she felt more protected.
- “Inch by inch, it’s a cinch. By the yard, it’s hard”

**Ask:** What characteristics do Bob and Shirley have in 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

**Ask:** 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.

**Ask** participants if they know of any local resources that might have similar peer-to-peer mentorship like Shirley did for Bob.

SLIDE #30

## Health Literacy Defined:

- How well a person can get the health information and services that they need, and how well they understand them.
  - Using them to make good decisions.
  - Access to information that they can understand
  - Finding information, communicating with health care providers, managing a disease
  - Knowledge of medical words, and of how their health care system works

(medlineplus.gov/healthliteracy)



**TRAINER NOTE:** Explain Health Literacy using the following quoted information as part of the explanation.

### TOPIC: Health Literacy

Health literacy refers to how well a person can get the health information and services that they need, and how well they understand them. It is also about using them to make good health decisions. It involves differences that people have in areas such as

- Access to information that they can understand
- Skills, such as finding that information, communicating with health care providers, living a healthy lifestyle, and managing a disease
- Knowledge of medical words, and of how their health care system works
- Abilities, such as physical or mental limitations
- Personal factors, such as age, education, language abilities, and culture

"More than 90 million adults in the United States have low health literacy. It affects their ability to make health decisions. This can harm their health. They may have trouble managing chronic diseases, and leading a healthy lifestyle. They may go to the hospital more often, and have poorer health overall." (<https://medlineplus.gov/healthliteracy.html>)

SLIDE #31

## 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

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

**Ask:** Given your advanced education, have you ever had problems navigating the health care system?

For example: 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?

**Wait** for responses.

**Ask** them to imagine how difficult this would be if English was their second language, they got easily confused or were very shy about asking for information?

## SLIDE #32

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 often too embarrassed to admit they have trouble reading and understanding.

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

**TRAINER NOTE:** As the participants are giving their response, pause and ask them to pretend you, as the Trainer, are their client, and have them demonstrate exactly how they would say this to their clients in the field. This gives them the ability to practice and others to hear what works and does not work. It is sometimes easy to say “I would ask...” but hard to actually ask.

**Explain** that one of the best ways to determine whether a client understands your directions or information is to ask the client to “tell 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 I explained it correctly and that you understand what is going to happen next.”

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# Assessment Tools

TIME ALLOTTED: 10 minutes

SLIDE #33

## Assessment Tools

- ❖ Self-Neglect Assessment Tool:
  - Elder Self-Neglect Assessment (ESNA)
- ❖ Functional Assessment Tools:
  - Activities of Daily Living (ADL) scales
  - Instrumental Activities of Daily Living (IADL) scales
  - CLOX 1
  - EXIT 25
- ❖ Health Literacy Evaluation
- ❖ Hoarding Scales
- ❖ Cognitive Assessments:
  - St. Louis University Mental Status (SLUMS)
  - Montreal Cognitive Assessment (MoCA®)
  - CLOX 2
  - Assessment of Capacity for Everyday Decision-Making (ACED)
- ❖ Home or Environmental Safety Assessments
- ❖ Memory Measurements
  - Blessed MSQ
  - Kahn



## HANDOUT #6

### Cognitive Assessment & Self-Neglect Screening Tools

## TOPIC: Self-Neglect-Related Assessment Tools

**Explain:** There are a lot of tools available for measuring people's ability to manage, but there is currently one validated tool specifically assessing for self-neglect. Some of these tools are proprietary. They are available for purchase. Many of these tools are being developed and are being used in research.

**Inform** participants that they will need to follow up with their supervisor and agencies' policy on specific tools and assessments.

**Provide** background information under each type of tool below.

Continued

### Self-Neglect Assessment Tool

Up until very recently (2017), most tools used in self-neglect assessments were not specifically assessing self-neglect, but a person's ability to function and their mental capacity. There is currently one validated tool, the Elder Self-Neglect Assessment (ESNA), that can be used by Adult Protective Services programs; not just clinicians or medical personal. There are two versions; a 77-item assessment and short form which have indicators of self-neglect align into two broad categories: behavioral characteristics and environmental factors, which must be accounted for in a comprehensive evaluation. The scoring includes: Yes, Suspected, No, Don't Know or Not Applicable, with a total of 2 points for each question. ESNA can be found by contacting Dr. Madelyn Iris at [irisassociates2014@gmail.com](mailto:irisassociates2014@gmail.com).

### 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. 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.

### Other Tools

Other tools are also available. Some of these include: tools that manage memory, health literacy evaluations, scales for hoarding behavior, and home or environmental safety assessments.

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**Review HANDBOUT #6 Cognitive Assessment & Self-Neglect Screening Tools** with the participants.

**HANDOUT #6****COGNITIVE ASSESSMENT AND SELF-NEGLECT SCREENING TOOLS**

Cognitive assessment scales and tools can help provide a framework for more consistent and thorough assessments of cognitive functioning in APS clients. There is no one best tool for measuring decision-making capacity, as none of these tools measure capacity directly, but rather aspects of cognitive functioning. It is important to choose the tool that best fits the concerns you have for each client.  
*Consult your supervisor, state and local laws and policies to learn which tools are approved for use by your agency.*

