



The Academy for Professional Excellence is a project of the San Diego State University School of Social Work



SOCIAL SERVICES

This training, Version 3, was revised by the Academy for Professional Excellence, with funding from the California Department of Social Services, Adult Programs Division.

Curriculum Developer, 2023

Dina Bagues, MSW

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Curriculum Developer, Kevin Bigelow, 2018



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Curriculum Developer, Lisa Nerenberg, 2011

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Introduction

We are pleased to welcome you to **Working with Clients Experiencing Self-Neglect Trainer Manual**, developed by Adult Protective Services Workforce Innovations (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), which offers both a bachelor's and master's degree in Social Work. The School of Social Work at San Diego State University was founded in 1963 and has been continuously accredited by the Council of Social Work Education since 1966.

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, effective interventions and services.

In partnership with state and national organizations, APSWI is developing curriculum available to APS programs throughout the nation. This curriculum is developed, 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)
- California's Curriculum Advisory Committee (CAC)

Version 3, June 2023

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Academy for Professional Excellence

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Acknowledgements

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

Agencies

California Department of Social Services, Adult Programs Division National Adult Protective Services Association

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Kevin Bigelow (2018 revisions)

Lisa Nerenberg (2011 original)

How to Use This Manual

This curriculum was developed as 5 hour (excluding breaks) workshop either in-person or virtual using the Zoom platform, paying close attention to virtual training best practices. It can be tailored to a different virtual platform (WebEx, GoTo Training, etc.), if necessary. If training virtually, it's suggested to deliver in two days.

<u>Use of language:</u> Throughout the manual, APS professional is used most often to describe APS staff conducting interviews and assessments. The term client is used most often to describe the individual at the center of the APS investigation. However, if concept or material was directly quoted from copyrighted material, another term may be used.

"He" and "she" have 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.

Customizing the Power Point: This manual is set up so that the trainer script/ background material is on the same page as the accompanying PowerPoint 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 a line through it to show you have hidden it.

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

The course outline, provided in the later in this manual, is the class schedule used for development of this curriculum. 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.

Participant Manual:

If training in person, each participant will need a Participant Manual. If training virtually, the Participant Manual should also be sent ahead of time as a fillable PDF if using Adobe Acrobat or to allow participants to print a hard copy.

Trainer Guidelines

It is recommended that someone with experience working with individuals experiencing self-neglect facilitate this training. Having a background in behavioral health can also be helpful.

Suggestions for virtual training when possible:

- Have a moderator or co-host who can primarily focus on the virtual aspects of this training (e.g., monitoring chat box, launching polls, assigning breakout groups, monitoring participant reactions, etc.).
- Test out the use of the breakout room feature prior to conducting this training as well as audio.
- Log in 30 minutes prior to the training to ensure the virtual classroom is fully functioning and that you are comfortable navigating it.
- Your equipment and platform may dictate how you do some activities or discussion. There are times you may not be able to see everyone's faces, names or reactions. There is a need for both verbal discussion and chat discussion. At such times, the moderator will fill a critical role monitoring those features you cannot. Practice during a run through how you will use the various functions for each section.
- The optimal size for this virtual training is 20-25 participants.

Teaching Strategies

The following instructional strategies are used:

- Lecture segments
- Interactive activities (e.g. breakout groups, chat box discussion, polling activities)
- Experiential Activity (case scenarios, video demonstration)
- Question/answer periods
- PowerPoint Slides

Materials and Equipment

The following materials are provided and/or recommended:

- Trainer Manual
- Participant Manual (fillable PDF)
- PowerPoint Slides
- Headset with microphone
- Computer

Virtual Training Tips

Training and facilitation have always been an art. Virtual training is no exception. Below are some helpful tips to remember and implement when training in a virtual environment.

Assume nothing.

• Do not assume everyone has the same knowledge/comfort level with technology or has access to equipment like printers, video camera, headsets or even reliable Wi-Fi.

Distractions are everywhere.

• Participants have greater access to distractions (email, phone, others at home) which can take their focus away from the training. Therefore, explain everything and summarize before asking participants to complete an activity and check for clarification.

Over explain when possible.

• The virtual room doesn't allow for participants to see everything you're doing as they can in- person. Share as you navigate the virtual environment. If you are silent while looking for something or finding a screen, they may think something is frozen.

Mute with purpose.

• "Mute all" function can help ensure we don't hear conversations we're not supposed to. However, it can also send a message to the participants that they are a passive participant and may not make them feel comfortable taking themselves off mute when you want them to speak.

Two screens can be a lifesaver.

• This allows you to move your chat box or participant gallery view away from your presentation so you can see more of what's going on.

Rely on practice, not luck.

• Winging it during an in-person training or facilitation may work from time to time, but doesn't work in the virtual environment. In addition to covering the content, you have to manage all of the technology issues, learning styles in a virtual room, and it will show if you're not prepared.

Bring the energy.

 As trainers, we are no strangers to being "on," standing and moving around. However, some of the body language, subtle nonverbal skills we relied on the in-person training room do not translate well in the virtual environment. While this may make you more tired, it's important to up your enthusiasm, voice, and presence in order to engage with attendees.

Be mindful of your space.

- Training virtually brings an entirely new component of what we're willing to share with others. Learners can get distracted with what's in your background, whether what is physically there or if you set your video to use a virtual background.
- It's important to reflect on questions of privilege, diversity and equity when thinking of your training space.
- Are there objects in your background that can symbolize status, privilege and/or power? If so, consider removing them to dismantle any added power dynamics that already exist with you as the Trainer.
- Unknowingly, objects can come across as offensive or can activate unpleasant or traumatic memories, and can instantly discredit your rapport building. Think of neutral backgrounds that are not distracting and allow you to be the focus of what learners see.

Executive Summary

Working with Clients Experiencing Self-Neglect

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 promising interventions to incorporate when working with individuals experiencing self-neglect. They will explore how to develop service plans, 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 NAPSA 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); video demonstrations; and transfer of learning activity to assess knowledge and skill acquisition and how these translate into practice in the field.

Instructor-Led Training

This course was developed to be delivered either in-person or virtually. The following instructional strategies are used: lecture segments; interactive activities/exercises (e.g. small group discussion and case studies); question/answer periods; video demonstrations, PowerPoint slides; participant guide (encourages self-questioning and interaction with the content); and transfer of learning activity to assess knowledge and skill acquisition and how these translate into practice in the field.

Participants will need their participant manual either printed or send virtually. If training virtually, access to a computer with video conferencing capability and be able to connect to the virtual platform being used to deliver this training. A headset or earbuds with microphone and a video camera are highly encouraged.

Intended Audience

This course is designed for new APS professionals as an introduction to selfneglect as well as Older Adults/Adults with Disabilities partner agencies (e.g. conservatorship investigators, staff 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

After completing this course, participants will be able to:

- Define self-neglect, its prevalence, risk factors, and indicators
- Assess self-neglect in 5 domains
- Describe promising techniques for working with adults experiencing selfneglect
- Identify safety and risk reduction interventions for adults experiencing selfneglect
- Demonstrate an understanding of the elements to document in self-neglect cases
- Identify community partners to work with in self-neglect cases

Course Outline

| CONTENT | MATERIALS | TIME |
|---|---|----------------------|
| WELCOME, INTRODUCTIONS, COURSE OVERVIEW | | TOTAL: 20 minutes |
| Welcome to training and trainer Intro Housekeeping Technology, Content Warning | | |
| Participant Intro (name, agency, time in APS) Chat Question and Discussion: Experience with Self Neglect cases & Fears and Challenges | | |
| Prevalence of Self-Neglect | | |
| Learning Objectives with Course Overview | | |
| INTRODUCTION TO SELF-NEGLECT | | TOTAL: 60 minutes |
| Self-Neglect Defined (WIC & AB 135) | State Statutes | |
| Activity #1 – Is it Self Neglect? (Individual/Large Group) | Handout #1-Case Scenarios | 10 minutes |
| Activity #2- The Diverse Spectrum (Individual/Large Group) | Handout #2- Maria and John | 15 minutes |
| Potential Indicators of Self-Neglect Factors Mistaken for Self-Neglect Health Literacy Implications Ethical Issues Safety vs. Self-Determination | Handout #3- NAPSA Ethical Principles | |
| BREAK | | |

| ASSESSING SELF-NEGLECT: DOMAINS, SEVERITY AND URGENCY | | TOTAL: 60 minutes |
|--|---|----------------------|
| Assessing in Self-Neglect 5 Domains with | Handout #4: Self- Neglect in Five Domains | |
| Activity #3- Name the Domain! (Individual/ Large Group Discussion) | | 5 minutes |
| Severity and Urgency Activity #4 – Assessing for Severity and Urgency (Breakout groups) | Handout #4: Self- Neglect in Five Domains | 35 minutes |
| Assessment Tools | Handout #5 APS TARC Brief- Capacity Screening in Adult Protective Services: Guidance and Resources | |
| SCREENING DECISION-MAKING ABILITY | | TOTAL: 45 minutes |
| Decision-Making Capacity Ability Screening for Capacity Executive Function Enhancing Decisional Ability | Handout #6- Demensions of Capacity Handout #7- Capacity for Medical Treatment | |
| Activity #5- Mrs. Green: Assessing Decisional Ability (<i>Breakout groups</i>) | Handout #8- Case Study: Mrs. Green | |
| CHALLENGING FACTORS | | TOTAL: 15 minutes |
| Challenging Factors Working with Clients Who are Hesitant Reasons People May Refuse Help Hoarding and Self-Neglect Hoarding Disorder Defined Impact of Compulsive Hoarding Substance Use Disorder and Self-Neglect | | |
| Break | | |

| TREATMENT TECHNIQUES AND MODALITIES | | TOTAL: 30 minutes |
|--|---|----------------------|
| Motivational Interviewing Core Concepts of MI Decisional Balance Worksheet Activity #6: Self-Neglect Home Visit Video and Decisional Balance Worksheet (Individual & large group) | 7-minute video clip Handout #9- Decisional Balance Worksheet | 15 minutes |
| Substance Use Disorder TreatmentTreatment for Hoarding | | |
| DETERMINING APPROPRIATE INTERVENTIONS | | TOTAL: 40 minutes |
| Interventions Types of Interventions Social Support /Supportive Services Mental Health Treatment Involuntary Interventions | Handout #10 – Support and Services to Clients or Caregivers to Prevent Self-Neglect | |
| Responding to Someone Experiencing Self- Neglect Activity #7: Responding to Someone Experiencing Self-Neglect (breakout groups) | Handout #11A /B– SELF-NEGLECT CASE STUDIES (Trainer & Participant Copy) | 30 minutes |
| DOCUMENTATION | | TOTAL: 10 minutes |
| Importance of Good Documentation Activity #8 (only if time permits) | Handout# 12 – Documentation in Self Neglect | 5 minutes |
| PARTNERS IN SELF-NEGLECT | | TOTAL: 5 minutes |
| Partners in Self-Neglect | Handout# 13 – Community Partners in Self Neglect Cases | |
| COURSE WRAP UP AND EVALUATIONS | | TOTAL 15 minutes |

| Review Learning Objectives 1 Take-away? (only if time allows) Plus/Delta EOD | Evaluations | |
|---|-------------|---------|
| TOTAL (EXCLUDING BREAKS) | | 5 hours |

Welcome, Introductions, and Course Overview

Time: 20 minutes

Associated Objective: NA

Method: Lecture, discussion and chat (if virtual)

Slide #1: Welcome, Title Slide



Welcome participants and introduce yourself by name, job title, organization, and qualifications.

Ask participants to introduce themselves verbally or in the chat by name, county, position, and years with APS.

Ask participants to think about the following question which we'll connect on in a few slides: What is your biggest fear or has been your biggest challenge with working with someone who is experiencing self-neglect?

Slide #2: Academy for Professional Excellence and APSWI



Explain that the Academy for Professional Excellence is a project of San Diego State School of Social Work. Its mission is to provide exceptional workforce development and learning experiences for the transformation of individuals, organizations, and communities.

Explain that Adult Protective Services Workforce Innovations (APSWI) provides innovative workforce development to APS professionals and their partners. APSWI is a program of the Academy for Professional Excellence along with others listed on the slide.

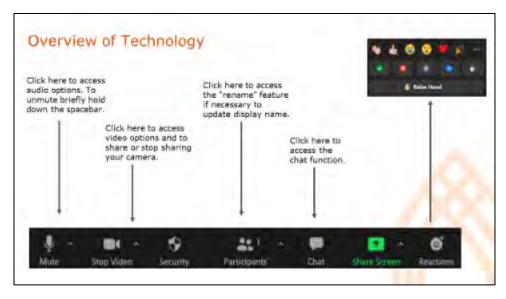
Slide #3: Housekeeping



Share:

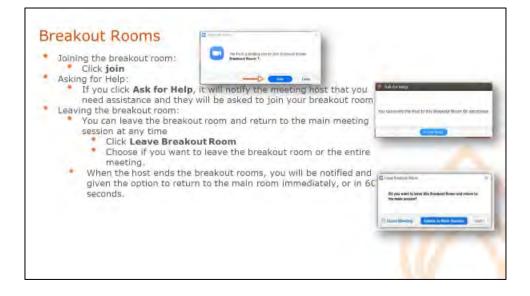
- Timing of training including breaks
- We encourage dialogue and connection in this training, so it is great to see **and** hear from each and all participants. Verbal, chat, raised hand and other forms of communication are welcomed. If virtual, please turn video on.
- Please try to give us your undivided attention for the time we are together. We know you all have busy jobs so if you do need to excuse yourself, please send a "be right back (brb)" message if virtual to one of us privately and return as quickly as possible. Check the course outline to see what you missed.
- **Content Warning:** We recognize that APS work is both challenging and rewarding and APS professionals are whole human beings who have their own experiences before and during APS work. The content today may activate feelings based on personal or professional experiences, including vicarious trauma and we encourage everyone to do what they need to do to engage safely in the training today.

Slide #4: Technology Overview



If training virtually technology functions including breakout rooms.

Slide #5: Breakout Rooms



Slide #6: Connection Question



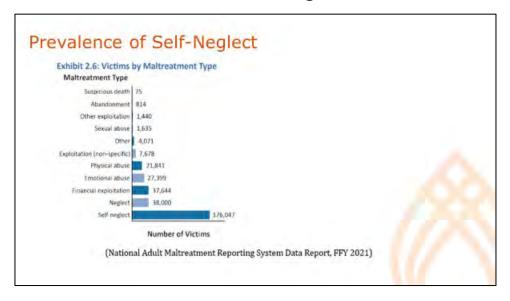
Welcome and acknowledge the variety of participants, their counties, their positions, and especially their years of experience with APS.

