

Working with Clients Experiencing Self- Neglect

Virtual Course

PARTICIPANT MANUAL



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

Funding Sources



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

Version 2 was revised by the Academy for Professional Excellence, with funding from the California Department of Social Services, Adult Programs Division.

Curriculum Developer, Kevin Bigelow, 2018



Version 1 was developed by the Academy for Professional Excellence, with funding through a generous grant from the Archstone Foundation.

Curriculum Developer, Lisa Nerenberg, 2011

©2023. San Diego State University School of Social Work, Academy for Professional Excellence. Please acknowledge this copyright in all non-commercial uses and attribute credit to the developer and those organizations that sponsored the development of these materials. No commercial reproduction allowed.

Introduction

THE ACADEMY FOR PROFESSIONAL EXCELLENCE

We are pleased to welcome you to **Working with Clients Experiencing Self-Neglect Participants 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 a national APS Supervisor Core Competency Training Curriculum. 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)

Partner Organizations

Dawn Gibbons-McWayne, Program Manager, APSWI

Academy for Professional Excellence

<https://theacademy.sdsu.edu/programs/apswi/>

Kat Preston-Wager, Curriculum Development Supervisor, APSWI

Academy for Professional Excellence

<https://theacademy.sdsu.edu/programs/apswi/>

Jennifer Spoeri, Executive Director, National Adult Protective Services Association (NAPSA)

<https://www.napsa-now.org/>

Paul Needham, Chair, NAPSA Education Committee

<https://www.napsa-now.org/>

James Treggiari, Adult Protective Services Liaison, Adult Protective Services Division

California Department of Public Social Services

<https://www.cdss.ca.gov/adult-protective-services>

Melinda Meeken and Carey Aldava, Co-Chairs, Protective Services Operations Committee of the County Welfare Director's Association (PSOC)

<https://www.cwda.org/adult-protective-services>

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

Curriculum Advisory Committee

Ralph Pascual, Human Services Administrator I, Los Angeles County,
Rachel Vo, Senior Social Services Supervisor, County of Orange
Jessica Burke, Staff Development Officer, Riverside County
Nancy McPheeters, Training and Development Specialist, San Bernardino County
E. Penny Jacobo, APS Supervisor, San Diego County
Whitney Barnes, Social Work Supervisor, Santa Cruz County
Mary Grace Juanta, Sr. Adult Protective Services Specialist, San Diego County
Quatana Hodges, Social Services Supervisor 1, County of Orange

Committees

National Adult Protective Services Association (NAPSA) Education & Development Committee

Curriculum Developers

Dina Bagues, MSW (2023 revisions)
Kevin Bigelow (2018 revisions)
Lisa Nerenberg (2011 original)

Table of Contents

Introduction.....	3
Partner Organizations.....	4
Acknowledgements.....	5
Table of Contents.....	6
Executive Summary	8
Course Outline	9
Virtual Learning Tips.....	12

PRESENTATION

WELCOME AND INTRODUCTIONS

Welcome/Housekeeping	14
Connection Questions	15
Learning Objectives	16

INTRODUCTION TO SELF-NEGLECT

What is Self-Neglect?	16
Activity #1: Case Scenarios	17
Handout #1: Self-Neglect Case Scenarios.....	18
Activity #2: The Diverse Spectrum	19
Handout #2: John and Maria	20

CAUSES OF SELF-NEGLECT

Potential Indicators of Self-Neglect	21
Implications of Self-Neglect	22
Ethical Issues in Self-Neglect	23
Handout #3 NAPSA Ethical Principles	24
Activity #3 Name the Domain!	25

SCREENING CAPACITY IN SELF-NEGLECT CASES

Activity #4: Assessing for Severity and Urgency	26
Handout #4: Self-Neglect in Five Domains	27
Handout #5: APS TARC Brief	29
Decision Making Capacity	44
Handout #6: Dimensions of Capacity	45
Handout #7: Capacity for Medical Treatment	46
Executive Function	47
Handout #8: Case Study-Mrs. Green	48