Elder Self Neglect Assessment (ESNA)	Currently, this is the only validated tool specific to self-neglect assessment. A 77-item assessment as well as a short form are available for use by APS professionals. Items are arranged in order of severity and this clustering can help the assessor in determination of the severity of self-neglect. The ESNA focuses on assessing Behavioral Self-Neglect and Environmental Self-Neglect.
SLUMS St. Louis University Mental Status	11-item scale to detect mild cognitive impairment and dementia includes orientation, word memory, arithmetic, naming, clock drawing, story memory. It is free, quick, and easy. It is relatively well-known and integrates the even better known Clock Drawing tool. There are scoring options, or education corrected norms, which differentiate between clients with a high school education and those with less than a high school education. Unfortunately, language translations are in development but are not yet available. Some stimuli are very small, thus reducing the overall reliability in some areas, but that is an issue common to many of the shorter tools. Utilizing SLUMS would in many cases require staff-retraining and outside providers may be less familiar with it. It is not useful for clients who are visually or hearing impaired.
MoCA® Montreal Cognitive Assessment	30-point cognitive screening instrument that assesses visuospatial/executive, naming, memory, attention, language, abstraction, delayed recall, and orientation to time. It is also free, and translations are available in many languages. It is more sensitive than some other tools, and interest in the MoCA is increasing. Challenges include that it is more complicated and takes longer to administer than some of the shorter tools, and some of the directions are not printed on the form. It doesn't include age and education norms, provides relatively small normative data, and some stimuli very small. Outside providers less familiar with the MoCA than they are with other tools. <a href="http://www.mocatest.org/">http://www.mocatest.org/</a>



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**CLOX 1 & 2**

Like two tools in one. Each provides distinctly different information and can be used together or independently. It is free, fast, and easy to use. CLOX 1 measures for executive function, which few do. The second part, the CLOX 2 integrates the old familiar Clock Drawing in an improved and measurable fashion to key in on possible dementia. Interest in tool increasing. Challenges include the fact that it isn't very flexible. You must use the actual form as it is printed for it to be interpretable, and you must follow the instructions and give the instructions exactly as they are written. And, outside providers are less familiar with these tools.

**Exit 25**

A newer tool developed by Dr. David Royal which tests for executive function, or executive control function (EFC). It is free to use. It utilizes a bedside scale which includes 25 items derived from frontal lobe sequelae. With training and practice the test can easily be completed in 15 minutes, and is designed to be administered by a lay interviewer.

When properly administered, the tool is extremely accurate, which allows for a high level of confidence that the scoring reveals the level of care needed. Like CLOX 1 & 2, the form must be used and instructions must be given as written, but the Exit 25 is more complicated and takes longer to administer. Training and practice are key for ensuring proper use and optimal efficiency. Dr. Royal has also developed a "QUICK-EXIT" version of the tool which reduces the number of items to 14 and according to the conclusions from a Rasch Analysis may even further improve the internal consistency and enhanced the validity.

## ADDITIONAL TOOLS AND RESOURCES

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**ACED****Assessment of Capacity for Everyday Decision-Making**

The first tool designed specifically for APS use, to effectively address a common clinical issue: is a patient who refuses an intervention to help manage an instrumental activity of daily living (IADL) disability capable of making this decision? The ACED is useful for assessing the capacity to solve functional problems of older persons with mild to moderate cognitive impairment from disorders such as Alzheimer's disease. Its reliability and validity are supported by data. Practitioners should be aware that the instrument is designed to guide what is ultimately a clinical interview; hence, practice and judgment are essential. In addition, issues of the client's literacy and trust in the interviewer can affect how they perform on the interview.

**Clock Drawing  
MINI-COG**

This tool is a quick method of assessing for cognitive impairment. It is a single task or tool which won't establish capacity but it will help identify clients who need further cognitive assessment.



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## COGNITIVE ASSESSMENT AND SELF-NEGLECT SCREENING TOOLS

<b>Environmental Safety Assessments</b>	Many focus on reducing the risk of falls, fires, and crime. An example is the Cougar Home Safety Assessment for Older Persons, Version 4.0. It contains 78 criteria that can be answered by observation, testing of certain home items, and questioning the resident.
<b>Hoarding Scale</b>	The Clutter Hoarding Scale assesses hoarding in five areas: Structure and Zoning, Animals and Pests, Household Functions, Health and Safety, and Personal Protective Equipment (PPE) needed on entering. It was developed by the National Study Group on Chronic Disorganization (NSGCD).
<b>Trail Making</b>	Connect the dots type puzzle with letter number letter sequence to be completed in 1 minute. A person with executive dysfunction will take much longer with this task, or may be unable to do it at all.
<b>Blessed MSQ</b>	This tool is one which will help you assess orientation, memory and concentration. A score of 10 or more indicates moderate cognitive impairment and capacity should be in question. The worker will need to screen for biases, since a person with limited education or with hearing problems is not a good candidate for this tool. It will not give you a complete capacity assessment unless the client's orientation, memory and concentration are what is placing the client at-risk.
<b>Kahn</b>	This instrument measures short and long term memory only. In addition to the standard tools the, Kahn, Blessed MSQ, Parables, and obtaining background information, which may be used, there are other tools which help determine Executive Functioning or impairments which other tools don't measure.
<b>Verbal Fluency</b>	Unimpaired persons will generate 9 to 10 words in 1 minute from a category provided by the worker. Impaired person will show fatigue and difficulty with switching sets with repeated categories.
<b>Luria Hand Sequence</b>	Unimpaired person will accurately mimic the examiners alternating hand movements.
<b>Background information</b>	Using historical knowledge of the client to frame questions to assess the client's short and long term memory is another method of assessment, and one which is less offensive to the client.

SOURCE: Oklahoma APS Academy Core Training on CAPACITY – 2015, found in Assessing APS Clients' Decision-Making Capacity eLearning

\*revised for Working with Self-Neglecting Clients Module 10



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# Interventions with Clients who Self-Neglect

TIME ALLOTTED: 90 minutes

SLIDE #34

## Results of the Dublin Study

Overwhelmed Caregiving Systems

The Dysfunctional Caregiving System

The Self Interested Caregiver

The Elder Alone

Elders Who Refuse Care

### HANDOUT #7

**Neglect & Self-Neglect  
as the Absence or  
Breakdown of  
Caregiving Systems  
(Part 2)**

## TOPIC: Results of the Dublin Study

Earlier we talked about the study of Tina Dubin and her colleagues and the various categories of clients who were self-neglecting that they identified. Now, we'll take a closer look at how APS professionals intervened and how well they did. As you might imagine, APS professionals had better results working with some clients than others.