Segue into the introductory question: What is your biggest fear or has been your biggest challenge when working with someone who is experiencing self-neglect (encourage participants to throw their answers in the chat if they haven't done so already).

- Validate & summarize chat answers and identify those that will be addressed in the training. Ask 1-2 participants to expand on their answers to stimulate discussion.
- Identify other potential answers that could include:
 - Eligibility barriers
 - Lack of available resources
 - Waiting lists for referred services
 - Mental Health Conditions
 - Substance Use Disorder
 - o Hesitant to accept services
 - o Capacity issues
 - o Refusing services when needs are obvious

<u>Trainer Note</u>: If training virtually, this can also be done as an anonymous poll to allow folks to participate without being called on.





TRAINER NOTE: The National Adult Maltreatment Reporting System (NAMRS) is a comprehensive, national reporting system for state APS programs. Since 2016, NAMRS has been used to collect annual data from states on adult maltreatment. The data collected from these reports have been critical to enhancing the effectiveness of APS programs.

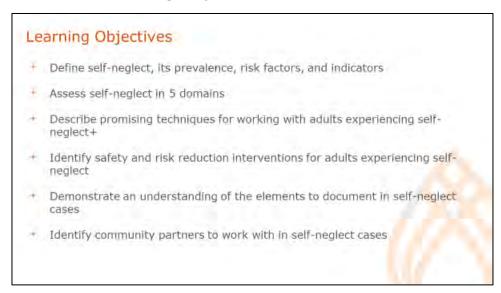
In NAMRS, a "client" is considered a "victim" if at least one maltreatment allegation within an investigation has the disposition "substantiated." This chart displays Maltreatment Types among "victims".

Acknowledge the participants' bravery in voicing their fears and challenges about working with clients who are experiencing self-neglect and their willingness to learn more about this population.

Explain:

- Chances are they will receive more self-neglect cases than any other type of abuse during their time in APS.
- Per the 2021 National Adult Maltreatment Reporting System (NAMRS), the number of substantiated self-neglect cases were significantly higher (more than double) than each of the other types of maltreatment.
- Therefore, being able to assess for self-neglect and provide effective interventions are critical skills that they will need.
- This training will provide them with the tools and foundation.

Slide # 8 Learning Objectives



Review the Learning Objectives with the class:

- Define self-neglect, its prevalence, risk factors, and indicators
- Assess self-neglect in 5 domains
- Describe promising techniques for working with adults experiencing selfneglect
- Identify safety and risk reduction interventions for adults experiencing selfneglect
- Demonstrate an understanding of the elements to document in self-neglect cases
- Identify community partners to work with in self-neglect cases

Ask if there are any specific skills or information they are hoping will be covered in this module. **Clarify** what will and will likely not be covered based on the learning objectives.

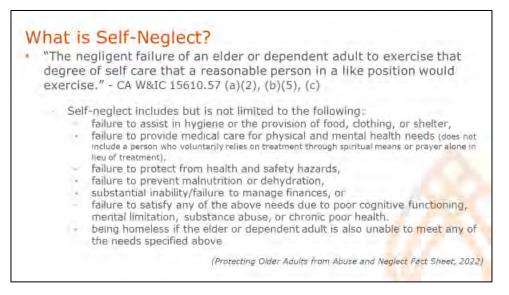
Introduction to Self-Neglect

Time: 60 minutes

Associated Objective: Define self-neglect, its prevalence, risk factors and indicators

Method: Lecture, discussion, chat and poll features (if virtual)

SLIDE #9: Self-Neglect Defined



<u>Trainer notes</u>: If not training in CA, replace with your state statutes.

For this training, the self-neglect definition and updates were sourced from <u>Assembly Bill</u> <u>135 (Chapter 85, Statutes of 2021)</u>, <u>WIC 15610.57 (a)(2), (b)(5), (c)</u>, and <u>ACL No. 21-138 (ca.gov)</u>.

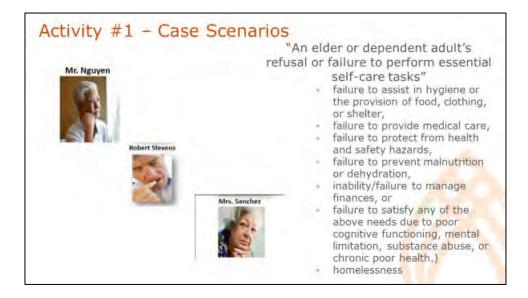
Please note the exception noted in parenthesis for medical care states: "does not include a person who voluntarily relies on treatment through spiritual means or prayer alone in lieu of treatment." You may want to refer to this exception as needed in upcoming discussions surrounding the following slides/topics: Factors That Could Be Mistaken for Self-Neglect, Ethical Issues, Safety vs Self-Determination, Decisional Ability, and Assessing Self-Neglect in 5 Domains.

Explain:

- Now that you have learned about the "prevalence" of self-neglect, it is time to break it down further to understand what the term, "self-neglect", means.
- Disagreement exists, even among experts, about what defines self-neglect. It is important to understand how your state and agency define self-neglect. For example, some states don't even recognize the category of self-neglect and therefore, do not investigate it at all.
- For California, our Welfare and Intuitions Code (WIC) dictates the definition of self-neglect and directs all 58 California county APS Programs to adhere to it.
- As per this slide, the California WIC code emphasizes one to consider how an elder or dependent adult's *impaired cognitive function, mental limitation, substance abuse and or chronic health condition impacts their ability to meet the needs identified in the slide in a safe and responsible manner.*

It should be noted that the WIC code was updated in 2021 because of the passage of Assembly Bill 135 which expanded the definition of self-neglect to include an elder or dependent demonstrating a substantial inability or failure to meet their finances and being homeless *if* the elder or dependent adult is also unable to meet any of the needs specified above.

Slide# 10: Self Neglect Case Scenarios



Trainer Note: This activity allows the participants to apply their understanding of the definition of self-neglect with actual case scenarios. Read each situation, which are animated on the slide, and prompt discussion with the participants deciding if the scenario meets the definition of self-neglect and why. The WIC code definition of self-neglect is on the slide. Potential answers to the scenarios are listed below the activity instructions.

Activity #1- Is it Self-Neglect?- (10 minutes) Large Group Discussion/Chat

Explain:

Self-neglect cases can encompass a wide range of situations. Let's test out your understanding of the definition with a few case scenarios.

Refer the participants to **Handout #1** – Self Neglect Case Scenarios in their Participant Manual so they can read along.

Instructions:

- 1) Ask, verbally and/or typed in chat:
 - Does this case scenario meet the definition of self-neglect?
 - If so, why? If not, why not?
- 2) As you click on each scenario give them 1 minute after each scenario to enter their answers to the questions into the chat.

3) Use their responses and the answers listed below to prompt a brief discussion for each scenario as it relates to the definition of self-neglect.

Potential Answers:

• **Mr. Nguyen** is alert and oriented but is experiencing short-term memory loss. He has neglected to pay his bills and recently had his electricity shut off which resulted in a neighbor having to step in to assist in getting his electricity turned back on.

Answer: Mr. Nguyen may be self-neglecting in that his short-term memory loss may prevent him from managing his finances and may put him at risk of not meeting his basic needs.

• **Robert Stevens** is 53 years old and suffers from moderate cognitive impairment due to a traumatic 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 and left the hospital against medical advice.

Answer: Mr. Stevens's cancer and cognitive impairment from his brain injury make him more vulnerable than most other people his age. His inability to follow instructions, 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 how he is meeting his basic needs and if he can live on his own safely.

• Mrs. Sanchez lives with her son who has been diagnosed 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 to seek out help for him because he has gotten agitated in the past when others have tried. Mrs. Sanchez feels that he is her responsibility. Mrs. Sanchez has missed her last few medical appointments because her son wants her to stay home with him all day.

Answer: Mrs. Sanchez appears to be at risk of abuse by others due to the behaviors of her son, his untreated substance use and mental health, and his refusal to allow visitors in and/or let Mrs. Sanchez leave the home. Mrs. Sanchez's ability to make decisions, care for herself, and her mental capacity to understand the danger her son represents will have to be assessed. This case may have a self-neglect component (especially self-neglect of medical care) in addition to other risk factors.

Handout #1 – Self Neglect Case Scenarios

- **Mr. Nguyen** is alert and oriented but is experiencing short-term memory loss. He has neglected to pay his bills and recently had his electricity shut off which resulted in a neighbor having to step in to assist in getting his electricity turned back on.
- **Robert Stevens** is 53 years old and suffers from moderate cognitive impairment due to a traumatic 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 and left the hospital against medical advice.
- Mrs. Sanchez lives with her son who has been diagnosed with schizophrenia and has a substance abuse 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 to seek out help for him because he has gotten agitated in the past when others have tried. Mrs. Sanchez feels that he is her responsibility. Mrs. Sanchez has missed her last few medical appointments because her son wants her to stay home with him all day.

Slide #11: The Diverse Spectrum



<u>**Trainer Notes</u>**: This activity 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 to investigate a new report containing self-neglect allegations.</u>

Ultimately, it will demonstrate the spectrum of the clients that APS serves, environments and causes of self-neglect for all participants, and it will highlight that we likely have our own biases when investigating these allegations.

There are two potential case scenarios for this activity – Maria or John – both are provided here but it's suggested to only pick one to use for activity. The objective is for them to read the scenario on their own and fill in the blank with the first descriptor that comes to their mind based on their experience, fears, or ideas of what they might expect.

<u>Activity #2: The Diverse Spectrum (15 minutes)</u> Individual/Large Group Discussion

Explain: We now know the definition of self-neglect. Before we dive any deeper let's explore how your own experiences, thoughts, and/or biases may come into play when you are responding to a report of a client who may be experiencing self-neglect.

Refer participants to Handout #2 (Maria/John scenarios) in their Participant Manual.

Instructions: (this activity can be done either on a whiteboard or using chat to share answers):

- 1) **Select** 1 of 2 available scenarios to be used for this activity (Maria or John) and identify which scenario you plan to use for today's activity.
- 2) **Explain** that you will give them 2-3 minutes to review the scenario on their own and fill in the blank with the first descriptor that comes to their mind based on their experience, fears, or ideas of what they might expect for this home visit.
- 3) Once their time is up, **explain** that you will now read the scenario aloud and when you pause at each blank, everyone should enter their answer for that respective blank in the chat.
- 4) Just for fun (optional) –capture one of the most interesting/unique/biased/culturally influenced answers for each blank and make note of it on their own activity sheet. With this, you have created a "unique" scenario that mishmashes all their experience/biases/thoughts/fears into one example. At the conclusion of this activity, read your unique scenario back to them at the very end of the activity to further reflect their unique and varied responses.
- 5) **Wrap up** the activity with a brief discussion tying this into the diversity in the self-neglect cases we may investigate and the diversity in which we may bring our own preconceived ideas/experiences and biases to each investigation.
- 6) **Ask** what did they learn from this exercise?
 - a. Point out the more common answers that participants provided (possibly hoarding, clutter, dirty, smell of urine, confused, angry), and ask how those answers may represent their own internal biases. You could point out that not all self-neglect is hoarded homes and poor hygiene.
 - b. What about the other answers they provided, what might they reflect?

Handout #2 – Maria and John

SLIDE #12: Potential Indicators of Self-Neglect



Explain: The allegation of self-neglect can encompass a very broad range of characteristics or indicators. The ones listed in this slide are just some of the more common or more "visible" red flags that are typically associated with self-neglect and might activate an APS report.

However, please keep in mind that many of these same indicators could be categorized as abuse or neglect by others or they could have plausible explanations. Some examples of plausible explanations might include:

- Josey Smith's refrigerator is empty because Josey's daughter takes her to her home for all meals so there is no need for Josey to keep food in her refrigerator.
- You receive a report from Dr. Gutierrez's office stating that Alejandro Lopez missed his last 2 doctor visits and hasn't been seen in over a year. Upon further invegistation, you discover that Alejandro started going to a new medical doctor 8 months ago and was last seen by the new doctor 2 weeks ago.
- You received a report that Asa Taha is self-neglecting as their water and electricity were shut off for non payment. However, upon investigation, you discover that Asa's cousin has Power of Attorney for finances and was responsible for paying all of their bills. Therefore this could be financial abuse/neglect by the cousin instead of self-neglect.

SLIDE #13: Factors that Could be Mistaken for Self-Neglect



<u>**Trainer Note</u>**: This slide is animated to first cover situations that might be mistaken for self-neglect and then to cover situations that might lead to selfneglect. The objective of this slide is that APS investigations and assessments require digging deeper and completing a comprehensive assessment, which will be discussed later in the training.</u>

Explain: It is also important that we do not impose our own (or others) values or beliefs on our clients. What first may appear to be self-neglect, may reflect the client's personal lifestyle choice which could include eccentricity, a lifestyle that varies from the dominant culture, their religious or cultural practices/beliefs, or their belief in alternative medicine.

Ask: Does anyone have any case examples for the above listed factors?

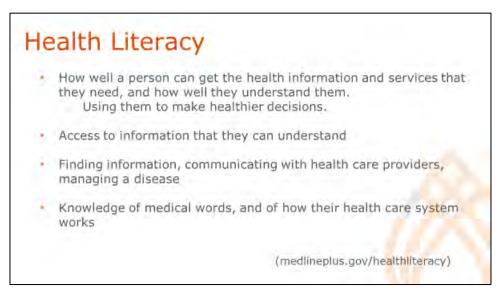
Remind participants that the WIC code definition for self-neglect for *medical care* states: "does not include a person who voluntarily relies on treatment through spiritual means or prayer alone in lieu of treatment."

Ask: How would an APS Professional distinguish the difference between selfneglect and lifestyle choice or spiritual belief?

Explain that there are other factors that can lead to self-neglect and also require further assessment to develop collaborative services plans, which we'll discuss later. Some of these factors are: trauma, low health literacy, or neglect/abuse by others.

Remind: It is up to YOU as the APS Professional to do your due diligence when investigating these allegations by asking respectful but probing questions and obtaining as much historical and corroborative information as you can (or as the client will allow you) to guide you through your investigation.

Slide# 14: Health Literacy



Before we move on, let's expand on the topic of health literacy that we touched on in the previous slide.

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 informed 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, including previous interactions with medical providers

"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." (medlineplus.gov, 2020)

Slide #15: Clients With Low Literacy



Ask: Given your advanced education and technological acuity, have they ever had problems navigating the health care system?