INTERVENTIONS WITH CLIENTS WHO SELF-NEGLECT

Working with Clients who are Hesitant	49
---	----

Hoarding Disorder and Self-Neglect.....	50
Overview of Available Approaches.....	51
Handout #9: Decisional Balance Worksheet.....	53

DETERMINING APPROPRIATE INTERVENTIONS

Treatment for Hoarding	54
Handout #10: Support and Services to Clients or Caregivers to Prevent Self-Neglect.....	56
Supportive Services	59
Activity #5: Working with Someone Experiencing Self-Neglect.....	60

DOCUMENTING SELF-NEGLECT

Handout #11B: Self-Neglect Case Studies	61
Importance of Good Documentation	62
Handout #12: Documentation in Self-Neglect.....	63
Handout #13: Community Partners in Self-Neglect Cases.....	65

WRAP-UP AND CONCLUSIONS

Review: Learning Objectives	66
Thank You	66
References	67

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.

Course Requirements:

As this is an introductory course, there are no course requirements. Participants are asked to engage in a variety of activities. If delivered virtually, access to a computer, headset and microphone will be needed.

Intended Audience

This course is designed for new APS professionals as an introduction to self-neglect 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 self-neglect
- Identify safety and risk reduction interventions for adults experiencing self-neglect
- Demonstrate an understanding of the elements to document in self-neglect cases
- Identify community partners to work with in self-neglect case

Course Outline

<u>CONTENT</u>	<u>MATERIALS</u>	<u>TIME</u>
WELCOME, INTRODUCTIONS, COURSE OVERVIEW		TOTAL: 20 minutes
<ul style="list-style-type: none"> Welcome to training and trainer Intro Housekeeping Technology, Content Warning 		
<ul style="list-style-type: none"> Participant Intro (name, agency, time in APS) <i>Chat Question and Discussion: Experience with Self Neglect cases & Fears and Challenges</i> 		
<ul style="list-style-type: none"> Prevalence of Self-Neglect 		
<ul style="list-style-type: none"> Learning Objectives with Course Overview 		
INTRODUCTION TO SELF-NEGLECT		TOTAL: 60 minutes
<ul style="list-style-type: none"> Self-Neglect Defined (WIC & AB 135) 	State Statutes	
<ul style="list-style-type: none"> Activity #1 – Is it Self Neglect? (<i>Individual/Large Group</i>) 	Handout #1-Case Scenarios	10 minutes
<ul style="list-style-type: none"> Activity #2- The Diverse Spectrum (<i>Individual/Large Group</i>) 	Handout #2- Maria and John	15 minutes
<ul style="list-style-type: none"> 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
<ul style="list-style-type: none"> Assessing in Self-Neglect 5 Domains with 	Handout #4: Self-Neglect in Five Domains	
<ul style="list-style-type: none"> Activity #3- Name the Domain! (<i>Individual/Large Group Discussion</i>) 		5 minutes
<ul style="list-style-type: none"> Severity and Urgency Activity #4 – Assessing for Severity and Urgency (<i>Breakout groups</i>) 	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
<ul style="list-style-type: none"> 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
<ul style="list-style-type: none"> 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
<ul style="list-style-type: none"> Motivational Interviewing Core Concepts of MI Decisional Balance Worksheet Activity #6: Self-Neglect Home Visit Video and Decisional Balance Worksheet (<i>Individual & large group</i>) 	7-minute video clip Handout #9- Decisional Balance Worksheet	15 minutes
<ul style="list-style-type: none"> Substance Use Disorder Treatment Treatment for Hoarding 		
DETERMINING APPROPRIATE INTERVENTIONS		TOTAL: 40 minutes
<ul style="list-style-type: none"> 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	