Refer participants to **HANDOUT #7 Neglect & Self-Neglect as the Absence or Breakdown of Caregiving Systems**.

**Read** the description of each type of client who self-neglects and after each one, **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."
- **Inform** participants they can write their thoughts in the section labeled Prognosis and Promising approaches as they brainstorm.
- **Follow up** by asking: "What types of promising approaches or interventions would you think are effective?"
  - Possible 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.

After you have covered each type, **explain** that for the rest of the training we will be discussing how to intervene with clients who resist our help.

**HANDOUT #7****Neglect and Self-Neglect as the Absence or Breakdown of Caregiving Systems<sup>A</sup>  
(Part 2)****1. Overwhelmed Caregiving Systems**

- Definition: The older person or adult dependent 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 older adult or adult dependent really should be in nursing home or board and care - they need extensive care - but they are 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 person 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.
  - Some examples would be: offering information about caregiving or referrals to provide this, providing information or a referral to Adult Day Health Care if appropriate, and assistance with finding additional funding for services, visiting nurses, In Home Supportive Services (IHSS), or the Multipurpose Senior Services Program (MSSP).

**2. The Dysfunctional Caregiving System**

- Definition: A caregiving system is in place but the dynamics between various caregivers or between caregivers and older person are characterized by dysfunction.
- Examples:
  - The older person is difficult and alienates others - house keepers and/or caregivers 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.
  - Families with substance use disorders.
- Prognosis: Not good unless "tolerant outsiders" (people who are not involved in the conflict) can be found.

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## Neglect and Self-Neglect as the Absence or Breakdown of Caregiving Systems<sup>^</sup> (Part 2)

- 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.
  - An example of possible interventions would be: notifying them of any interventions (with client permission), assessing for guardianship or conservatorship, assisting client with identifying the issues they have with the assistance they are (supposed to be) receiving, and problem solving to help avoid conflicts, possible mental health evaluation if appropriate
- 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 preoccupied with their own interests.
  - Prognosis: Interventions are relatively simple if caregivers were removed as responsible parties.
  - Promising Approaches: Guardianship. Money management.  
(Accounted for the fewest number of cases.)
- 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, relatives, or spouses who were providing care and alternative arrangements have not 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 do not 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

2 of 3

- Definition: Same as above but senior has refused help.

## Neglect and Self-Neglect as the Absence or Breakdown of Caregiving Systems<sup>^</sup> (Part 2)

- Examples:
  - Senior is depressed. May be close to dying and wants to die.
  - Senior does not 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.

<sup>^</sup> Dubin, T., Garcia, R., Lelong, J., & Mowesian, R. (1986). Family neglect and self-neglect of the elderly: Normative characteristics and a design for intervention. Austin, TX: Hogg Foundation for Mental Health, Family Eldercare, Inc.

## SLIDE #35

## Working with Clients who are Hesitant



### TOPIC: Working With Clients Who Are Hesitant

**Explain:** Clients who self-neglect and 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. It might feel frustrating to the APS professional when a client is reluctant to accept services, however, it’s always important to remember to take a trauma-informed, client centered approach. We will spend the next portion of the training learning methods for working with these clients.

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## SLIDE #36

## Reasons People Refuse Help

- Dementia
- Anxiety
- Grief
- Depression
- Lack of insight
- Behavioral Health
- Shame
- Distrust
- Fatigue
- Fear
- Pain
- Anger



**TRAINER NOTE:** This slide is animated. Before showing answers solicit input during SHOUT OUT activity.

### 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.

#### **SHOUT OUT #3:**

**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.

**Explain** that often clients are self-protective and it's up to APS professionals to try and convince them that what our programs have to offer are better than their current situations. We should look at these resistant behaviors as the fact we were unable to identify a program that was acceptable to them or met their needs.

**Encourage** participants to look back at this portion of the training when they're in the field and feeling frustrated or in disbelief that their clients do not want APS intervention. Remind them that adults have the right to refuse services.

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SLIDE #37

## Motivational Interviewing

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

Rollnick S., & Miller, W.R. (1995). What is motivational Interviewing? *Behavioral and Cognitive Psychotherapy*, 23, 325-334 (<http://www.motivationalinterview.org/clinical/whatismi.html>).

**TRAINER NOTE:** The term counselor is used in this section as information is taken directly from the Motivational Interviewing research. Remind the participants that they can utilize Motivational Interviewing techniques, but they are not counselors themselves in the role of an APS professional.

### TOPIC: Motivational Interviewing

**Explain:** Motivational Interviewing is a short-term counseling technique which has proven to be very effective with other populations who may resist assistance, such as people with substance use disorders and some populations in the behavioral health system. 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 their own ambivalence.
- Direct persuasion does not work!
- Your style must be quiet and eliciting while helping the client examine and resolve the ambivalence.
- Readiness to change is the product of the interpersonal interaction.
- You are a partner not "the expert."

## SLIDE #38

## Core Concepts of MI

- Express empathy
  - Seeing through their eyes, feeling as they feel
- Support self efficacy
  - Help them stay motivated. Solutions can change
- Roll with resistance
  - Avoid arguing, encourage creating own solutions
- Develop discrepancy
  - Help develop their discrepancy between current behavior and future goals



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**TRAINER NOTE:** This slide is animated in order to spend time on each principle.

For each principle, demonstrate with the participants how to use that skill in APS work. You can do this by either providing the example yourself, or if time allows, you can give the statement as a client and have the participants answer you back as the APS professional, practicing the skill.

## TOPIC: Core Concepts of Motivational Interviewing (MI)

*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, and 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 experience with you in depth allows you to assess when and where they need support, and what potential pitfalls may need focus 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.