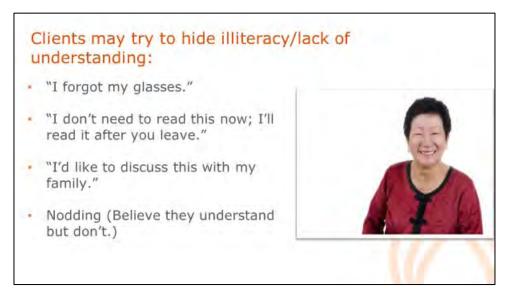
• Have they ever waited hours on hold or been passed around to numerous departments? Have you had trouble figuring out where to go or who to call for a test or procedure? What kind of problems have you had getting to see a specialist or settling billing errors?

Wait for and validate responses.

Ask: How might might a disability (such as hearing loss or speech deficits), language differences or previous negative experiences with healthcare impact navigating the health care system?

Ask: Does it seem likely that some adults who are experiencing self-neglect may not understand how to access appropriate self-care or navigate the systems? How might these same limitations affect your service planning?

Slide #16: Hiding Health Literacy



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?

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.

 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."

SLIDE #17: Implications of Self-Neglect



Explain:

- The consequences of self-neglect can be devastating. It can lead to premature death, institutionalization, housing insecurity, 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, could be affected?

Answers may include:

- Fractured relationships with family, friends, neighbors who tried to assist and intervene but became frustrated, reluctant, and/or unwilling when their efforts were not accepted.
- Impact on property values or safety of neighbors/community (rodent infestations, mold, fire hazards, car accidents, etc.) when the self-neglect involves severe hoarding, unmaintained home/environment, or actions (such as driving or cooking) that the self-neglecting adult may no longer be able to do safely due to their impairments.
- Expensive treatment, hospitalization, or placement, the costs of which may be borne by the client, their families, or taxpayers.

SLIDE #18: Ethical Issues in Self-Neglect



Explain: Before we go any further, we need to consider the ethical prinicples that should guide your assessment and intervention with all clients, incuding those who are experiencing self-neglect. APS professionals are guided by their professional orientation and values. Although there isn't just one universally accepted set of ethical principles, many subscribe to those developed by the National Adult Protective Services Association (NAPSA).

Review the slide to highlight why ethical principles are important and inform them that, for the purpose of our training today, we will be referencing the NAPSA principles to see how they can guide us in working with our self neglecting clients.

Direct participants to **HANDOUT #3- Ethical Principles** in their Participant Manual and give them to time to review.

Lead participants into a deeper discussion of these eithical principles and how the principles may intersect with their self-neglect investigation.

Some example discussion questions may include:

- Of these principles, do any stand out to you as being particularly relevant for working with clients who are experiencing self-neglect?
 - Which ones and why?

Handout #3 – NAPSA Ethical Principles



Ethical Principles and Best Practice Guidelines

Dedicated to the memory of Rosalie Wolf ©NAPSA 2018

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

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SLIDE #19: Safety vs. Self-determination



This may be one of the most challenging tasks APS professionals face when working with people experiencing self-neglect – weighing a client's safety/risk factors against that client's right to self determination.

Explain:

- Clients' rights to exercise freedom and autonomy may come into conflict with an APS professional's 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 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 experiencing self-neglect may require intervention from a community partner to enforce safety measures without their consent?

Answers may include:

- When a person threatens harm to themselves or others (mental health/law enforcement)
- When a person hoards animals and endangers them (animal control)
- When the person who is self-neglecting refuses to leave a condemned home (code enforcement/law enforcement)

- When a person identified as living with a hoarding disorder refuses to follow orders to clean up a home which is a fire hazard or pest infestation (code enforcement)
- When a person with significant impairment continues to drive unsafely (DMV/law enforcement)

Remind participants that determining between safety and self-determination can be a fine line. They are not alone in this task. When an APS professional is faced with a scenario in which a client's safety vs. self-determination is in question or where a forced intervention may need to be considered due to the safety of the client or others, you are not alone. You should always consult with your supervisor and/or an appropriate community partner who can assist with the enforcement aspect. Later in the training, we will be talking more about community resources and collaborating with community partners.

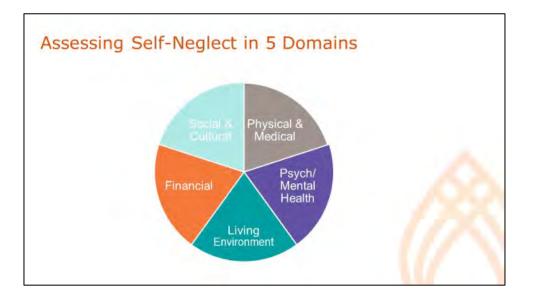
Assessing Self-Neglect: Domains, Severity and Urgency

Time: 60 minutes

Associated Objective: Assess self-neglect in five domains

Method: Lecture, discussion, and chat (if virtual), breakout groups

SLIDE #20: Assessing Self-Neglect in 5 Domains



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

As an APS Professional, at times you may receive a report with a barrage of various self-neglect allegations or just one complicated allegation, trying to sort the information out and prioritize your next steps can be overwhelming.

Breaking down the abuse factors into "domains", can help you consider the causes and manifestations of each allegation a little clearer which can then help you with other tasks such as prioritizing needs and identifying the most appropriate resources.

Here we have "5 domains" and we will talk specifically about assessing self-neglect in each domain.

Refer participants to the **Handout #4** –Self-Neglect in Five Domains.

Ask participants to follow along as you talk specifically about assessing selfneglect in each domain.

Domain 1: Physical/Medical Factors

These are some of the common conditions that affect older adults' ability to manage independently.

Explain: Some factors in this category 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.)

- 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 themselves or place them at 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 conditions that may affect a client's ability to manage.

- Mental illness
- Substance use disorder
- Trauma
- Neurocognitive Disorders (formerly called Dementia)
- Depression
- Diminished mental capacity
- Anxiety
- Hoarding disorder

Explain Some cognitive impairments result from conditions or situations that are treatable and reversible. These treatable or reversible conditions that are often mistaken for neurocognitive disorders. They include delirium and depression and can be caused by:

- Problems with medications, including over/under dosing or interactions between medications
- Infections (including urinary tract infection)
- Substance use disorder
- Depression
- Adverse reaction to anesthesia

Domain 3: Environmental

- Older and dependent adults who are experiencing self-neglect may live in homes that are unsafe or unhealthy or they may no longer be able to manage themselves in their nice clean home that has lots of stairs, inaccessible bathroom features, etc.
- 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. This can result in important bills being unpaid such as utilities, mortgage/rent.

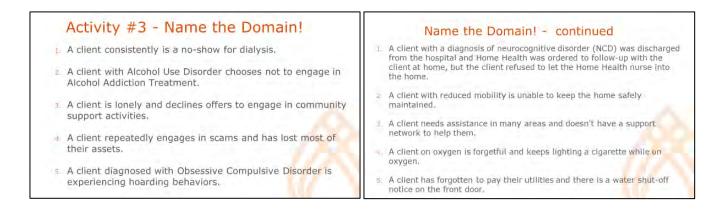
Domain 5: Social and Cultural

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.

- 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).
- Low health literacy

Explain that 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 or getting the government involved in personal issues. 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 persons or cultures have a fear of the government and may fear deportation (e.g. someone who does not have documention or persons with restricted documentation or institutionalization.)

SLIDE #21: Activity #3- Name the Domain!



Activity #3: Name the Domain! (5 min) Individual, Large Group Discussion

Objective: Participants will apply their understanding of the 5 domains with case examples.

Now that you have an understanding of the 5 different domains, let's NAME THE DOMAIN!

Instructions:

- 1. **Read** the scenarios one at a time and participants will share their answers either outload or in the chat.
- 2. After each scenario, **review** responses in the chat and initiate a brief discussion regarding the responses. You may want to ask participants specificially why they made the choices they did or what additional information they may need to make a more informed decision.
- 3. *Remember that some of these scenarios may fall into more than one domain of self-neglect or may need additional information to determine if it is self-neglect. Use this as opportunity to focus on core issues that may lead to self-neglect or additonal information that might be needed.

Answers:

• A client consistently is a no-show for dialysis. Physical/Medical or could be Social and Cultural (no one to take them or help them set up appts)

- A client with Alcohol Use Disorder chooses not to engage in Alcohol Addiction Treatment. **Psychological/Mental Health**
- A client is lonely, and declines offers to engage in community support activities. **Social and Cultural**
- A client repeatedly engages in scams and has lost most of their assets. Financial or could be Social and Cultural (maybe they are lonely?)
- A client diagnosed with Compulsive Hoarding Disorder is experiencing hoarding behaviors. **Psychological/Mental Health**
- A client with a diagnosis of neurocognitive disorder (NCD) was discharged from the hospital and Home Health was ordered to followup with the client at home, but the client refused to let the Home Health nurse into the home. Psychological/Mental Health Or Social/cultural
- A client with reduced mobility is unable to keep the home safely maintained. Physical/Medical Factors could also be Environmental
- A client needs assistance in many areas and doesn't have a support network to help them. **Social and Cultural**
- A client on oxygen is forgetful and keeps lighting a cigarette while on oxygen. **Environmental**
- A client has forgotten to pay their utilities and there is a water shut-off notice on the front door. **Financial could also be Environmental**

Reminder: Again, it is up to you as an APS professional to ask the questions that will help you get the details you need to properly assess the allegations, assess the risks and develop an appropriate intervention plan.

Handout #4 –Self-Neglect in Five Domains

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

- Could include psychological or mental health conditions. Some examples include mental illness, substance use disorder, trauma, neurocognitive disorder, diminished mental capacity, or anxiety.
- Could include cognitive impairments resulting from conditions which situations which could be treatable or reversible. Some examples include problems with medications, infections, substance use disorder, or depression.

Domain 3: Environmental

- Could include an unsafe or unhealthy living environment.
- Some examples could include non-working utilities, non-working appliances, infestation, structural damage, unclear pathways or exits, or smoking while using oxygen.

Domain 4: Financial

• Primarily refers to a client's inability or disinterest in managing their finances which could result in other factors such as inability to pay rent, buy food, pay for medications, or pay utilities.

Domain 5: Social and Cultural

- Lack of a strong support network or low health literacy could have significant consequences not having anyone to ask for help or not knowing that there is assistance out there.
- Cultural factors could contribute to self-neglect such as shame in asking for help, not accessing services due to fear of government or deportation.

SLIDE #23: Severity and Urgency

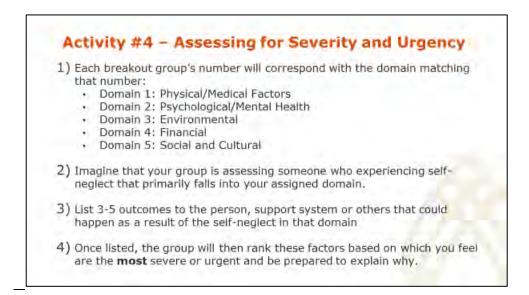
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Explain:

Cases of clients who are experiencing self-neglect vary widely in terms of severity of harm and well-being and the urgency of interventions needed. Clients' behaviors or circumstances may result in gradual decline or life-threatening emergencies.

As an APS professional, it is important that you assess the severity of their possible harm and well-being and the urgency of interventions that may result from each clients' unique circumstances.

SLIDE #24: Activity #4 - Assessing for Severity and Urgency



<u>**Trainer Note:**</u> This activity involves 5 breakout groups, one for each domain. You can modify for smaller classes. This activity also requires a reminder alert 10 minutes into their 15-minute discussion to remind them to move from identify the self-neglect factors to ranking their severity and urgency. This can be done either verbally in-person or via a message if virtual.

Activity #4: Assessing for Severity and Urgency (35 min)

Breakout Groups (5) (Approximate timing is: 10-minute introduction/explanation, 15-minute breakout room discussion, 15-minute group report/discussion)

Activity #4 Instructions:

- 1. Explain that for this activity, we will be breaking you up into smaller groups and return to the large group for discussion. Please note, you will need to use your imagination when thinking of the person you're assessing and the outcomes you will need to rank by severity and urgency.
- 2. **Refer** participants back to **Handout #4** Self Neglect in Five Domains for references and ideas.
- Inform participants that they will be divided and sent to 5 different groups/breakout rooms. Each group number will correspond with the domain that the group is assigned to. For example, Group 1 will have Domain 1 Physical and Medical. The Domains are listed on the slide for your reference.
- 4. Once participants are in their group **Identify** a note taker and person to report out to the larger group.

- 5. Imagine that your group is assessing someone experiencing self-neglect that primarily falls into your assigned domain.
- 6. **Quickly** list 3-5 possible outcomes that could occur to the person, support system or others as a result of the self-neglect in your domain. (hint, we just provided multiple examples in the last exercise).
- 7. Once you have your list, prioritize your list by severity/urgency with #1 being the most severe/urgent and why you believe in the order of severity/urgency. **Since this exercise is a lesson in assessing severity/urgency, spend more time on prioritizing your list vs creating it.
- 8. **Provide** them with an example from the Debrief section below to get them started if needed.
- 9. Each group will get 15 minutes in their breakout groups. We will give you a reminder when you have 5 minutes left to remind you that you should have already be prioritizing for urgency/severity.

Once participants have returned to the larger group, call on each domain group by name and have them:

a. Read their list in rank order starting with most urgent/severe. Briefly explain their thought process/considerations in how they prioritized their list.

Activity #4 Debrief:

Debrief:

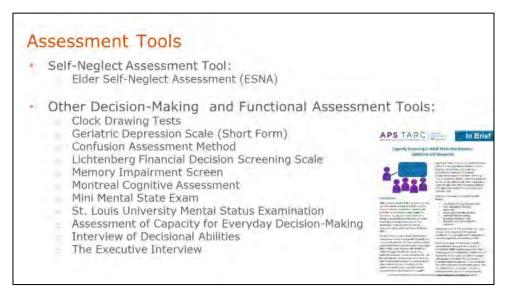
- Explain that for this activity, the rank orders were a matter of opinion and there wasn't necessarily a right/wrong answer since we did not know all the facts. However, it was the reason for the order is the important teaching point.
- 2) The key take away is for just one self-neglect case, you may be juggling various conditions across several domains. Being able to identify any conditions that rank highest on the severity and urgency scale or being able to justify those that don't will be important ensuring the health and safety of your client.

Below is a list of possible examples:

- 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, suicidality
 - 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
 - Complications to self, home, etc due to isolation
 - Caregivers lack the skills or ability to provide needed care
 - Caregivers are withholding needed care

SLIDE #25: Self-Neglect-Related Assessment Tools



Explain: APS professionals have many ways to assess someone for risk and we just demonstrated a few ways.