<ul style="list-style-type: none"> Responding to Someone Experiencing Self-Neglect Activity #7: Responding to Someone Experiencing Self-Neglect (<i>breakout groups</i>) 	Handout #11A /B– SELF-NEGLECT CASE STUDIES (Trainer & Participant Copy)	30 minutes
DOCUMENTATION		TOTAL: 10 minutes
<ul style="list-style-type: none"> Importance of Good Documentation Activity #8 (<i>only if time permits</i>) 	Handout# 12 – Documentation in Self Neglect	5 minutes
PARTNERS IN SELF-NEGLECT		TOTAL: 5 minutes
<ul style="list-style-type: none"> Partners in Self-Neglect 	Handout# 13 – Community Partners in Self Neglect Cases	
COURSE WRAP UP AND EVALUATIONS		TOTAL: 15 minutes
<ul style="list-style-type: none"> Review Learning Objectives 1 Take-away? (only if time allows) Plus/Delta EOD 	Evaluations	
<u>TOTAL (EXCLUDING BREAKS)</u>		TOTAL: 5 HOURS

Virtual Learning Tips

DEVELOPED BY APS WORKFORCE INNOVATIONS (APSWI)



Below are some helpful tips to remember and implement when participating in a virtual learning environment.

- **Choose an appropriate learning environment.**
 - Upon enrolling to a virtual instructor-led training, APS professionals are agreeing to set time apart and fully commit to the entire duration of the training. With that commitment, APS professionals have an obligation to choose an appropriate and conducive learning environment such as a home office, business office, etc. Participants who are not in an appropriate learning environment (driving, conducting home visits, etc.) will be removed from the training regardless of their participation and will **not** receive credit for the session.
 - This agreement also entails having an appropriate Zoom background if learners wish to have the virtual background feature activated.
- **Zoom screen name must be participant's first and last name.**
 - We ask that learners pay attention to the screen name displayed on their Zoom video window upon entering the session as sometimes the display name can appear as a series of letters and numbers. Learners can also identify themselves by typing their first and last name, and their county in the chat for the moderator to see.
 - **To update your screen name in Zoom**, select the ellipsis (the three dots) on the top right corner of your video window, click "rename" and type in your first and last name.
 - The moderator is also available to assist with updating screen names. Simply send the moderator a message via chat expressing your need for assistance.
 - Participants who do not identify themselves within the first 15 minutes of training and the moderator has attempted to contact them multiple times via direct message and verbally, the unidentified learner will be removed from the training for security purposes.
 - If learners do not have access to the chat function, they can email the APS Training email with their first and last name and county to identify themselves at apstraining@sdsu.edu.
- **Please turn on your camera.**
 - For a more conducive training experience, we ask participants to turn on their cameras if they have access to a functioning camera as it allows the trainer to connect with participants much better, and also allows for a connection among fellow participants as well.
- **Mute when others are speaking.**
 - We ask that participants remain courteous of the trainers when they are delivering, and when their fellow participants are speaking. However, we encourage participants to unmute themselves should the trainer ask for interactions and participation.

Reach out to the moderator for any assistance.

- We acknowledge that everyone has a different comfort level with technology, and that some participants may need to step away during a session. Please be sure to reach out to the moderator for any assistance if you experience any technical difficulties during a virtual training, and if you need to step away momentarily. Letting the moderator know when you have returned is also appreciated.
- If you would like to meet with the moderator before a training feel free to send us an email at apstraining@sdsu.edu to set up a quick tech-check at your earliest convenience to ensure you have the best learning experience.



Visit us at theacademy.sdsu.edu

We create experiences that transform the heart, mind, and practice.





Working With Clients Experiencing Self-Neglect

Instructor-Led Training

We create experiences that transform the heart, mind, and practice.



About the Academy & APSWI

The Academy is a project of San Diego State School of Social Work. Serving over 20,000 health and human services professionals annually, the Academy's mission is to provide exceptional workforce development and learning experiences for the transformation of individuals, organizations and communities.

APSWI, or Adult Protective Services Workforce Innovations, is a training program of the Academy that provides innovative workforce development to APS professionals and their partners.