#### **Example:**

Client: "I am just so angry I can't get around like I used to. I hate having to use that stupid walker!"

APS Professional expresses empathy: "Yes, I would be frustrated as well."

Continued

## 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 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.

### **Example:**

Client: "I'm never going to be able to throw out any of this stuff. It's just going to be too hard".

APS Professional expresses self-efficacy: "I noticed you made a pathway over there. How did you do that?"

### **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 the clients.

### **Example:**

Client: "I've had it with doctor's appointments. I'm not going there anymore. It's a waste of my time. I want to get better, but I don't ever see things changing."

Continued

APS Professional rolls with resistance: “That makes sense. I hear you’re frustrated and you feel it’s a waste of time. How do you see yourself getting better?”

### Develop Discrepancy

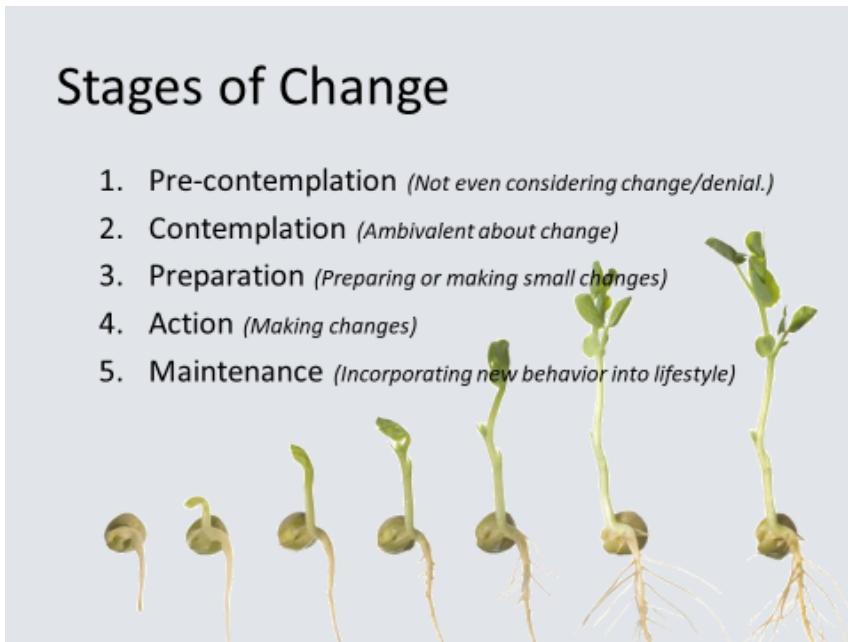
“Motivation for change occurs when people perceive a discrepancy between where they are and where they want to be” (Miller, Zweben, DiClemente, & Rychtarik, 1992, p. 8). MI counselors work to develop this situation through helping clients examine the discrepancies between their current behavior and future 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.

Example:

Client: “I just can afford all these animals anymore. All of my bills are late because I have to pay for their food and I don’t have any left for my own groceries.”

APS Professional develops discrepancy: “It sounds like you’re in a difficult spot. You have been giving so much to these animals and they’re able to eat, but you might starve? Do I have that correctly? You mentioned that you haven’t been able to eat much and your bills are all late. It doesn’t look like you can scale back any further and getting sick or going broke won’t help the cats, so is there an option where some of the cats can still be taken care of, but not at your expense?”

SLIDE #39



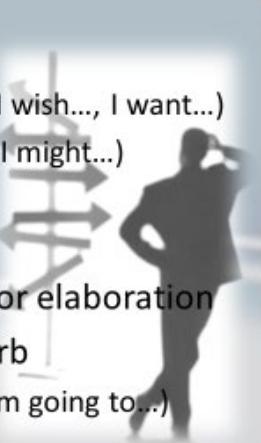
### TOPIC: Stages of Change

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 APS professional's job to determine the client's readiness to change and to accept help.

## SLIDE 40

## 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...)



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## TOPIC: Change Talk

**Explain:** In order to determine the client's willingness to change, the professional 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/she is ready to change.

If the client is not ready to change, how can you motivate them to change? (Remember that direct persuasion does not work!)

**SHOUT OUT #4: (10 minutes)**

**TRAINER NOTE:** This will be an opportunity to demonstrate the skills just covered. For each statement on the slide, ask the participants to give you an example of what they've seen/heard a client say/do in the field and either reply to them yourself demonstrating MI or ask for the other participants to reply as they would, using MI techniques. Examples are below.

Continued

**Example:**

**Trainer:** Someone tell me of a time when your client expressed a desired statement.

Participant raises hand and shares, "My client told me she wishes she could ask her son to move out because he's draining her resources. She said she doesn't want to enable him but she doesn't think she's ready to make him move out."

**Trainer:** "How would you reflect that back to them and ask for elaboration?"

Answers may include: "I imagine it would be very nerve racking to ask him to leave. It sounds like you might be ready to make a change and ask him to leave because you feel like your money is being depleted. Did I get that correctly? Where have you seen the biggest hit in your resources?"

**Trainer:** Can you give an example of a client (possibly same one) who gave a commitment verb?

Example might be: "I'm planning on telling him I'm willing to give him 45 days to find a place, but I don't know if that's really enough time or if he'll leave".

**Trainer:** How can we motivate them to make the change without being directly persuasive?

Answers may include: "45 days seems pretty generous. How do you think you'll feel if he stays 90 days and you no longer can pay for gas money to make your weekly bingo nights?"

## SLIDE 41

## Decisional Balance Worksheet

Good things about behavior:	Good things about changing behavior:
Not so good things about behavior:	Not so good things about changing behavior:

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**TRAINER NOTE:** There are two activities to allow participants to demonstrate their understanding of the Decisional Balance Worksheet. Either or both can be done depending on time and experience with MI.