There are also a lot of assessment tools out there that can assist an APS professional in assessing a person's decision-making, cognitive and functional abilities; however, there is currently only one validated tool that can specifically assessing for self-neglect that can be used when working with older adults.

Elder Self-Neglect Assessment or ESNA

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. The Elder Self-Neglect Assessment (ESNA), 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 selfneglect 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 Applicaple, with a total of 2 points for each question. ESNA can be found by contacting Dr. Madelyn Iris at <u>irisassociates2014@gmail.com</u>.

Share that participants can review *Handout #5* - *APS TARC Brief, Capacity Screening in Adult Protective Services: Guidance and Resources* on their own. This is a great document that gives you a more in depth overview of capacity and capacity screening, the relationship between capacity and abuse, and provides you with various other screening tools for cognition/depression/decisional abilities. Please note, this handout is for reference only. Check with your county to determine if you are allowed to incorporate some of these tools into your assessment and intervention and ensure that you take the proper training.

Handout #5 – APS TARC Brief



enhancing effectiveness of APS programs



Capacity Screening in Adult Protective Services: Guidance and Resources



Introduction

Adult protective services (APS) case workers and/or law enforcement are often the first to encounter situations where an older person or person with disabilities who is a victim of abuse, neglect or exploitation may also have impaired decisionmaking. Issues involving decision-making capacity are complex, cross-disciplinary and include knowledge of medical syndromes, clinical assessment, ethics, and the law (Moye & Marson, 2007).

APS caseworkers do not perform clinical health or capacity assessments unless specifically qualified or authorized by state law. They may perform an initial capacity screening or assessment when they suspect that an older person or person with disabilities suffers from impaired decision making. The needs/risk assessment process outlined in the Final National Voluntary Consensus Guidelines for State Adult Protective Services Systems, published by the Administration for Community Living in 2016, identifies several domains that could help APS caseworkers screen for indications of cognitive impairment. When concerns are identified, APS can refer the client to qualified professionals such as physicians, geriatricians, psychologists, or psychiatrists to administer professional, comprehensive capacity evaluations. Screening tools, in general, are helpful in determining whether clients have the ability to make informed decisions, to give or deny consent for APS services and/or to meaningfully participate in care planning (Falk & Hoffman, 2014).

A comprehensive capacity evaluation should include:

- physical and neurological examination,
- short- and long-term memory assessment,
- assessment of executive function,
- examination for any existing psychological disorders, and
- diagnosis of any existing addictive syndromes.

Unfortunately, not all APS jurisdictions have access to resources to assess each of these areas; nonetheless, it is important that APS advocate for the most comprehensive evaluation possible.

Due to the complexity of the issue, this brief is broken into several sections. Part I focuses on screening for decision-making capacity including terminology and important terms to understand; an explanation of what capacity is and civil capacities (aka capacity to do what?). Part II explores the relationship between capacity and abuse; and why APS professionals need to understand capacity. Part III provides information on capacity screening including cognitive domains and screening tools.

Part IV identifies research on capacity screening; research to practice highlights; and available training and resources.

Part I: Understanding Capacity Terminology

Below is a list of the terms used throughout the brief that are important for APS professionals to understand:

Capacity Assessment/Evaluation – A functional assessment and clinical determination related to a person's capacity to decide (decisional capacity) and implement a decision (executional capacity) in various domains. The six civil capacities identified for psychological assessment that are particularly important to APS client populations are "medical consent capacity, sexual consent capacity, financial capacity, testamentary capacity, capacity to drive, and capacity to live independently" (American Bar Association Commission on Law and Aging & American Psychological Association, 2008). The assessment process typically requires specific materials, supervised testing experience, and/or credentials.

Capacity Screening – Brief tools and/or questionnaires used to determine if a referral for further assessment/evaluation is required.

Competency – A global assessment and legal determination made by a judge in court. (Dastidar & Odden, 2011).

(Mental) Capacity – An individual's physical or mental ability; a legal status presumed to apply to all adults (unless proven otherwise). Capacity is generally defined in law in reference to a specific task (e.g., capacity to execute a will) (American Bar Association Commission on Law and Aging & American Psychological Association, 2008). Decision-Making and/or Decisional Capacity – Decisional capacity is the ability to adequately process information in order to make a decision based on that information (National Center on Elder Abuse, 2015). In the literature, the term decisionmaking capacity is often used interchangeably with capacity, or to describe capacity domains that are specifically and only decisional in nature (American Bar Association Commission on Law and Aging & American Psychological Association, 2008).

Diminished Capacity – A reduced ability to understand the nature of one's acts in one or more domains. A person may have capacity in some domains but not in others (American Bar Association Commission on Law and Aging & American Psychological Association, 2008).

Executive Function – The ability to plan, sequence, monitor, and inhibit complex goal-directed behavior. Executive function involves judgment, insight, and problem solving, and poor executive function is expressed behaviorally as lack of interest or disinhibition (Schillerstrom, et al., 2013).

Incapacity – The inability to receive and evaluate information or to make or communicate decisions to such an extent that an individual is unable to meet essential requirements for: physical health, safety, or self-care, even with the appropriate technological assistance. Clinical incapacity is a judgment about one's functional abilities (National Center on Elder Abuse, 2015).

What is Capacity?

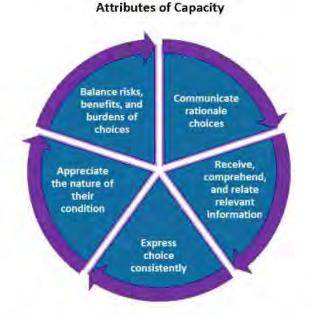
Capacity is complex, multidimensional, and affected by many factors. It is the "cluster of mental skills", such as:

- memory and logic,
- behavioral and physical functioning that people use in everyday life,
- a continuum of decision-making abilities,

- contextual, and varies by the complexity of the task or the decision,
- an element that should always be evaluated in relation to the particular act that is at issue (e.g., signing over a home, creating a will, marrying, testifying about abuse)."
 (Judicial Council of California & Mosqueda, 2012)

The Judicial Council & Mosqueda (2012) state, "capacity is rarely lost completely or globally, except in very severe cases. For example, in the early phases of dementia/Alzheimer's disease, the older adult can often recall, state their desires, and testify appropriately."

The NAPSA Core Competency Module 17 on <u>Assessing APS Clients' Decision-Making Capacity</u> offers a helpful graphic to consider the attributes of capacity and how they are interrelated. In general, the more important the decision and the results of the decision, the higher the level of capacity required.



An individual's decision-making abilities may vary as a result of physical or mental stress, the complexity of the decision, and can vary from day to day or from morning to evening. Differentiating a physical disability, such as stroke-related aphasia, from decisional incapacity is critical (Ramsey-Klawsnik, The Complexities of Cognitive Capacity, 2014). Medications, medication interactions and sensory deficits can also play a role.

Medical conditions such as malnutrition, dehydration, urinary tract infections (UTI), trauma, and depression can cause temporary confusion or delirium and disorientation. Delirium is an acute confused state, disturbance in alertness, consciousness, perception and thinking that has a sudden onset. It can be caused by infection, dehydration, chemical imbalance, head trauma, or anesthesia, etc. It is a medical emergency that is reversible and treatable (National Center on Elder Abuse, 2015).

Consideration also needs to be given to the role of cultural variables in decision-making. Language, immigration status, economic status, perceptions of institutions, perceptions of disability, and the role of family in care and decision-making is critically important (American Bar Association Commission on Law and Aging & American Psychological Association, 2008).

In a report prepared by the National Ethics Committee (NEC) of the Veterans Health Administration (VHA), they concluded "in clinical practice, decision-making capacity is often assessed informally or inconsistently and misconceptions about decision-making capacity and its assessment are surprisingly common" (Ganzini, Volicer, & Fox, 2004). Based on a study of clinicians and ethics committee chairs, the NEC identified "Ten Myths About Decision-Making Capacity". While the frame of reference is health care/patients, the points made relate to anyone working with clients who may have reduced decisional abilities.

1. Decision-making capacity and competency are the same;

- Lack of decision-making capacity can be presumed when patients go against medical advice;
- There is no need to assess decision-making capacity unless patients go against medical advice;
- Decision-making capacity is an "all or nothing" phenomenon;
- Cognitive impairment equals lack of decision-making capacity;
- 6. Lack of decision-making capacity is a permanent condition;
- 7. Patients who have not been given relevant and consistent information about their
- 8. treatment lack decision-making capacity;
- All patients with certain psychiatric disorders lack decision-making capacity;
- 10. Patients who are involuntarily committed lack decision-making capacity; and
- 11. Only mental health experts can assess decision-making capacity.

(Ganzini, Volicer, & Fox, 2004)

Civil Capacities - Capacity to Do What?

The six civil capacities identified for psychological assessment that are particularly important to APS client populations include "medical consent capacity, sexual consent capacity, financial capacity, testamentary capacity, capacity to drive, and capacity to live independently" (American Bar Association Commission on Law and Aging & American Psychological Association, 2008). Medical consent, sexual consent, financial capacities and capacity to live independently are highlighted below.

Medical Consent Capacity – Medical consent capacity involves a variety of healthcare related capacities such as the capacity to consent to medical treatment, the capacity to manage one's healthcare and medications, and the capacity to appoint a healthcare proxy in case of one's incapacity. The capacity to manage healthcare and medications is strongly linked to the capacity to live independently.

The ability to consent to medical treatment involves cognitive "functional" abilities based on four case law standards including "expressing a choice, understanding, appreciation, and reasoning" (American Bar Association Commission on Law and Aging & American Psychological Association, 2008).

Sexual Consent Capacity - Sexual consent capacity requires balancing the rights of individuals to engage in sexual expression with the need to protect the individual as a member of a group that may be vulnerable to abuse (Tang, 2015). The definition of sexual abuse in many states is based on the issue of consent to sex. Legal standards and criteria for sexual consent vary across states and knowledge of an individual's state law is necessary. It is important to note that there are no universally accepted criteria for capacity to consent to sexual relations, and the standards and criteria vary across states. According to the ABA & APA Assessment of Older Adults with Diminished Capacity (2008), "the most widely accepted criteria [for sexual consent], which are consistent with those applied to consent to treatment, are: (1) knowledge of relevant information; (2) understanding or rational reasoning; and (3) voluntariness." Syme and Steele (2016) offer this breakdown of the criteria and questions to consider:

- Does the individual possess the "knowledge" needed to make the decision? This covers areas such as basic knowledge of sexual activities in question, illegal sexual activities, and appropriate times/places for sexual activities present.
- Does the individual display a "reasoned understanding" or demonstrate an ability to take into account relevant knowledge (i.e., nature of the situation) and weigh the risks and benefits of engaging in it

(i.e., appreciate the potential consequences)?

 Does the individual demonstrate "voluntariness" or the ability to make a decision without undue influence or coercion (i.e., autonomy)? This may include the ability to take self-protective measures against coercion when making a sexual decision.

Financial Capacity - Financial capacity is a medical/legal construct meaning the capacity to independently manage one's financial matters consistent with personal self-interest and values. It involves both performance skills such as counting coins/currency, completing a check register accurately, paying bills and using good judgment. It is important to have knowledge of an individual's lifetime values and approach to managing money and finances. More broadly, financial capacity also includes specific legal capacities, such as contractual capacity, donative capacity, and testamentary capacity. Financial capacity is sensitive to medical conditions that affect cognitive and behavioral functioning such as dementias, Parkinson's disease, psychiatric disorders, substance abuse disorders and developmental disorders (American Bar Association Commission on Law and Aging & American Psychological Association, 2008).

Testamentary Capacity – Criteria for testamentary capacity vary across states but according to the ABA & APA Assessment of Older Adults With Diminished Capacity (2008), there are generally four criteria identified including "a testator must have (1) knowledge of what a will is; (2) knowledge of that class of individuals that represents the testator's potential heirs ("natural objects of one's bounty"); (3) knowledge of the nature and extent of one's assets; and (4) a general plan of distribution of assets to heirs." It is important to note that the functional elements of testamentary capacity are almost completely cognitive and to "exercise this capacity, a client must communicate and work with an attorney, which introduces a professional relationship and some element of social discourse into the exercise of this capacity" (American Bar Association Commission on Law and Aging & American Psychological Association, 2008).

Capacity to Live Independently - In most states, the most relevant legal standards for the capacity to live independently are those which are defined in state guardianship law. They may include one or more of the "four tests": 1) a disabling condition; 2) a functional issue and/or the inability to meet essential needs to live independently; 3) a cognitive problem; and 4) a necessity component (e.g., a guardianship is necessary because less restrictive alternatives have failed). In some states, legal guidance relevant to independent living may be provided in the APS statutes (American Bar Association Commission on Law and Aging & American Psychological Association, 2008). The ABA/APA (2008) proposes the assessment of capacity to live independently "requires the integration of understanding what is required to live independently, the functional ability to apply one's knowledge ("application"), and the ability to problem solve and appreciate consequences of potential choices ("judgment"). Additional considerations include if the individual is a danger to themselves due to limited functional abilities and/or cognitive or psychiatric disturbances, and can they comply with the assistance/supports that would allow them to live independently.

Part II: The Relationship Between Capacity and Abuse

Why APS Professionals Need to Understand Capacity

At the heart of APS work is balancing duty to protect the client with their right to self-determination. In

addition, APS should follow the ethical principle of "Do No Harm", because inappropriate or insufficient intervention may be worse than no involvement at all. Discerning if APS clients can make informed decisions about their situations and care is one of the greatest challenges faced by APS caseworkers. The following case example reflects the complexities:

Myrtle Jones, age 75, lives alone and has recently paid \$20,000 to a contractor for repairs on her house. Myrtle's daughter, who lives out of state, claims her mother fell victim to a "scam" contractor who came to the door and told Myrtle she needed a new roof. The daughter also claims Myrtle is missing appointments and has stopped seeing friends. A concerned friend called the daughter recently to report that she stopped by to see Myrtle and she did not open the door. The friend could see garbage piled in the hallway. The daughter is concerned and calls APS.

Fast forward - The APS case worker knocks on Myrtle's door and she refuses to open it. Myrtle says, "she is fine and does not need her daughter and government getting into her affairs." She insists the APS worker leave immediately.

The APS caseworker is concerned but leaves. The caseworker documents the encounter and reports the situation to their supervisor. What does APS do next?