ACADEMY PROGRAMS



Housekeeping

- Schedule for training
- Encourage all types of communication and participation
- Content warning
- Overview of Technology & Breakout Rooms

Overview of Technology

Click here to access audio options. To unmute briefly hold down the spacebar.

Click here to access video options and to share or stop sharing your camera.

Click here to access the "rename" feature if necessary to update display name.

Click here to access the chat function.



Breakout Rooms

- Joining the breakout room:
 - Click **join**
- Asking for Help:
 - If you click **Ask for Help**, it will notify the meeting host that you need assistance and they will be asked to join your breakout room.
- Leaving the breakout room:
 - You can leave the breakout room and return to the main meeting session at any time.
 - Click **Leave Breakout Room**
 - Choose if you want to leave the breakout room or the entire meeting.
 - When the host ends the breakout rooms, you will be notified and given the option to return to the main room immediately, or in 60 seconds.



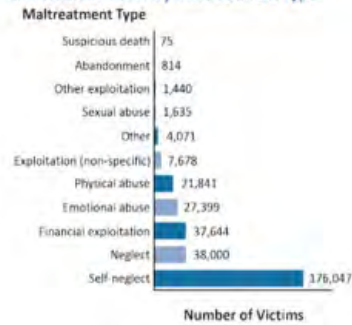
Connection Question

What is your biggest fear or has been your biggest challenge when working with someone who is experiencing self-neglect?



Prevalence of Self-Neglect

Exhibit 2.6: Victims by Maltreatment Type



(National Adult Maltreatment Reporting System Data Report, FFY 2021)

Learning Objectives

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

What is Self-Neglect?

- "The negligent failure of an elder or dependent adult to exercise that degree of self care that a reasonable person in a like position would exercise." - CA W&IC 15610.57 (a)(2), (b)(5), (c)
- Self-neglect includes but is not limited to the following:
 - failure to assist in hygiene or the provision of food, clothing, or shelter,
 - failure to provide medical care for physical and mental health needs (does not include a person who voluntarily relies on treatment through spiritual means or prayer alone in lieu of treatment),
 - failure to protect from health and safety hazards,
 - failure to prevent malnutrition or dehydration,
 - substantial inability/failure to manage finances, or
 - failure to satisfy any of the above needs due to poor cognitive functioning, mental limitation, substance abuse, or chronic poor health.
- being homeless if the elder or dependent adult is also unable to meet any of the needs specified above

(Protecting Older Adults from Abuse and Neglect Fact Sheet, 2022)

Activity #1 – Case Scenarios

Mr. Nguyen



Robert Stevens



Mrs. Sanchez



“An elder or dependent adult’s refusal or failure to perform essential self-care tasks”

- failure to assist in hygiene or the provision of food, clothing, or shelter,
- failure to provide medical care,
- failure to protect from health and safety hazards,
- failure to prevent malnutrition or dehydration,
- inability/failure to manage finances, or
- failure to satisfy any of the above needs due to poor cognitive functioning, mental limitation, substance abuse, or chronic poor health.)
- homelessness

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.

Activity #2- The Diverse Spectrum



Handout #2: John and Maria

Maria is 82 years old and her neighbors describe her as “unable to care for herself.”

When you make your home visit, Maria seems

(behavior/emotion). She invites you to come in and your first impression of her home is

(adjective). While you try and interview her, Maria

continually

(behavior). When you ask about her diet,

she says that

(behavior/feeling). You notice Maria has

a couple of cats that do not look well cared for and when you ask about them, she says

. During the interview you noticed a strong odor and

you eventually concluded it was

. The interview

concluded when Maria

.

John is 76 years old and is described by his neighbors as a “hoarder.” John lives in a

(type of residence). You can tell that it is John’s place because

when you approach, you

(see/hear/smell)

(Noun). John lives

(with/what).

When you talk with John, he is friendly but adamant that he cannot

(activity of daily living).