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## 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 APS professional needs to ask the client for the good and not so good things about their current behavior and about changing their behavior.

**OPTION #1: SHOUT OUT #5: (15 mins.)**

On a flip chart or white board, draw the chart displayed on the PowerPoint slide. **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. **Capture** their results on the flip chart.

The result might look like this:

<b>Good things about behavior:</b> Don't need to change/do anything different I get to keep my things Don't need to buy things that I already own I have keepsakes/memories/documents	<b>Good things about changing behavior:</b> My home would be more comfortable I could have company My neighbors would stop bugging me My home would be safer
<b>Not so good things about behavior:</b> The neighbors complain I can't use some of my rooms/appliances I can't always find things I'm embarrassed to have company	<b>Not so good things about changing behavior:</b> Important papers might get thrown out My anxiety level would be high It's a lot of work I might fail and let everyone down

Continued

**TRAINER NOTE:** Download and save the clip prior to class, to avoid any challenges with it playing in the PowerPoint. The clip embedded, is from a longer version. For purposes of this activity, clip is focused just on his diet and decision to not take medication. It's suggested that you review video in its entirety, in case there are questions, but embedded is clip from 3:23-10:00. If clip does not work, you can access it at  
<https://www.youtube.com/watch?v=RBCo4UB0liU&feature=youtu.be>.

**OPTION #2:**

Activity #6-VIDEO: Self-Neglect Initial Home Visit (20 mins.)

On a flip chart or white board, **draw** the chart displayed on the PowerPoint slide. **Play** the Successful Initial Home Visit, Self-Neglect video clip. **Ask** participants to work individually to fill in the Decisional Balance Worksheet chart, focusing on his decision not take his Rx and his decision to not follow the healthy diet recommendation, for 7 min. Report out and **capture** their results on the flip chart.

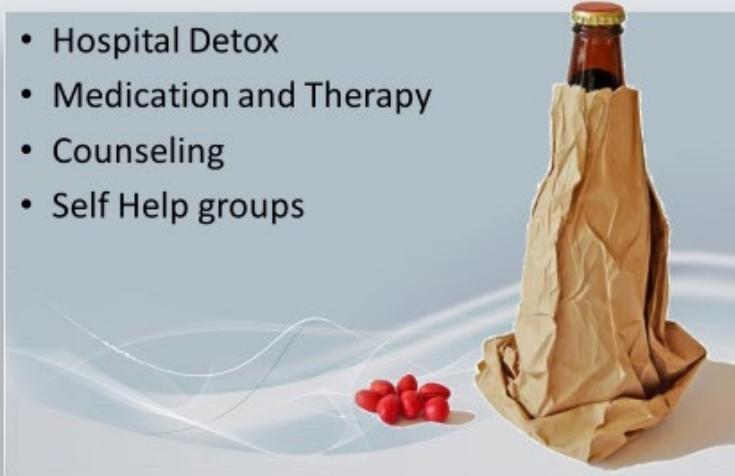
The result might look like this:

<b>Good things about behavior:</b> I eat what I want Don't have to remember to take medication My heart may fail me and I can be with my spouse in eternal life	<b>Good things about changing behavior:</b> My blood pressure might stay down I might feel better
<b>Not so good things about behavior:</b> I am eating fatty/processed foods I'm not following Doctor's orders	<b>Not so good things about changing behavior:</b> Medication and healthy foods can be expensive I might die or be hospitalized (which can add even more expenses)

## SLIDE #42

## Substance Use Disorder Treatment

- Hospital Detox
- Medication and Therapy
- Counseling
- Self Help groups

A photograph of a dark glass bottle with a gold foil seal on top, partially wrapped in crumpled brown paper. To the left of the bottle, a small pile of several red, oval-shaped pills lies on a light blue surface with faint, wavy white lines.**TOPIC: Substance Use Disorder Treatment**

For some, their self-neglecting behavior is associated with having a substance use disorder. These treatments may be effective with those older adults and dependent adults.

- Detoxification in controlled settings, provided in hospitals, therapeutic communities or outpatient programs.
- 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)

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Continued

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**Ask:** What are some challenges you see with our clients who have a substance use disorder accepting/utilizing these treatments? Are there reasons that these services and interventions may not be as effective for them?

Answers may include:

- Clients may lack transportation to meetings.
- They may not be comfortable in group settings, especially with younger members.
- They may have communication barriers.

Before moving to next slide, **ask** participants when do they think people with substance use disorder will make a change and accept treatment or shift to sobriety?

Answers may include:

- When they've hit rock bottom.
- When they're almost dead.
- When they are court ordered to.
- When they have nothing left.

## SLIDE #43

*"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 use disorder 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 use disorder prevention programs for older adults who are frail.

Spencer and others suggest that “harm reduction” may be a more appropriate approach for older adults.

SLIDE #44

## Harm Reduction Coalition Principals

-a set of practical strategies and ideas aimed at reducing negative consequences with drug use.



**HANDOUT #8  
The Harm  
Reduction Coalition  
Principles**

TOPIC: Harm Reduction Coalition Principles

Activity #7 Understanding Harm Reduction (5 min)

Refer participants to **HANDOUT #8 The Harm Reduction Coalition Principles**. Ask someone from each table to read aloud a principle and discuss as needed.

## The Harm Reduction Coalition Principles

The Harm Reduction Coalition considers the following principles central to harm reduction practice.