Staffing this case with a supervisor and, potentially an MDT, allows the APS worker to get insights from others and to determine whether a capacity assessment is warranted. Additional visits, potentially with an APS nurse, may help the APS worker establish a relationship and gain access to the home.

APS case workers screen for cognitive impairment when assessing client functioning, safety, and risks. The purpose of screening is to determine if further assessment is required. Assessment and/or evaluation is a more comprehensive process typically requiring specific materials, supervised testing experience, and credentialed professionals.

According to Dr. Holly Ramsey-Klawsnik, "case planning decisions hinge on capacity and APS caseworkers need to understand what mental capacity involves, indicators of cognitive loss, effective strategies for gathering and documenting capacity information, and indicated next steps when clients are in danger due to limited capacity. APS workers must also understand how their state law specifically defines capacity and practice accordingly" (Ramsey-Klawsnik, The Complexities of Cognitive Capacity, 2014).

Demographics

According to U.S. Census Bureau, Population Projections, the number of Americans age 65 and older is projected to nearly double from 52 million in 2018 to 95 million by 2060; a rise from 16 to 23 percent of the total population (Population Reference Bureau, 2020).

Moye and Marson (2007) state, "the prevalence of cognitive aging, dementia, and medical and neurological comorbidities increases dramatically with age. Such cognitive and physical changes are intimately linked with declines in everyday functioning that include loss of decision-making skills." It is estimated 40-50% of persons over the age of 85 have some degree of cognitive impairment, placing them at increased risk for mistreatment (Abrams, et al., 2019). How medical conditions effect decision-making abilities varies across individuals and may affect some aspects of decision making and not others. It is recommended practitioners use a "sophisticated and functionally oriented capacity assessment" (Moye & Marson, 2007).

Additionally, due to advancements in medicine, public policy and advocacy, the life expectancy for persons with intellectual/developmental disabilities (I/DD) has increased significantly. It is projected that by 2030 the number of adults with I/DD aged 60 and older is projected to grow to 1.2 million. In addition, adults with I/DD can experience age-related changes in their mid-forties to mid-fifties, 10-20

years ahead of the general population. These agerelated changes are linked to cognitive and physical functions include Alzheimer's disease and other related dementias, osteoporosis, mobility impairment, types of cancer, and diabetes (Kerins, 2019).

Client Vulnerabilities

Financial Exploitation - Research has found agerelated cognitive impairments such as Alzheimer's disease are highly correlated with financial exploitation and poorer decision-making abilities. It is important to note that cognitive function is an important predictor of decisional capacity, but other factors may also influence these abilities. Lichtenberg et al., (2016) point to Boyle's 2013 work that highlights the fact that financial decisionmaking capacity differs from executional capacity. They state, "in nearly 25% of the couples studied, the person with dementia retained decisional capacity, even in the absence of executional capacity" (Lichtenberg, et al., 2016). This research points to individual differences and the complexities of financial exploitation cases. Thus, to protect the individual's autonomy, APS should not assume that all older adults are at risk for financial scams and theft.

Undue Influence – Undue influence, generally summarized, occurs "when a fiduciary or confidential relationship exists in which one person substitutes his own will for that of the influenced person's will" (Quinn M. J., 2018). Some states define the term, some cite it in probate, criminal or other sections of code. For that reason, it is recommended that APS caseworkers be familiar with how the term is applied in their state laws. Though cognitive deficits can make an individual more vulnerable to undue influence, undue influence and incapacity often occur independent of each other. Psychological manipulation over time is the constant in undue influence cases. The International Psychogeriatric Association Task Force on Testamentary Capacity and Undue Influence, comprised of professionals from the legal, medical and psychological fields identified three areas of risk for undue influence;

- social or environmental risk factors such as dependency, isolation, family conflict, and recent bereavement;
- psychological and physical risk factors such as physical disability, deathbed wills, sexual bargaining, personality disorders, substance abuse, and mental disorders including dementia, delirium, and mood and paranoid disorders;
- legal risk factors such as unnatural provisions in a will, or provisions not in keeping with previous wishes of the person making the will, and the instigation or procurement of a will by a beneficiary.

(Quinn, Nerenberg, Navarro, & Wilber, 2017)

These areas of risk align with the domains and themes identified by Quinn, et al., when developing the *California Undue Influence Screening Tool* (*CUIST*). Based on APS supervisor and caseworker focus group feedback, they identified four domains and related themes if present:

- Vulnerability of the victim. Themes: dependency on others, isolation, and fear.
- Influencer Apparent Authority (the many ways the role of power fits into the process of undue influence). Themes: Authority/power derived from victims' reliance on influencers for professional role, knowledge or direct care.
- Actions or Tactics Used by Influencer. Themes: manipulation, processes over time, and deliberate isolation.
- Fairness of the result or consequences (psychological repercussions and financial losses). Themes: loss of assets, physical harm, neglect, and self-neglect. On the

individual level themes include depression, shame, loss of motivation, and suicidality. (Quinn, Nerenberg, Navarro, & Wilber, 2017)

Self-Neglect – Research has found an association between decline in executive function and cases of self-neglect. Substance use disorders may also play a role in diminishing an individual's ability for selfcare and can contribute to recidivism (Terracina, Aamodt, & Schillerstrom, 2015).

Sexual Abuse – Older adults with sensory impairments, physical frailty, mobility issues, memory and/or cognitive issues are more vulnerable to sexual abuse. According to Tang (2015), "a 2004 study of 120 adults, consisting of sixty individuals with intellectual disabilities and sixty without, found that the intellectually impaired adults were significantly less knowledgeable about almost all aspects of sex and appeared significantly more vulnerable to abuse, having difficulty at times distinguishing abusive from consenting relationships."

Late Onset Intimate Partner Violence (IPV) - "The late onset IPV describes a pattern of IPV that begins in late adulthood and is thought to be related to a) retirement, which may bring on new roles for the couple; b) disability, especially cognitive impairment; and c) sexual changes related to the aging process or cognitive impairment. For example, couples between the ages of 60 and 80 may still be sexually active, but forced/unwanted sex may cause injuries to reproductive tissue and increase the risk for sexually transmitted infections. Also, during this age period cognitive impairment may begin or progress to more obvious changes, resulting in demanding or forced sex from a long-term male sexual partner. In some cases, women who have been victims of long-term abuse by their male partners may become physically abusive toward their frail male partners" (Beach, Carpenter, Rosen, Sharps, & Gelles, 2016).

Part III: Capacity Screening – Cognitive Domains and Screening Tools

An effective APS cognitive screening tool is interviewing, interacting and observing the client during one or more home visits. When possible, assess at times best for the client utilizing multiple methods to "observe and document client statements, appearance, behaviors, home environment, functional abilities, and limitations but avoid premature conclusions or statements regarding the cause of problems observed" (Ramsey-Klawsnik, The Complexities of Cognitive Capacity, 2014).

"Natural assessments" can be less intimidating than brief screening tools, and both methods can be used in conjunction to facilitate rapport as well as to assess needs and supports and cognitive status.

Four basic questions to ask when assessing a client's ability to make informed decisions:

- Does the client understand relevant information?
 Ask – Do you know you have a serious cut on your leg?
- What is the quality of the client's thinking process?
 Ask How can you get treatment for the cut on your leg?
- Is the client able to demonstrate and communicate a choice?
 Ask – Do you want to get treatment for the cut on your leg?
- Does the client understand the nature of their situation (risks and benefits)? Ask – What will happen if you do not get the cut on your leg treated? (National Center on Elder Abuse, 2015)

Standardized screening tools can assist APS caseworkers in determining if a client needs further

assistance from a physician, psychiatrist, psychologist and/or attorney. Capacity assessment scales and tools should not be used alone but as a "package" of observations, interviewing, and assessments. Each tool has its strengths and limitations and it is important that the APS caseworker, if at all possible, not rely on only one assessment tool to determine whether a client needs a professional capacity evaluation.

Generally, there are six domains assessed by capacity assessment scales and screening tools, they include orientation, attention, memory, language, visual-spatial organization and executive functioning.

Clock Drawing Tests (CDTs) - CDTs are brief, costeffective screening tools which provide information on general cognitive functioning such as memory, information processing, visuo-spatial organization, and executive function. They can also offer clues regarding the area of brain change or damage. CDTs vary in the details of their administration and scoring, Royall et al., (1999) states, "the widest variations occur with regard to three aspects: (a) whether a pre-drawn circle is provided; (b) what time is to be set on the clock; and (c) whether the clock is drawn freehand or copied" (Royall, Mulroy, Chiodo, & Polk, 1999). The CLOX (Royall, Cordes, & Polk, 1998) is comprised of two parts, CLOX1 and CLOX2. The CLOX measures "Executive Control Functions (ECFs) or complex goal directed behavior in the face of novel, irrelevant, or ambiguous environmental cues" (Royall, Cordes, & Polk, 1998). The CLOX1 is sensitive to assessing executive function by requesting the individual draw a picture of a clock that says 1:45. The CLOX2 is sensitive to visuo-spatial organization and construction praxis and is a clock copying activity (Terracina, Aamodt, & Schillerstrom, 2015).

Confusion Assessment Method (CAM) – <u>CAM</u> is a standardized evidence-based tool that enables nonpsychiatrically trained clinicians to identify and recognize delirium quickly and accurately in both clinical and research settings. The CAM includes four features found to have the greatest ability to distinguish delirium from other types of cognitive impairment (McCabe, 2019). It can be administered in less than 5 minutes and measure two areas. Part one is an assessment instrument that screens for overall cognitive impairment. Part two includes only those four features that were found to have the greatest ability to distinguish delirium or reversible confusion from other types of cognitive impairment.

Geriatric Depression Scale (Short Form) - The Geriatric Depression Scale (GDS) has been tested and used extensively with older populations. Validity and reliability of the tool have been supported through both clinical practice and research. The Short Form is more easily used by physically ill and mildly to moderately demented patients and it takes about 5 to 7 minutes to complete. It is not a substitute for a diagnostic interview by mental health professionals but is a useful screening tool in the clinical setting to facilitate assessment of depression in older adults; however, it does not assess for suicidality (Greenburg, 2019).

Lichtenberg Financial Decision Screening Scale (LFDSS) – The Lichtenberg Financial Decision Screening Scale (LFDSS), aka, "Financial Decision Tracker," is a brief, 10-item standardized web-based screening scale designed to assess deficits in financial capability and an individual's decisional ability at the point in time when the adult is making a significant financial decision (Lichtenberg, et al., 2016). The tool assesses a client's choice, rationale, understanding, and appreciation of a financial decision in the context of the client's values. It was developed to be used by financial and legal professionals and others such as APS caseworkers investigating potential exploitation. <u>No-cost training</u> and certification are required to use the tool.

Memory Impairment Screen (MIS) - The MIS is a brief four-item screening tool to assess recall memory. It is often used as a preliminary test, along with other screening tools, to evaluate the cognition of someone who seems to display some possible impairment in their ability to think and recall. It is recommended for use with the GPCOG and Mini-Cog in the Medicare Annual Wellness Visit by the Alzheimer's Association. Advantages include: a) it is very brief to administer, b) it does not require the client to write, c) it has consistent results when used in various languages and cultural settings, d) the client's education level does not affect the score, and e) it involves very little training to administer. Disadvantages include: a) it cannot be used with a client with visual impairment or who is illiterate, and b) it does not evaluate executive function or visuo-spatial ability (Heerema, 2020).

Mini Mental State Exam (MMSE®) - The MMSE® is a commonly used screening instrument for general cognition that assesses orientation, memory, concentration, and language. According to the NAPSA Core Competency Module 17, Assessing APS Clients' Decision-Making Capacity, the advantages of the MMSE[®] include, "used by APS programs, psychiatrists, physicians, large normative data with age and education norms, translated into many languages, and it's brief to administer. The disadvantages include it doesn't assess the client's decision-making skills for specific tasks, does not detect mild cognitive impairment or degrees of far advanced cognitive disorders, the results may be influenced by the client's personal characteristics and experiences (e.g., educational background, occupational status, cultural background) and other variables, it can be incorrectly administered and interpreted (e.g., if cutoff scores are used and particularly if the client has low literacy), and it is copyrighted and there is a cost per form" (National Center on Elder Abuse, 2015).

Montreal Cognitive Assessment (MoCA[©]) - The MoCA[©] was developed as a quick screening tool for mild cognitive impairment (MCI) and early Alzheimer's dementia and assesses the domains of attention and concentration, executive function, memory, language, visuo-spatial organization, conceptual thinking, calculation, and orientation. The advantages include: a) it has been tested across a variety of cognitive disorders and in noncognitively impaired older adults as well as tested across age ranges (49-85+ years old) and educational levels, b) it has been translated and tested in multiple languages, c) it has greater sensitivity in the detection of mild cognitive impairment, d) it integrates the clock tests, and e) a modified version, MoCA-B[©], is offered for those with visual impairments, and there is an electronic version (Doerflinger, 2019). The tool takes approximately 10 minutes to administer. Disadvantages include: a) it can take longer and is more complex to administer than other cognitive screens, b) threshold scores may need to be adjusted for client's level of education and adjusted to control for possible over-identification of noncognitively impaired individuals (Doerflinger, 2019). Training and certification to administer and score the MoCA® test is mandatory as of September 2019 to ensure consistency and accuracy.

St. Louis University Mental Status (SLUMS)

Examination – The <u>SLUMS</u> is a brief oral/written method of screening for Alzheimer's and other kinds of dementia. It consists of 11 items that measure orientation, short-term memory, calculations, the naming of animals, the clock drawing test, and recognition of geometric figures. It takes approximately seven minutes to administer. Advantages include: a) simple instructions and administration, b) education corrected norms, c) it covers many cognitive domains, d) it detects mild cognitive problems, and e) it has been <u>translated</u> into various languages. Disadvantages include: a) it

has been less researched for reliability and validity than the MMSE[®], and b) it requires the client to write (Rosenzweig, 2019).

Assessment of Capacity for Everyday Decision-Making (ACED)/Short Portable Assessment of Capacity for Everyday Decision-Making (SPACED) -ACED and SPACED are tools developed to address whether a person refusing an intervention is capable of making this decision (i.e., an informed refusal). The practitioner identifies a functional problem the client is having, and at least one option to solve that problem. They adapt the interview questions according to that functional problem and options. The resulting scores/data are client specific. 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 and can also inform the assessment of complex cases of the "self-neglect syndrome."