When you ask to see what John has been eating, you see

.

When discussing his living situation, John seems

(emotion/behavior). In an effort to evaluate John and his situation, you

(assessment tool). As you leave, you are thinking that John may be experiencing

(medical or mental health condition).

Potential Indicators of Self-Neglect

- Unpaid bills
- Utilities shut off
- Empty refrigerator or spoiled food
- Pest infestation
- Trash piled up
- Poor personal hygiene
- Unorganized or expired medications
- Sudden weight loss
- Frequent falls
- Interior/Exterior home in state of disrepair
- Unmaintained living environment
- Lack of medical care
- Untreated wounds/sores or dirty bandages
- Lack of assistive medical devices – glasses, hearing aid, walker/cane

Factors That Could Be Mistaken For or Lead to Self-Neglect

- Eccentricity
- Lifestyles that vary from the dominant culture(s)
- Religious/cultural practices/beliefs
- Use of alternative medicine or medical practices
- Trauma
- Neglect or abuse by others
- Low Health Literacy

Health Literacy

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

(medlineplus.gov/healthliteracy)

Low Health Literacy and Self-Neglect:

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



(Villaire, M., 2009)

Clients may try to hide illiteracy/lack of understanding:

- "I forgot my glasses."
- "I don't need to read this now; I'll read it after you leave."
- "I'd like to discuss this with my family."
- Nodding (Believe they understand but don't.)



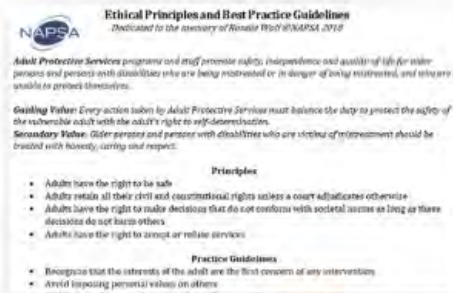
Implications of Self-Neglect

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



Ethical issues in Self-neglect

- Avoid imposing personal values
- Informed consent
- Least restrictive services
- Rights of Adults:
 - Safety
 - Civil Rights
 - Decision Making
 - Right to Refuse



Handout #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

Safety versus Self-Determination

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

There are two exceptions:

- When clients do not understand risks AND the risks or dangers are substantial, involuntary measures may be warranted.
- Other interventions may be pursued without the consent of the client.

Assessing Self-Neglect in 5 Domains



Activity #3 - Name the Domain!

1. A client consistently is a no-show for dialysis.
2. A client with Alcohol Use Disorder chooses not to engage in Alcohol Addiction Treatment.
3. A client is lonely and declines offers to engage in community support activities.
4. A client repeatedly engages in scams and has lost most of their assets.
5. A client diagnosed with Obsessive Compulsive Disorder is experiencing hoarding behaviors.

Name the Domain! - continued

1. A client with a diagnosis of neurocognitive disorder (NCD) was discharged from the hospital and Home Health was ordered to follow-up with the client at home, but the client refused to let the Home Health nurse into the home.
2. A client with reduced mobility is unable to keep the home safely maintained.
3. A client needs assistance in many areas and doesn't have a support network to help them.
4. A client on oxygen is forgetful and keeps lighting a cigarette while on oxygen.
5. A client has forgotten to pay their utilities and there is a water shut-off notice on the front door.

Severity and Urgency



Activity #4 – Assessing for Severity and Urgency

- 1) Each breakout group's number will correspond with the domain matching that number:
 - Domain 1: Physical/Medical Factors
 - Domain 2: Psychological/Mental Health
 - Domain 3: Environmental
 - Domain 4: Financial
 - Domain 5: Social and Cultural
- 2) Imagine that your group is assessing someone who experiencing self-neglect that primarily falls into your assigned domain.
- 3) List 3-5 outcomes to the person, support system or others that could happen as a result of the self-neglect in that domain
- 4) Once listed, the group will then rank these factors based on which you feel are the **most** severe or urgent and be prepared to explain why.