- Accepts, for better and/or worse, that licit and illicit drug use is part of our world and chooses to work to minimize its harmful effects rather than simply ignore or condemn them.
- Understands drug use as a complex, multi-faceted phenomenon that encompasses a continuum of behaviors from severe abuse to total abstinence and acknowledges that some ways of using drugs are clearly safer than others.
- Establishes quality of individual and community life and well-being – not necessarily cessation of all drug use – as the criteria for successful interventions and policies.
- Calls for the non-judgmental, non-coercive provision of services and resources to people who use drugs and the communities in which they live in order to assist them in reducing attendant harm.
- Ensures that drug users and those with a history of drug use routinely have a real voice in the creation of programs and policies designed to serve them.
- Affirms drug users themselves as the primary agents of reducing the harms of their drug use and seeks to empower users to share information and support each other in strategies which meet their actual conditions of use.
- Recognizes that the realities of poverty, class, racism, social isolation, past trauma, sex-based discrimination and other social inequalities affect both people's vulnerability to and capacity for effectively dealing with drug-related harm.
- Does not attempt to minimize or ignore the real and tragic harm and danger associated with licit and illicit drug use.

## SLIDE #45

## Treatment for Hoarding

- Simply cleaning up doesn't work
- Support/treatment groups



## TOPIC: Treatment for Hoarding

**Ask** "What interventions might work with people who hoard?"

Answers may include: Pharmacotherapy, CBT, and Intensive Treatment

*Pharmacotherapy* – As Black et al., 1998; Mataix-Cols et al., 1999; & Winsberg et al., 1999 concluded separately “Hoarding and saving compulsions have been strongly associated with poor response to SRIs” [Serotonin Reuptake Inhibitors] (Maidment & Saxena, 2004, p. 1146).

*Cognitive-Behavioral Therapy (CBT)* – 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 excavation of saved material, decision-making training, and cognitive restructuring. Treatment may also include Exposure Response Prevention (ERP) – which refers to exposing yourself to the thoughts, images, objects and situations that make you anxious and/or start your obsessions. While the Response Prevention part of ERP refers to making a choice not to do a compulsive behavior once the anxiety or obsessions have been “triggered.” All of this is done under the guidance of a therapist.

Continued

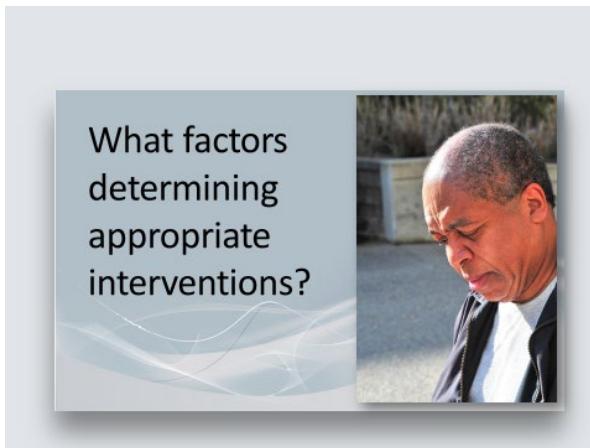
*Intensive Multimodal Treatment* – Intensive treatment (at the UCLA OCD Partial Hospitalization Program) begins with a thorough assessment of the patient's amount of clutter; beliefs about possessions; information-processing; decision-making and organizational skills; avoidance behaviors; daily functioning; 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*.

# DETERMINING APPROPRIATE INTERVENTIONS

TIME ALLOTTED: 10 minutes

SLIDE #46



TOPIC: Factors Determining Appropriate Interventions

**Explain** that there are multiple interventions that can be employed in self-neglect cases. Determining which ones are appropriate depends on multiple factors.

**Ask:** "What factors do you think are important to know in every self-neglect case?"

**Write** their answers on a flip chart.

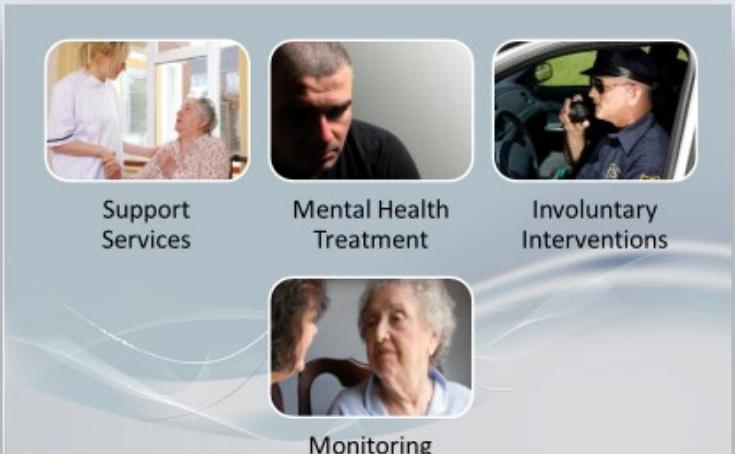
Possible answers include:

- What the client wants
- Is the client capable of consenting or refusing services
- Client's 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 right to self-determination.

SLIDE #47

## Types of Intervention



Support Services      Mental Health Treatment      Involuntary Interventions  
Monitoring

**HANDOUT #9**  
**Services to Clients or**  
**Caregivers to Prevent**  
**Self-Neglect**

### TOPIC: Types of Interventions

A wide range of services may be helpful in helping adults who self-neglect. **Refer** the participants to **HANDOUT #9 Services to Clients or Caregivers to Prevent Self-Neglect** in the Participant's Manual.

**Explain** we will review the handout as we work through the following slides.

**TRAINER NOTE:** The handout does not mirror the slides in exact order. It's suggested to give participants a few moments to review the handout individually and then continue the discussion on the corresponding PowerPoint slides.

**HANDOUT #9****SUPPORT AND SERVICES TO CLIENTS OR CAREGIVERS TO PREVENT SELF-NEGLECT****Social Support:**

Research has shown that social support can be a key intervention and prevention component in elder abuse. Those involved in various community agencies, or have ties to organizations like church or volunteering, are less likely to become isolated. The National Elder Mistreatment Study indicates that the rates of emotional, physical and sexual abuse were lower in older adults who had high social support versus those with low social support.