Karlawish (2012) highlights the common dilemma faced by APS caseworkers, "whether to respect an older adult's choice to continue a potentially harmful activity or to decline an intervention that might reduce that harm, or, instead, to take action. To help to address this dilemma, staff ought to include an assessment of their client's decisionmaking capacity. The more skilled they are in doing this, they better they can help a client make a decision that respects the client's autonomy" (Karlawish, 2012). ACED was developed to guide a clinical interview, so practitioners require practice and judgement and must be aware of issues with the client's literacy and the level of interviewer/interviewee trust.

The Executive Interview (EXIT25) – The EXIT 25 is a standardized multi-task assessment of executive function comprised of twenty-five tasks that can be administered in APS clients' homes. It takes 10-15 minutes to administer and does not require

advanced training to score and interpret. According to Schillerstrom et al., "tasks include having the client name as many different words as they can think of that start with the letter "A," list the months of the year backward starting from January and respond appropriately to a spontaneous clap. Each item challenges the examinee to go against their habits to solve the task at hand" (Schillerstrom, et al., 2013).

Interview of Decisional Abilities (IDA) – The IDA is a method and training curriculum, including a semistructured interview tool that helps APS caseworkers evaluate the decisional abilities of adult clients. IDA focuses on the client's ability to accept or refuse APS services and can be applied to physical, sexual, or emotional abuse; financial exploitation; self-neglect; and neglect by others. The tool offers a structure to engage clients in a conversation about risk (Abrams, et al., 2019). The interview can be administered at any point in the APS investigation and consists of three main components:

"Pre-IDA" – The APS caseworker selects the risk that presents the most imminent danger for the client from the list.

3 Steps of IDA – During each step the APS caseworker documents phrases and observations that support their judgements/scores.

- The caseworker assesses client understanding of the general problem or risk, determining whether the client acknowledges that the problem exists or has been experienced by others. The client's understanding of the problem is then rated as a "yes," "no," or "maybe." If the rating is firmly "no," the interview may be stopped because the next steps would not apply.
- 2. The caseworker assesses whether the client has personal insight into the risk

discussed in Step 1. This step is administered because it is possible for an individual to understand a problem but deny that the problem applies to themselves. The client's appreciation is rated as a "yes," "no," or "maybe."

3. The caseworker assesses the client's ability to reason. The client is asked if they have a plan to address the risk. Or, the worker may propose a plan, especially in cases where the client has not demonstrated insight in the previous step. The APS worker inquires, separately, about the advantages and disadvantages of the plan, without attempting to persuade. This step is then scored as "yes," "no," or "maybe".

"Post-IDA" – The APS caseworker indicates the future direction of the decisional abilities assessment. Often the next step will be a case review with an APS supervisor. Referral for formal capacity assessment will be determined with a supervisor based on the complete APS assessment, the severity of risk, and the worker's judgments and supporting documentation on the IDA. (Abrams, et al., 2019)

The training curriculum and tool have been piloted with New York City APS, Massachusetts APS, and select counties in California. The tool is currently undergoing testing; no psychometric data is available to date.

Part IV: Research on Capacity Screening

Executive Function and Recidivism

In a study by the University of Texas Health Science Center at San Antonio (UTHSCSA) and Texas APS, researchers conducted a retrospective medical record review of APS clients referred to the UTHSCSA Department of Psychiatry for decisionmaking capacity assessments over four years. They found the "proportion of cases referred for capacity assessment that were recidivistic was higher (at 60%) than the baseline for the region studied (at 13.5%). They also found that both recidivistic and non-recidivistic cases had poor cognitive performance across multiple domains but recidivistic clients performed significantly worse on measures of executive function and were more likely to carry a dementia diagnosis" (Terracina, Aamodt, & Schillerstrom, 2015).

The authors cited the following observations and APS practice implications:

- There is a disproportionately high prevalence of older adults referred by APS for decisionmaking capacity assessments with executive function impairments compared to other cognitive domains.
- APS caseworkers appear more sensitive to memory, concentration, and orientation impairments than they are to executive function deficits. Though executive function deficits greatly affect self-care abilities.
- There is a large cost to investigating repeat alleged victims of abuse, neglect, or exploitation. Identifying risk factors for recidivism could significantly decrease caseloads, cost, and suffering.
- Executive function deficits may diminish APS clients' abilities to utilize least restrictive interventions offered by APS, predisposing them to recidivism.
- Identifying risk factors for recidivism, such as executive function impairments, may help target appropriate client interventions and supports to decrease reoccurrences.

(Terracina, Aamodt, & Schillerstrom, 2015)

Capacity Screening in Adult Protective Services: Guidance and Resources.

Research to Practice Highlight: Michigan APS and Wayne State University, Institute of Gerontology – The Intersection of Financial Decision-Making and Financial Exploitation

On February 13, 2020, the NAPSA Research to Practice Interest Group hosted a webinar entitled, <u>New Findings</u> <u>in the Intersection of Financial Decision Making and Exploitation: Results from Michigan APS and the SAFE</u> <u>Program</u>. Presenter Dr. Peter Lichtenberg highlighted the partnership between Wayne State University, Institute of Gerontology and Michigan APS to 1) cross-validate the Lichtenberg Financial Decision Screening Scale (aka Financial Decision Tracker) and 2) provide training and certification to APS supervisors and caseworkers on administering, scoring and using the scale for statewide implementation. To date, the partnership has been fruitful for both research and practice and provided opportunities to change and adapt the scale for more practical use in the field as well as identifying gaps in knowledge and training for appropriate, uniform tool administration.

Over 400 caseworkers have been trained and certified and 700 plus *Lichtenberg Financial Decision Screening* (aka Financial Decision Tracker) scales administered (Lichtenberg P., 2019). Responses from interviews with Michigan APS caseworkers who have been trained and certified to use the scales are overwhelmingly positive. One caseworker was able to save a client over one million dollars, another shared it helped them ask all the questions they need to cover with a client, and another shared it helped them communicate with other professionals.

From the data gathered from the scale to date, the top five financial decisions made by an older adult that prompted APS involvement including gifting of money, a big ticket purchase, giving money to a scammer, allowing access to personal accounts, and having someone take over finances (Lichtenberg P., 2019). Based on the same collaboration with Michigan APS, Campbell et al. (2019) found out of 105 APS cases, workers determined that 61% (n = 64) of the cases had substantiated financial exploitation; the remaining cases did not. Thus, substantiated cases had significantly higher risk scores than non-substantiated cases (Campbell, Gross, & Lichtenberg, 2019).

Additionally, another research to practice program is <u>SAFE (Successful Aging thru Financial Empowerment)</u>, offered by the Institute on Gerontology, Wayne State University in Detroit based on a program at the Lifespan Program in Rochester, New York. The program has four goals, including: 1) educating older adults on finances and financial management; 2) disseminating fraud and identity theft information to older adults and professionals serving older adults; 3) providing one-on-one services to older adults who are fraud or identity theft victims; and 4) determining if those older adults seeking services are more psychologically or cognitively vulnerable than those who are not financially exploited. In approximately two years, SAFE has provided one-on-one services to over 100 older adults and education to nine thousand older adults and professionals. The data on those SAFE participants suggest there is an important interconnection between fiscal, physical, and mental health and professionals working with older adults need to be mindful in screening and assessments. The data also suggested older clients who cannot resolve their credit or other financial issues demonstrated reduced cognitive and mental health functioning (Lichtenberg P., 2019).

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Conclusion

As Quinn et al., (2017) states, "there is no single, universally accepted assessment or screening tool that satisfies APS needs for detection of cognitive impairment." Additionally, there has not been a study or survey on which capacity screening tools are currently being used by APS programs nationally. One can surmise anecdotally from a review of the literature, APS caseworkers are using a variety of tools, both standardized and nonstandardized, and there may be APS programs that do not use any tools in their investigation and case planning.

What is clear is there are obstacles to the use of capacity screening tools which warrant further research and discussion. These obstacles appear to include knowledge of tool availability, training to administer tools appropriately, costs related to training and/or administration of tools, and the use of standardized versus non-standardized tools. Further research and discussion are needed to develop a consensus on "principles of practice" for APS capacity screening tools. Such principles may include a better understanding of how tools can enhance caseworker judgement, training requirements so that tools are administered correctly and for their intended purpose, and requirements for testing of tools, to name a few.

Training Resources: Adult Protective Services Workforce Innovations (APSWI)

- <u>APS Core Assessing Client Capacity</u> <u>Instructor-Led Training</u>
- <u>APS Core Assessing Client Capacity</u> eLearning
- Undue Influence eLearning Mini-Module
- <u>Undue Influence Committed by</u> <u>Professionals eLearning</u>

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References

- Abrams, R. C., Ansell, P., Breckman, R., Karlawish, J., Lachs, M., Holt-Knight, D., . . . LoFaso, V. (2019). The Interview of Decisional Abilities (IDA): a tool to assess the decisional capacity of abused and neglected older adults. *Journal of Elder Abuse and Neglect*, 244–254.
- Administration on Community Living. (2016). Final Voluntary Consensus Guidelines for State Adult Protective Services Systems. Washington, D.C.: Administration on Community Living, U.S. Department of Health and Human Services.
- Administration on Community Living, (2019). National Adult Maltreatment Reporting System (NAMRS). Retrieved from Administration on Community Living: https://acl.gov/sites/default/files/programs/2019-12/2018%20Adult%20Maltreatment%20Report%20-%20Final%20v1.pdf
- American Bar Association Commission on Law and Aging & American Psychological Association. (2008). Assessment of Older Adults With Diminished Capacity: A Handbook for Psychologists. Retrieved from American Psychological Association: https://www.apa.org/pi/aging/programs/assessment/capacity-psychologist-handbook.pdf
- APS Technical Assistance Resource Center. (2019). An interview with Bill Benson about funding sources for Adult Protective Services. Retrieved from APS Technical Assistance Resource Center: https://apstarc.acl.gov/APSTARC/media/APSTARC/InterviewswithExperts-APSFunding.pdf
- Beach, S. R., Carpenter, C. R., Rosen, T., Sharps, P., & Gelles, R. (2016). Screening and detection of elder abuse: Research opportunities and lessons learned from emergency geriatric care, intimate partner violence, and child abuse. *Journal of Elder Abuse and Neglect*, 185-216.
- Brown, K. (2019). APS Leadership Development Framework: APS Leadership Development Plan. Oakland: n/a.
- California Department of Social Services. (2018). Grants to Enhance State Adult Protective Services HHS-2018-ACL-AOA-EJSG-0265: Administration for Community Living. Sacramento: CDSS.
- Campbell, R. J., Gross, E., & Lichtenberg, P. A. (2019). Cross-validation of the screening scale in an adult protective services sample. Journal of Elder Abuse and Neglect, 25-37.
- Choi, S. K., & Meyer, I. H. (2016, August). LGBT Aging: A Review of Research Findings, Needs, and Policy Implications. Retrieved from The National Resource Center on LGBT Aging: https://www.lgbtagingcenter.org/resources/resource.cfm?r=825
- Dastidar, J. G., & Odden, A. (2011, August). How Do I Determine if My Patient has Decision-Making Capacity? . Retrieved from The Hospitalist: https://www.the-hospitalist.org/hospitalist/article/124731/how-do-i-determine-if-my-patient-has-decisionmaking-capacity
- Doerflinger, C. (2019). Mental Status Assessment in Older Adults: Montreal CognitiveAssessment: MoCA@ Version 8.1. Retrieved from Try This: Best Practices in Nursing Care to Older Adults: https://consultgeri.org/try-this/general-assessment/issue-3.2.pdf

Falk, E., & Hoffman, N. (2014). The role of capacity assessments in elder abuse investigations. Clinics in Geriatric Medicine, 851-868.

- Ganzini, L., Volicer, L. N., & Fox, E. a. (2004). Ten Myths About Decision-Making Capacity. American Medical Directors Association, 263-267.
- Greenburg, S. A. (2019). The Geriatric Depression Scale (GDS). Retrieved from Try This: Best Practices in Nursing Care to Older Adults: https://consultgeri.org/try-this/general-assessment/issue-4.pdf
- Heerema, E. (2020, January). An Overview of the MIS (Memory Impairment Screen). Retrieved from Very Well Health: https://www.verywellhealth.com/what-is-the-mis-memory-impairment-screen-98642

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Screening Decision-Making Ability

Time: 45 minutes

Associated Objective: Assess self-neglect in five domains

Method: Lecture, discussion, and chat (if virtual), breakout groups

SLIDE #26: Decision-Making Capacity



<u>**Trainer note:**</u> Slide is animated to hide the definition until after you have briefly discussed the importance of screening for decisional capacity.

Ask: By a show of thumbs up/down how many of you have been asked about a client's "capacity" in terms of if they have it or not to make a certain decision such as live alone, refuse a caregiver, or sign a will?

Explain:

Decision-Making **Capacity**, also referred to as decisional capacity, is a complex concept and can only be determined after completion of a comprehensive assessment by a qualified professional. A legal judgement of "incapacity" could have lifelong implications and is viewed as the most restrictive.

For APS professionals working with clients who have not had a professional capacity evaluation, the term "**ability**" should be used instead of capacity. For example, "I have concerns with the client's ability to make informed decisions", or "I have concerns with the client's ability to understand consequences of decisions".

People are assessed or screened for making decisions on specific tasks, so we should be looking at each task or type of decision individually:

- Medical Consent;
- Sexual Consent;
- Financial;
- Testamentary

• Ability to Live Independently

Remind participants that we are not legally determining capacity, but we can indicate and document if, in our opinion, a client has decision-making *ability* or not based on our conversations, observations, and corroborating information.

In documenting our opinion on decision-making ability, **encourage** participants to use the word "appears" and carefully document what they heard or saw that lead to that opinion.

Share that this training is a foundational training on self-neglect which incorporates many factors and only touches on concepts of decisional capacity and decision making abilities. However, there are entire trainings on screening for decision-making ability for those who are interested in a deeper understanding. Academy for Professional Excellence, Adult Protective Services Workforce Innovations has such trainings: https://theacademy.sdsu.edu/programs/apswi/.

SLIDE #27: Ability



Explain that APS professionals need to know if our clients are capable of living and functioning safely in their current environment. This slide lists some of the activities and decisions that we need to assess.

<u>**Trainer notes</u>**: 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 to the red flags, it is strongly encouraged to highlight a few behaviors that might show a client's decision-making ability strengths.</u>

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.

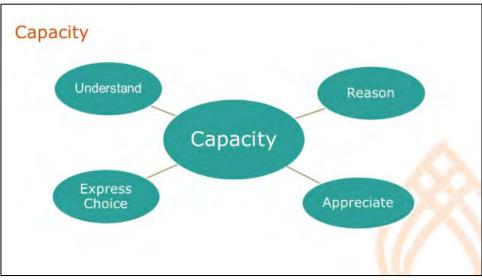
Ask: What red flags have you seen in your work that caused you to wonder about a client's decision-making ability?