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.

Assessment Tools

- Self-Neglect Assessment Tool:
 - Elder Self-Neglect Assessment (ESNA)
- Other Decision-Making and Functional Assessment Tools:
 - Clock Drawing Tests
 - Geriatric Depression Scale (Short Form)
 - Confusion Assessment Method
 - Lichtenberg Financial Decision Screening Scale
 - Memory Impairment Screen
 - Montreal Cognitive Assessment
 - Mini Mental State Exam
 - St. Louis University Mental Status Examination
 - Assessment of Capacity for Everyday Decision-Making
 - Interview of Decisional Abilities
 - The Executive Interview



Handout #5 – APS TARC Brief



enhancing
effectiveness of
APS programs

In Brief

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 decision-making. 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.

Adult Protective Services Technical Assistance Resource Center | <https://apstarc.acl.gov> | apstarc-ta@acl.hhs.gov | Page 1

Capacity Screening in Adult Protective Services: Guidance and Resources

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 (executorial 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 decision-making 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,

Capacity Screening in Adult Protective Services: Guidance and Resources

- 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 *Assessing APS Clients' Decision-Making Capacity* 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.

Attributes of Capacity



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-Klawnsnik, *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;

Capacity Screening in Adult Protective Services: Guidance and Resources

2. Lack of decision-making capacity can be presumed when patients go against medical advice;
3. There is no need to assess decision-making capacity unless patients go against medical advice;
4. Decision-making capacity is an “all or nothing” phenomenon;
5. 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;
9. 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:

1. 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.
2. 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

Capacity Screening in Adult Protective Services: Guidance and Resources

- (i.e., appreciate the potential consequences)?
3. 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

Capacity Screening in Adult Protective Services: Guidance and Resources

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-Klawnsnik, “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-Klawnsnik, 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

Capacity Screening in Adult Protective Services: Guidance and Resources

years ahead of the general population. These age-related 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 age-related 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 decision-making capacity differs from executorial capacity. They state, "in nearly 25% of the couples studied, the person with dementia retained decisional capacity, even in the absence of executorial 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:

1. social or environmental risk factors such as dependency, isolation, family conflict, and recent bereavement;
2. 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;
3. 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 self-care 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-Klawnsnik, 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:

1. Does the client understand relevant information?
Ask – Do you know you have a serious cut on your leg?
2. What is the quality of the client's thinking process?
Ask – How can you get treatment for the cut on your leg?
3. Is the client able to demonstrate and communicate a choice?
Ask – Do you want to get treatment for the cut on your leg?
4. 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

Capacity Screening in Adult Protective Services: Guidance and Resources

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, cost-effective 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) – [CAM](#) is a standardized evidence-based tool that enables non-

psychiatrically 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. [No-cost training and certification](#) are required to use the tool.

Capacity Screening in Adult Protective Services: Guidance and Resources

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 non-cognitively 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 non-cognitively 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 [SLUMS](#) 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 [translated into various languages](#). Disadvantages include: a) it

Capacity Screening in Adult Protective Services: Guidance and Resources

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 decision-making 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 semi-structured 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.

1. 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

Capacity Screening in Adult Protective Services: Guidance and Resources

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 decision-making 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 decision-making 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, *New Findings in the Intersection of Financial Decision Making and Exploitation: Results from Michigan APS and the SAFE Program*. 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 *SAFE (Successful Aging thru Financial Empowerment)*, 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).

Capacity Screening in Adult Protective Services: Guidance and Resources

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 non-standardized, 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)

- [APS Core Assessing Client Capacity Instructor-Led Training](#)
- [APS Core Assessing Client Capacity eLearning](#)
- [Undue Influence eLearning Mini-Module](#)
- [Undue Influence Committed by Professionals eLearning](#)

Follow Us on Social Media!