**Social Services and Programs:**

- **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 the Multipurpose Senior Services program (MSSP) and Linkages or in private practice. Case managers conduct comprehensive assessments of clients' abilities and what they need help with. Then they arrange for services and monitor them, responding to problems. Specifically:
  - 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

**1 of 3**

## SUPPORT AND SERVICES TO CLIENTS OR CAREGIVERS TO PREVENT SELF-NEGLECT

- **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 clients' homes, attorney's fees, court filing fees, repairs, relocation costs, security deposits, respite care, and home modification. In cases of serious neglect, a one-time "deep cleaning service" may be needed to make the client's home habitable, thus preventing placement in a more restrictive environment.
- **Home delivered meal programs.** Programs deliver nutritious meals to older adults or adult dependents in their homes. Also called Meals on Wheels.
- **Friendly Visitor.** A number of senior organizations offer a friendly visitor or similar option where volunteers check in with designated people. This type of intervention can help promote social interaction and help build relationships. It provides another pair of eyes to see how the client is doing, and to contact APS if the person seems to be at risk again.
- **Mental health** assessments are often needed to determine if an older or dependent adult 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 exams that can be performed quickly by persons with minimal training to geriatric assessments, which involve multiple professionals performing a comprehensive battery of tests.

2 of 3

## SUPPORT AND SERVICES TO CLIENTS OR CAREGIVERS TO PREVENT SELF-NEGLECT

- **Regional Centers** are nonprofit, private corporations that contract with the Department of Developmental Services to provide or coordinate services and support 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.** Clients 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 have been terminated or arrested; or when their homes are unsafe or unhealthy. Shelter options may include beds or rooms in senior apartment houses, board and care homes, or free-standing elder shelters.
- **Telephone reassurance programs** can make routine “check in” calls to isolated older or dependent adults or provide telephone counseling to seniors who are in emotional distress.

## SLIDE #48



## TOPIC: SOCIAL SUPPORT

**Explain:** Research by Acierno and Hernandez-Tejada (2018) explained that social support can be a key intervention and prevention component in elder abuse. They looked at how social support improves health and mental health, irrespective of environmental stressors in the Main Effect/Direct/Positive Affect Model.

Acierno and Hernandez-Tejada (2018) also looked at the Buttering (Interaction) Model, where social support mitigates the negative effects of environmental stressors: They suggest that “redesigned meeting places (benches, tables, public café permits) or easy public transportation are very likely the most effective, useful, and efficient mental health and socialization elder abuse interventions for older adults. The “evening walk” in the community has to return” (Acierno & Hernandez-Tejada, 2018).

## SLIDE #49

## Supportive Services



Support Services

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

### TOPIC: Supportive Services

Support services help people who are not 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.

## SLIDE #50

## Mental Health Treatment



Mental Health Treatment

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

**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.

## SLIDE #51

## Mental Health Treatment

- Involuntary assessments or hospitalizations
- Protective Custody
- Appointment of Representative
- 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



Involuntary Interventions

**TOPIC: Mental Health Treatment**

Involuntary interventions are only used when the client does not understand the risks they face AND the risk is high.

Appointment of representatives 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 it is 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 Representatives
- 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)

## SLIDE #52

## Monitoring

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



Monitoring

## TOPIC: Monitoring

When clients refuse help and risk remains, APS professionals may attempt to arrange for services to ensure that clients have help and access when they need it.

## SLIDE #53

## Working the Self-Neglect Case



HANDOUT #10a  
& 10b  
Case Studies

### TOPIC: Working with Clients Who Are Self-Neglecting

#### Activity #8: Working the Self-Neglect Case (30 min)

- **Divide** the class into 4 groups of six. **Give** each group one of the following two cases.
- **Allow** the groups 15 minutes to read through the case and respond to the questions.
- **Explain** that there are no correct answers. The purpose of the exercise is to stimulate discussion and try new skills.
- **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.

## SELF-NEGLECT CASE STUDIES (Trainer Copy)

**HANDOUT #10a****CASE #1 John Sumner**

Robert, an APS professional, 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 that John is willing to talk with him.

Questions: What should Robert do? (e.g. what should he do next, what additional information should he gather, what should he consider?)

Some examples:

- 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, or pay his rent?
- If he does not seem to understand his situation, ask for his permission to call family members, his physician, or others.

## SELF-NEGLECT CASE STUDIES (Trainer Copy)

### 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 and 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 had 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.

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

Some examples:

- 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 #10b****SELF-NEGLECT CASE STUDIES- (Participant Copy)****CASE #1 John Sumner**

Robert, an APS professional, 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 that John is willing to talk with him.

Questions: 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. 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 and 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 had 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.

Questions: 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

SLIDE #54

## Importance of Good Documentation

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



**Handout #11**  
**Documentation in**  
**Self-Neglect**

### 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 clients who self-neglect (e.g. client is scammed due to difficulties with memory)
- Validate the actions of staff or their agencies when they are being sued
- When APS professionals' conduct is question by licensing boards or professional associations

Activity #9- Documenting (5 min)

Refer the class back to their case studies in **HANDOUT #10** and ask them what they should document in each case.

Some examples:

**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's hygiene
- Questions the APS professional asked and John's response

**Case #2. Mrs. Albertson**

- Information from the firefighters as to the 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 APS Professional asked and Mrs. Albertson's response.

Refer the participants to **HANDOUT #11 Documentation in Self-Neglect** for more information on what to document.