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

Remind participants that the term "capacity" and decision-making ability is not a one-size fits all and will impact people differently. A lack of decision-making ability may impact clients' lives differently based on who they are, what the possible cause of the ability 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.

SLIDE #28: Capacity



Explain that when screening for decision-making ability, 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

Remind participants of the right to self-determintation. All four of these components help APS assess if the person has the ability to make decisions, even if the decisions are ones that might put someone at risk. It's important to listen for their reasoning behind a choice, as this may provide some insight APS may not have thought of.

Review HANDOUT #6-Dimensions of Capacity and **HANDOUT #7-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 framework to other kinds of decision-making.

Handout #6 – 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 #7 – Capacity for Medical Treatment

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

SLIDE #29: Executive Function

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).



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 #30: Enhancing Decisional Ability

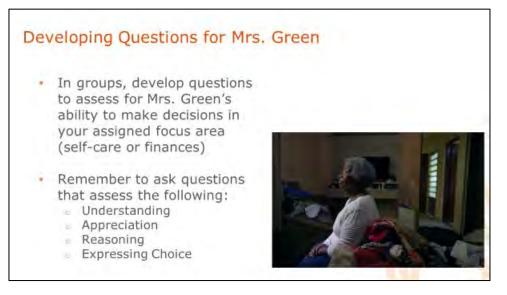


Sometimes clients' ability to understand can be improved through simple measures including:

- Determining when they're at they perform at their best and encourge decisions be made during those times
- Help secure assisitve devices, such as communication assistance, information in a language they prefer, etc.
- 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.

SLIDE #31 : Developing Questions for Mrs. Green



Now, let's practice screening a client for their decision-making ability. This exercise will give you practice in framing questions to help you screen for clients' ability to perform important tasks. Please refer to the **Handout #8**- Case Study of Mrs. Green in your Participant Manual.

Activity #5: Mrs Green: Assessing Capacity (25 min total with 15 minutes for breakout and 10 minutes for group discussion)

Breakout groups

<u>Trainer note</u>: Half of the participants will be working on self-care and the other half working on finances. Whether in-person or virtual, divide class up into small groups and ensure each group knows which area of focus they're working on.

Instructions:

- 1. Direct the participants to go to Handout #8- Case Study of Mrs. Green.
- 2. **Divide** the group into small groups
- 3. Ask each group to assign a note-taker and reporter.
- 4. Assign each group to assess Mrs. Green's ability to provide **self-care** OR to assess Mrs. Green's ability to manage her **finances**.
 - a. Note, there will be multiple groups working on the same focus area
- 5. **Inform** participants they will have 15 minutes to develop a list of questions that they would want to ask Mrs. Green to determine if she has the ability to make decisions using understanding, appreciation, reasoning, and expressing a choice in their focus area (self-care or finances).
- 6. After 15 minutes, debrief with the groups:

a. Ask each group's reporter to share a couple of questions they developed.

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).

Handout #8 – Case Study: Mrs. Green

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 Bruce 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.

Challenging Factors When Working with People Experiencing Self-Neglect

Time: 15 minutes

Associated Objective: N/A

Method: Lecture, discussion, and chat (if virtual)

Slide #32: Challenging Factors in Self Neglect



<u>**Trainer note</u>**: The hoarding and substance use slides are meant to be kept high level/introductory concepts as they can be standalone trainings.</u>

Explain: As you have been learning, self-neglect cases encompass a wide range of situations and factors. All of which can have their challenges, some more than others.

It may feel like there are constant challenges you face when assessing these types allegations.

The next few slides will touch on a few specific challenges that you may encounter when working with clients who are experiencing self-neglect.

SLIDE #33: Working With Clients Who Are Hesistant



Explain: Clients who experience self-neglect and decline 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 declining what we think might improve their safety and well-being.

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, person-centered approach. We will spend the next portion of the training summarizing various methods available for working with these clients.

Ask: Before we move on to the next slide – what are some reasons you think may cause some of our clients to be hesitant to accept services?

SLIDE #34: Reasons People May Refuse Help



<u>**Trainer note</u>**: this slide is animated to first ask some questions and the reveal possible answers. Acknowledge those answers already provided by participants.</u>

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

For the following questions, **spend** some time here encouraging participants to shout out or put their answers into chat. **Validate** and process some/all of their responses.

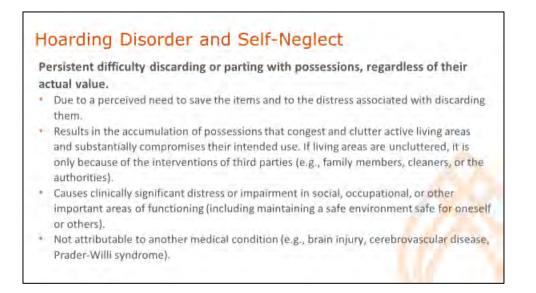
- 1. What cultural factors may contribute to clients declining help?
 - Answers may include: prevoius mistreatment from various providers or agencies, documentation status, sense of shame within cultures that have expectations for children taking care of parents, lack of knowledge about services, don't want to contribute to stereotypes, fear of government, patriarchal family systems, generational differences, desire to keep "family matters" private, immigration status, etc...
- 2. What are other general reasons that may cause people to decline services?
 - Answers may include: Neurocognitive Disorders,
 - Anxiety
 - Grief
 - Depression
 - Lack of insight

- Behavioral Health
- Shame

Explain: Often clients are self-protective and it's up to APS professionals to try and demonstrate to them that the programs and resources we can offer to them are better than their current situations.

Encourage participants to look back at this portion of the training when they're in the field and feeling frustrated or disheartened if their clients do not want APS intervention. Remember that adults have the right to refuse APS services. However, even if they turn you away, reassure them that they can always contact you or your agency if they change their mind or find that they want/need assistance in the future.

SLIDE #35: Hoarding Disorder and Self-Neglect



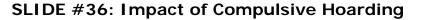
Explain: Another challenging factor that you may come across is hoarding.

Share that compulsive hoarding disorder is very complex and effective treatment goes far beyond simply cleaning up the environment. The topic of hoarding is typically a whole training in and of itself. Today, we are only going to spend a few minutes providing a higher level overview of hoarding and its intersection with self-neglect.

Explain: In the Diagnostics Study Manual 5 (revised version) published in 2022, hoarding disorder went from being a characteristic of obsessive compulsive disorder to being recognized as a distinct condition with its own criteria and treatments. 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 and maintain a safe environment.

Highlight the following key factors in the definition on the slide:

- Persistent difficultuy discarding or parting with possessions regardless of their actual value.
- Distress associated with discarding them.
- The accumulation of possessions that congest and clutter active living areas, substantially compromises that area's intended use.
- Causes significant distress or impairment in at least one important area of functioning.





Explain: Compulsive hoarding affects over 3 million Americans. 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.
- By family members coming for a long overdue visit, mail carriers, neighbors, or first responders.

Regardless of how it is brought to the attention of us or others, hoarding can create a serious health and safety condition for older adults and adults with disabilities and consequences can be very severe.

- It can result in death if the home poses a fire hazard or homelessness if the person is evicted.
- It can pose a fall risk for those whose mobility is already compromised or create barriers for them to access their basic needs if they are unable to use or access their bathrooms or kitchen.
- Some persons who hoard experience intense shame and depression.
- Many also lack insight into the safety hazards, risks and consequences that their hoarding behavior can incurr.

Explain: The issue of hoarding is not new, it has always been around but has become the focus of attention in recent years, with social media and television shows. Research into the causes of hoarding continues but it exists across all countries, cultures, race, socio-economic, and education levels.

The good news is that the increased visibility has contributed to more credibility and prompted the development of more research and treatment.

We will talk about interventions in a later slide.

SLIDE #37: Substance Use Disorder and Self-Neglect



Explain: Another challenging factor that we will discuss is those clients experience self-neglect is linked with a substance use disorder.

Whether it be prescription medications, alcohol, or illicit substances; substance use disorder can only amplify the health and safety risks that already exist in the aging or disabled adult population.

Again, we will talk about treatments specific to this population next.

Treatment Techniques and Modalities

Time: 30 minutes

Associated Objective: Describe promising techniques for working with adults experiencing self-neglect

Method: Lecture, discussion, and chat (if virtual), video demonstration

SLIDE #38: Overview of Available Approaches



<u>**Trainer note</u>**: Since this next section is a general overview to introduce the participants to various techniques and treatments, the following few slides should just be brief, high level overviews. APS Professionals can keep all of these in mind during their interviews and assessments and when developing a collaborative service plan.</u>

Explain that each approach or treatment that we'll be discussing can be all day or even week-long trainings on their own.

For the purpose of this training and APS's role, we'll summarize the concepts of motivational interviewing, substance use treatment and hoarding treatment. Participants can use some key takeaways in their practice and/or refer clients to resources that specialize in these treatments or approaches.

Share that as with all APS interventions, treatments and approaches will vary depending on the person, their situation and resources available.

It's up to APS to know what is out there and when and why to practice an approach or offer resources.

SLIDE #39: Motivational Interviewing



One of the most effective methods of engaging hesitant clients is Motivational Interviewing, which is "a directive, client centered counseling style for eliciting behavior change by helping clients to explore and resolve ambivalence".

<u>**Trainer Note</u>**: 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.</u>

Explain: MI 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. It is NOT a technique that is used with every client, every time. 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 #40: Core Concepts of Motivational Interviewing (MI)



<u>Trainer note</u>: This slide is animated in order to spend time on each principle.

For each principle, briefly demonstrate with the participants how to use that skill in APS work with the examples provided.

This should be short, to give practical application in APS work.

Share: There are four general principles behind Motivational Interviewing.

Express Empathy

- Empathy involves attempting to understand how the other person experiences the world, 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 of Expressing Empathy:

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

<u>APS Professional expresses empathy</u>: "Yes, that makes sense. I would likely be frustrated as well."

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 they 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 of Supporting Self-Efficacy:

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

<u>APS Professional expresses self-efficacy</u>: "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. T
- 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 of Rolling with Resistance:

<u>Client</u>: "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."

<u>APS Professional rolls with resistance</u>: "I'm glad you shared that with me and that's understandable. 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 of Developing Discrenpancy:

<u>Client</u>: "I just can't 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."

<u>APS Professional develops discrepancy</u>: "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 #41: Decisional Balance Worksheet

| Good things about behavior: (what's working for you with this behavior?) | Good things about changing behavior: (what are some benefits if the behavior changes) | |
|---|--|--|
| Not so good things about behavior: (what's not working for you with this behavior?) | Not so good things about changing behavior: (what might some challenges be if behavior changes?) | |

To move clients through the stages of change, motivational interviewing asks the client to consider the good and bad things about their current behavior and the good and bad things about changing this same behavior. The APS professional needs to ask the client about what's working and not working with their current behavior and about the potential benefits of changing their behavior.

Trainer note: For this activity, 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 ahead of training, 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=RBCo4UBOliU&feature=youtu.be.

Activity #6-VIDEO: Self-Neglect Initial Home Visit (7 minute video clip, 5 minute discussion)

Individual and large group discussion

Instructions:

1. Refer participants to the Decisional Balance Worksheet on the slide and give an overview of the layout of the slide.

- 2. Inform them that the 7 minute video clip will be played that shows a Successful Intial Home Visit and then they will work individually to fill out a Decisional Balance Worksheet.
- 3. Play video.
- Ask participants to take 3 minutes to fill out their worksheet from the perspective of the client in the video specifically about his decision/behavior to not take his medication or follow a diet that was suggested.
- 5. Ask for volunteers to report out what they captured for each section of the worksheet.

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

The result might look like this:

Handout #9 – Decisional Balance Worksheet

| Good things about behavior: | Good things about changing behavior: |
|------------------------------------|---|
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Now we are going to turn our attention back to substance use disorders and the options for treatment that are available.

Review the treatments on the slide.

- 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 messsages learned in treatment (Alcoholics Anonymous) or Peer Support.
- Harm Reduction "incorporates a spectrum of strategies that includes safer use, managed use, abstienence, meeting people who use drugs "where they're at" and addressing conditions of use along with the use itself (National Harm Reduction Coalition, 2020)

Explain that these treatments may be effective with older adults and adults with disabilities but there also may be challenges.

• **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.
- Programs may not be able to accommodate their needs (i.e.: limited mobility, incontinence, etc.).

Knowing your community resources and working with community partners may be the key to find specialized services that can meet the specific needs of the APS client population.

SLIDE #43: Treatment for Hoarding



Ask "What interventions might work with people living with a hoarding disorder?"

Treatments that have been determined to be effective include one or more of the following: Pharmacotheraphy, Cognitive Behavioral Therapy, BT, and Intensive Treatment, Intensive Multimodial Treatment, harm reduction, support groups, and peer to peer support.

Because people who living with a hoarding disorder have often experienced trauma, simply throwing their stuff out in a forced clean-up, can be extremely traumatizing and likley not provide long-term solutions.

Searching for "hoarding resources" on the internet, can provide you with many community based Hoarding Task Force Committees, support groups, treatment programs, and professional training opportunites.

Determining Appropriate Interventions

Time: 40 minutes

Associated Objective: Identify safety and risk reduction interventions for adults experiencing self-neglect

Method: Lecture, discussion, and chat (if virtual), breakout groups

SLIDE #44: 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?" Participants can type in the chat or unmute themselves.

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 and decision-making ability
- Are there supportive decision-makers in their life

Remind participants of the ethical issues raised by self-neglect, most notably, safety versus right to self-determination.

SLIDE #45: Types of Interventions



A wide range of services may be helpful in helping adults who self-neglect.

Refer the participants to **HANDOUT #10- 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.

<u>**Trainer note</u>**: 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. Be mindful of time and provide overviews if needed.</u>

Handout #10 – 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 verses 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
- **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 organizataions offer a friendy 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 2 of 3 r 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.

- **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 #46: Social Support/ Supportive Services



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 socializiation elder abuse interventions for older adults. The "evening walk" in the community has to return" (Acierno & Hernandez-Tejada, 2018).

Support services help people who are not able to meet their own self-care needs. The list on the slide is just a few of the many and varied services that may be available.

When clients decline help and risk remains, APS professionals may attempt to arrange for services or engage a client's support system to ensure that they have help and can access when they need it.

Ask: What are some resources in your community that might be able to provide formal or informal support and check-ins on your clients after APS your case is closed?