Continued

**HANDOUT #11****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
- Detreriorated 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, hypervigilance 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

**Indications of Capacity and Consent**

- Changes over time; has there been a gradual or rapid decline?
- Statements that indicate that client does not realize how dangerous or how serious the situation
- Client's judgment is impaired
- What services were offered and refused?
- Number of times offered and refused
- Client's stated reasons for refusing services

**1 of 2**

- How well is the client “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 client's (or others) statements about:

- Treatment and service preferences
- Wishes and preferences as told to others or as indicated in advance directives
- Values
- Life-style

### **APS Professional Actions**

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

# PARTNERS IN SELF-NEGLECT

TIME ALLOTTED: 10 minutes

SLIDE #55

## Partners in Self-Neglect: With whom should you partner?



HANDOUT #12

Community  
Partners in Self-  
Neglect Cases

## TOPIC: Partners in Self-Neglect

Self-neglect cases are among the most challenging cases APS professionals face. To optimize the chances of success, professionals 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. Write in 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.

Answers may include:

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

**TRAINER NOTE:** Cover any community partners they may have missed.

Refer to **HANDOUT #12 Community Partners In Self-Neglect Cases** in the Participant Manual.

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

- Local government bought a condemned property so that an owner who was self-neglecting 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 older adults who self-neglect 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.)

**HANDOUT #12**

<b>Community Partners in Self-Neglect Cases</b>	
<b>Professional, entity or group</b>	<b>Role in self-neglect cases</b>
Mental Health professionals, including county geriatric mental health program personnel or professionals in private practice (geriatric psychologists, psychiatrists, etc.)	<ul style="list-style-type: none"> <li>• <i>Can assess clients' mental status</i></li> <li>• <i>Can arrange for psychiatric hospitalization under W&amp;I Code §5150.</i></li> <li>• <i>Can diagnose and treat depression and other mental conditions</i></li> </ul>
Geriatric physicians and nurses	<ul style="list-style-type: none"> <li>• <i>Can diagnose, assess and treat medical conditions</i></li> <li>• <i>Can complete medical declarations (doctors) for conservatorship</i></li> <li>• <i>Can review medical records and distinguish injuries from effects of aging and disease</i></li> </ul>
Conservators, including private professionals	<ul style="list-style-type: none"> <li>• <i>Can file for and provide conservatorship services</i></li> </ul>
Public Guardians	<ul style="list-style-type: none"> <li>• <i>Can file for and provide conservatorship services</i></li> </ul>
Clergy	<ul style="list-style-type: none"> <li>• <i>Can provide emotional and spiritual support to clients</i></li> <li>• <i>Can provide or arrange for informal support services</i></li> </ul>
Local law enforcement, including police and sheriffs	<ul style="list-style-type: none"> <li>• <i>Can assist with well-being checks, psychiatric hospitalizations, protective custody, freezing assets</i></li> </ul>
Animal Welfare Organizations (municipal animal care and control) agencies, humane societies, SPCAs and rescue organizations	<ul style="list-style-type: none"> <li>• <i>Can provide information and assist with finding homes for animals</i></li> <li>• <i>Can make home visits to check on the welfare of the animals in the home</i></li> </ul>

Ethics Committees (most are convened by hospitals and nursing homes)	<ul style="list-style-type: none"><li>• <i>Can identify and address ethical issues raised in self-neglect cases</i></li></ul>
Multidisciplinary teams, including elder abuse multidisciplinary teams and death review teams	<ul style="list-style-type: none"><li>• <i>Can provide suggestions for interventions</i></li><li>• <i>Provides a "checks and balances" to ensure that all multiple options and points of view are considered</i></li><li>• <i>Can ensure that workers' actions reflect community standards of practice</i></li></ul>

## SLIDE #56

**Review:  
Learning Objectives**

- Define self-neglect, its prevalence, risk factors, and indicators
- Assess self-neglect in the 5 domains
- Identify tools used for evaluating self-neglect
- Describe promising techniques for working with adults who are self-neglecting, such as 'Harm Reduction', and 'Hoarding Treatment'
- Identify safety and risk reduction interventions for adults who are self-neglecting
- Demonstrate an understanding of the elements to document in self-neglect cases
- Identify community partners to work with in self-neglect cases

**TOPIC: Review**

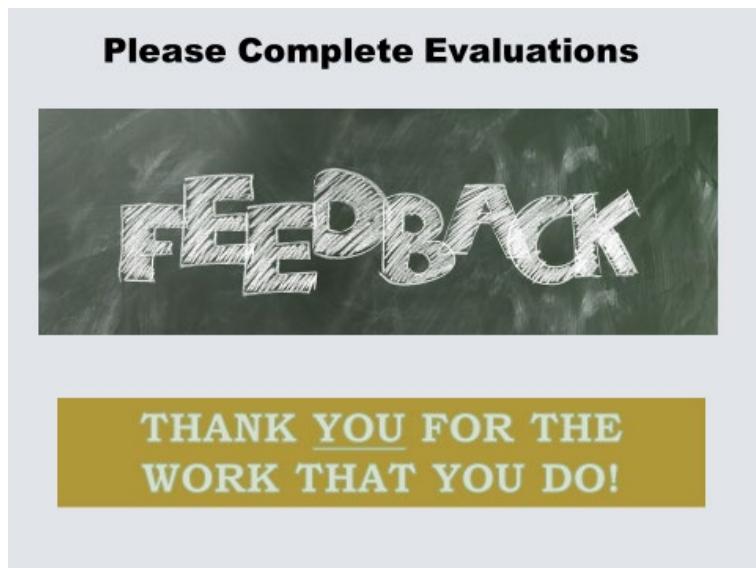
**Ask** the participants if they have any questions about the information that was covered in the training. **Review** each section of the training.

**Ask** the participants to write down in their Participant Manual at least two concepts or skills that really stood out for them and/or will be most useful once they return to the field.

**Have** at least one person per table (or all participants if time allows) state out loud what they wrote down.

**Remind** them of any specific information that they failed to recall.

## SLIDE #57

**TOPIC:** Evaluations

**Ask** the participants to complete the evaluations, as their feedback is extremely important to improve future trainings.

**Thank them** for their participation in today's training and for the work they do each and every day.

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