Answers might include: meals on wheels, friendly visitor, senior centers, case management services, home health.

It is important that APS professionals be aware of resources in their communities that can meet the needs of their clients on all levels.

SLIDE #47: 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.

Ask participants how they find out about local mental health services to refer clients to (online and in-person).

Share that there might be groups or peer to peer support that are specific to older adults or adults with disabilites. Geratric specialists or physicans may have referral recommendations.

SLIDE #48: Involuntary Interventions



Involuntary interventions are only used when the client does not understand the risks they face AND the risk is high AND all other least restrictive options have been explored.

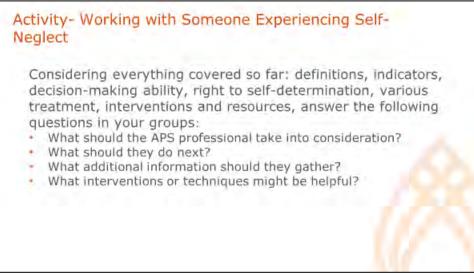
Appointment of representatives may involve going to court to ask for authority (e.g. under a conservatorship) or "activating" an advance directive like a durable power of attorney. The process and criteria depends on the instrument. For example, clients may have previously indicated that a durable power 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 severe 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
- "Activating" 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)
- Revokation of driver's license

SLIDE #49: Responding to Someone Experiencing Self-Neglect



<u>**Trainer note:**</u> Handout #11A has possible answers for you as the trainer. Handout #11b is the Participant Copy.

Activity #7: Working with Someone Experiencing Self-Neglect (30 minutes total: 15 minutes in breakout room and 15 min debrief in large group) Breakout groups

Breakout groups

Explain that we are going to take everything we have learned so far (the definition of self-neglect, indicators, decision-making ability, right to self-determination, various treatment, interventions, resources) and apply it in a case study.

Instructions:

- 1. Refer participants to Handout #11b.
- 2. Divide groups into breakout groups (3-4 per group)
- 3. Assign each group one of the following two cases: John Sumner or Paula Albertson
- 4. 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, apply lessons learned from content in today's training and try new skills.
- 6. Once in breakout groups, provide an alert that they have 3 minutes left.
- 7. After 15 min, Reassemble the groups.

- 8. Ask a representative from each group to describe the group's discussion, calling on other groups with the same scenario to add.
- 9. Allow 15 minutes for discussion and point out differences in how the groups working with the same client approached their clients.

Handout #11A – SELF-NEGLECT CASE STUDIES (Trainer 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, what interventions or techniques might be helpful?)

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 (urgency/severity). 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.

CASE #2 Paula Albertson

Paula Albertson called the fire department about a kitchen fire. When the firefighters arrived, they found Paula 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 Ms. Albertson had similar incidents over the past few months. When Trudy went to the hospital ER to talk to Paula, she was told that she'd felt better and left. The next day, Trudy visited Paula in her home. When she expressed concern about the incident Paula insisted that it was the medication her doctor had given her and that she had thrown it away. With Paula'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 Paula had had several falls and on one occasion had been on the floor for several hours before the mailcarrier 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, what interventions or techniques might be helpful?)

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 #11B – 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, what interventions or techniques might be helpful?)

CASE #2. Paula Albertson

Paula Albertson called the fire department about a kitchen fire. When the firefighters arrived, they found Paula 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 Ms. Albertson had similar incidents over the past few months. When Trudy went to the hospital ER to talk to Paula, she was told that she'd felt better and left. The next day, Trudy visited Paula in her home. When she expressed concern about the incident Paula insisted that it was the medication her doctor had given her and that she had thrown it away. With Paula'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 Paula had had several falls and on one occasion had been on the floor for several hours before the mailcarrier 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, what interventions or techniques might be helpful?)

Documenting Self-Neglect

Time: 10 minutes

Associated Objective: Demonstrate an understanding of the elements to document in self-neglect cases

Method: Lecture, discussion, and chat (if virtual)

SLIDE #50: Importance of Good Documentation



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

Documentation is used for:

- Reasons for determining case findings
- Continuity of care
- Explanations as to why certain interventions were or were not offered
- 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 questioned by licensing boards or professional associations

Activity #8- Documenting (5 min or only if time permits)

Large Group

Refer the class back to their case studies in **HANDOUT #11b** 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 #12-Documentation in Self-Neglect** for more information on what to document.

Handout #12 – 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 assualt).
- 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

1 of 2

- Client's stated reasons for refusing services
- 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
- Lifestyle

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.

Direct quotes by client that might be relevant to their degree of insight or decision

Partners in Self-Neglect

Time: 5 minutes

Associated Objective: Identify community partners to work with in self-neglect cases

Method: Lecture, discussion, and chat (if virtual)

SLIDE #51: 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 with a community partner was able to help mitiagate risk in a case where someone was experiencing self-neglect. Write in that example below:

Ask the participants to name their community partners and to provide examples of the roles that these professionals can play via the chat box.

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

Refer to **HANDOUT #13- Community Partners In Self-Neglect Cases** in the Participant Manual and cover any community partners they may have missed.

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 experiencing self-neglect 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 experienced self-neglect in a number of jurisdictions were being targeted by a scammer and giving away large sums of money. (Different agencies had various pieces of the puzzle.)

Handout #13 – Community Partners in Self-Neglect Cases

| Professional, entity or group | Role in self-neglect cases |
|--|---|
| Mental Health professionals, including county geriatric mental health program personnel or professionals in private practice (geriatric psychologists, psychiatrics, etc.) | Can assess clients' mental status Can arrange for psychiatric hospitalization under W&I Code §5150. Can diagnose and treat depression and other mental conditions |
| Geriatric physicians and nurses | Can diagnose, assess and treat medical conditions Can complete medical declarations (doctors) for conservatorship Can review medical records and distinguish injuries from effects of aging and disease |
| Conservators, including private professionals | • Can file for and provide conservatorship services |
| Public Guardians | • Can file for and provide conservatorship services |
| Clergy | Can provide emotional and spiritual support to clients Can provide or arrange for informal support services |
| Local law enforcement, including police and sheriffs | Can assist with well-being checks, psychiatric hospitalizations, protective custody, freezing assets |

| Animal Welfare Organizations (municipal animal care and control) agencies, humane societies, SPCAs and rescue organizations | Can provide information and assist with finding homes for animals Can make home visits to check on the welfare of the animals in the home |
|---|---|
| Ethics Committees (most are convened by hospitals and nursing homes) | Can identify and address ethical issues raised in self- neglect cases |
| Multidisciplinary teams, including elder abuse multidisciplinary teams and death review teams | Can provide suggestions for interventions Provides a "checks and balances" to ensure that all multiple options and points of view are considered Can ensure that workers' actions reflect community standards of practice |

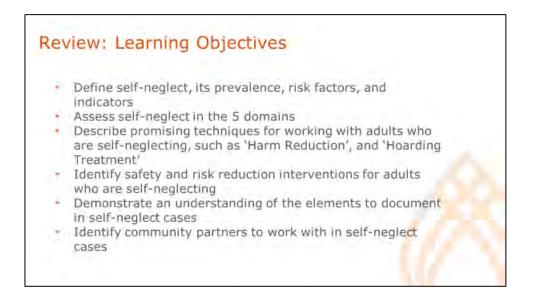
Course Wrap Up and Evaluations

Time: 15 minutes

Associated Objective: N/A

Method: Discussion, and chat (if virtual)

SLIDE #52: Review



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

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 group (or all participants if time allows) state out loud or in chat box what they wrote down.

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



SLIDE #53: 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.

Slide #54: Thank You!



REFERENCES

The work below influenced the material for the original or revised curriculum.

- Academy for Professional Excellence. (2018). APS Training Video: Successful Initial Home Visit [Video]. Adult Protective Services Workforce Innovations. Retrieved from <u>https://www.youtube.com/watch?v=RBCo4UBOliU&list=PLTkfyRcpER10MW7Qe4</u> <u>OB8mJGXEcBCD719&index=2</u>
- Acierno, R., Hernandez-Tejada, M., (2018). Protection Through Connection: Social Support as a Key Intervention & Prevention Component in Elder Abuse [PowerPoint slides]. Retrieved from <u>https://eldermistreatment.usc.edu/education/usc-tamkin-international-</u> <u>symposium-on-elder-abuse/presenter-slides/</u>
- Administration for Community Living. (2021). Adult Maltreatment Report 2021, National Adult Maltreatment Reporting System. Retrieved from <u>https://namrs.acl.gov/Data/Adult-Maltreatment-Reports/2021-Adult-Maltreatment-Report.aspx</u>
- Adult Protective Services Technical Assistance Resource Center (APS TARC). (2020). Capacity screening in Adult Protective Services: Guidance and resources. Administration for Community Living. <u>https://apstarc.acl.gov/getattachment/Education/Briefs/CapacityScreeningBrief.</u> <u>pdf.aspx?lang=en-US</u> accessed from https://apstarc.acl.gov/Education/Briefs.aspx.
- American Medical Association. (1999). Health literacy: Report of the Council on Scientific Affairs. Journal of the American Medical Association 281(6), 55-557. (PDF).
 http.jama.ama-assn.org/cgi/reprint/281/6/552.
- Aung, K., Burnett, J., Smith, S.M., & Dyer, C.B. (2006). Vitamin D deficiency associated with self-neglect in the elderly. *Journal of Elder Abuse Neglect*, *18* (4), 63-78.
- Badr, A., Hossain, A., & Iqbal, J. (2005). Diogenes syndrome: When self-neglect is nearly life threatening. Clinical Geriatrics, 13 (8), 10-13. <u>http://epublications.marquette.edu/cgi/viewcontent.cgi?article=1284&context=mulr</u>

- Beach, S.R., Liu, Pi-Ju, DeLiema, M., Madelyn, I., Howe, M., Conrad, K. (2017)
 Development of short-form measures to assess four types of elder
 mistreatment: Findings from an evidence-based study of APS elder abuse
 substantioation decisions, *Journal of Elder Abuse & Neglect, 29:4*, 229-253,
 DOI: 10.1080/08946566.2017.1338171
- Bradshaw, D., & Spencer, C. (1999). The role of alcohol in elder abuse cases. In J. Pritchard (ed.), *Elder abuse work: Best practice in England and Canada* (pp. 332-353). London, Eng.: Jessica Kingsley.
- Burnett, J., Coverdale, J. H., Pickens, S., & Dyer, C. B. (2006). What is the association between self-neglect, depressive symptoms and untreated medical conditions? *J Elder Abuse Negl*, *18*(4), 25-34.

Dong, X., Simon, M., Mendes de Leon, C., Fulmer, T., Beck, T., Hebert, L., et al. (2009).

Elder self-neglect and abuse and mortality risk in a communitydwelling population. *Journal of the American Medical Association 302*(5), 517-526.

- 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.
- Duke, J. (2003). *Investigating self-neglect*. Richmond, VA: Virginia Institute for Social Services Training Activities (VISSTA).
- Duke, J. (1991). A national study of self-neglecting adult protective services clients. In
 T. Tatara & M. Rittman (Eds.), *Findings of five elder abuse studies* (pp. 23-53). Washington DC: National Aging Resource Center on Elder Abuse.
- Dyer, C. B., Goodwin, J. S., Pickens-Pace, S., Burnett, J., & Kelly, P. A. (2007). Self- neglect among the elderly: a model based on more than 500 patients seen by a geriatric medicine team. *American Journal of Public Health*, 97(9), 1671-1676.
- Dyer, C. B., Kelly, P. A., Pavlik, V. N., Lee, J., Doody, R. S., Regev, T., et al. (2006). The making of a self-neglect severity scale. *Journal of Elder Abuse* & Neglect, 18(4), 13-23.
- Dyer, C. B., Pavlik, V. N., Murphy, K. P., & Hyman, D. J. (2000). The high prevalence of depression and dementia in elder abuse or neglect. *Journal of the American Geriatrics Society*, *48*(2), 205-208.

Gill, T.M. (2009). Elder self-neglect: Medical emergency or marker of extreme

vulnerability? Journal of the American Medical Association, 302(5):570-571.

- Gibbons, S. W. (2009). Theory synthesis for self-neglect: a health and social phenomenon. *Nursing Research*, *58*(3), 194-200.
- Harm Reduction Coalition. Principals of Harm Reduction. Retrieved from https://harmreduction.org/about-us/principles-of-harmreduction/.
- Karp, N., & Wood, E. (2003). Incapacitated and alone: Health care decisionmaking for the unbefriended elderly. Washington, D.C.: American Bar Association.
- Maidment K. Problems in treating compulsive hoarding. Obsessive Compulsive Foundation. http://www.ocfoundation.org/hoarding/treatment/problems-intreating-compulsive-hoarding.php. Accessed April 14, 2009.
- Mayo Clinic Feb. 3rd 2018- https://www.mayoclinic.org/diseasesconditions/hoarding-disorder/symptoms-causes/syc-20356056
- National Harm Reduction Coalition. (2020). *Foundational Principles Central to Harm Reduction.* Principles of Harm Reduction. Retrieved from https://harmreduction.org/about-us/principles-of-harm-reduction/.
- National Library of Medicine. (2020). *Health Literacy*, Medline Plus. Retrieved from https://medlineplus.gov/healthliteracy.html
- Nerenberg, L. (2000). Elder abuse & substance abuse: Making the connection [Interview with Charmaine Spencer and Jeff Smith]. *nexus: A Publication for NCPEA Affiliates.* 6(1), 1,4-5,7.
- Partnership for Clear Health Communication at the National Patient Safety Foundation. Health literacy: statistics at-a-glance. What is health literacy? ™ ww.npsf.org/askme3/pdfs/STATS_GLANCE_EN.pdf
- Pickens S, Naik AD, Burnett J, Kelly PA, Gleason M, Dyer CB. (2007). The utility of the Kohlman Evaluation of Living Skills test is associated with substantiated cases of elder self-neglect. *Journal of The American Academy of Nurse Practitioners.*

Schillerstrom, J. E., Salazar, R., Regwan, H., Bonugli, R. J., & Royall, D. R. (2009).

¹⁹(3):137-42.

Executive function in self-neglecting adult protective services referrals compared with elder psychiatric outpatients *American Association for Geriatric Psychiatry*, *17*(10), 907-910.

Steketee, G., and Frost, R. (2003). Compulsive hoarding: Current status of the research. *Clinical Psychology Review 23* (7), 905-27.

Villaire, M. (2009, May). *Health Literacy: Bridging Research and Practice.* Presented at the Institute for Healthcare Advancement Eight Annual Health Literacy Conference, Irvine, CA.

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