Capacity Screening in Adult Protective Services: Guidance and Resources

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-decision-making-capacity>
- Doerflinger, C. (2019). *Mental Status Assessment in Older Adults: Montreal Cognitive Assessment: 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>

Decision-Making Capacity

- Decision-Making Capacity is the ability to adequately process information in order to make a decision based on that information
- Task specific- ability to do what?
- Types of decisions include:
 - Medical Consent;
 - Sexual Consent;
 - Financial;
 - Testamentary
 - Ability to Live Independently

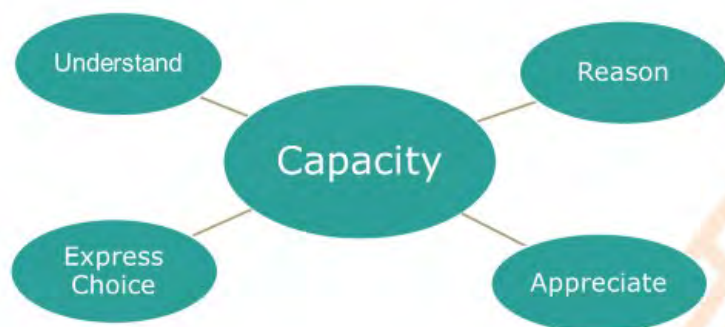


Ability

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



Capacity



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.	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<p>The process of comparing alternatives in light of consequences by integrating, analyzing, and manipulating information. It involves the ability to:</p> <ul style="list-style-type: none"> • 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 	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • Can you explain to me what you've decided and why? • How did you reach this decision?

Executive Function

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



Enhancing Decisional Ability

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



Developing Questions for Mrs. Green

- In groups, develop questions to assess for Mrs. Green's ability to make decisions in your assigned focus area (self-care or finances)
- Remember to ask questions that assess the following:
 - Understanding
 - Appreciation
 - Reasoning
 - Expressing 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 APS 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 in Self-Neglect

Multiple challenges can arise when assessing people experiencing self-neglect.

- This is a complex situation.



Working with Clients who are Hesitant



Reasons People May Refuse Help

- NCDs
- Anxiety
- Grief
- Depression
- Lack of insight
- Behavioral Health
- Shame
- Distrust (of government officials, caregivers, etc.)
- Fatigue
- Fear (losing control, added violence, costs involved)
- Pain
- Anger



Hoarding Disorder and Self-Neglect

Persistent difficulty discarding or parting with possessions, regardless of their actual value.

- Due to a perceived need to save the items and to the distress associated with discarding them.
- Results in the accumulation of possessions that congest and clutter active living areas and substantially compromises their intended use. If living areas are uncluttered, it is only because of the interventions of third parties (e.g., family members, cleaners, or the authorities).
- Causes clinically significant distress or impairment in social, occupational, or other important areas of functioning (including maintaining a safe environment safe for oneself or others).
- Not attributable to another medical condition (e.g., brain injury, cerebrovascular disease, Prader-Willi syndrome).

Impact of Compulsive Hoarding

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



(Los Angeles Times, June 02, 2016)

Substance Use Disorder and Self-Neglect

- Substance use disorder can amplify the health and safety risks that already exist in the lives of older adults or adults with disabilities.



Overview of Available Approaches

- Motivational Interviewing
- Substance Use Treatment
- Hoarding Treatment



Motivational Interviewing

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

- 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."

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

Core Concepts of MI

- Express empathy
 - Ability to share in the feelings of others and put oneself in another's situation
- Support self efficacy
 - Help them stay motivated. Solutions can change
- Roll with resistance
 - Avoid arguing, encourage creating own solutions
- Develop discrepancy
 - Help develop their discrepancy between current behavior and future goals

Motivationalinterviewing.org

Decisional Balance Worksheet

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



motivationalinterviewing.org

Handout #9 – Decisional Balance Worksheet

Good things about <i>behavior</i>:	Good things about changing <i>behavior</i>:
Not so good things about <i>behavior</i>:	Not so good things about changing <i>behavior</i>:

Substance Use Disorder Treatment

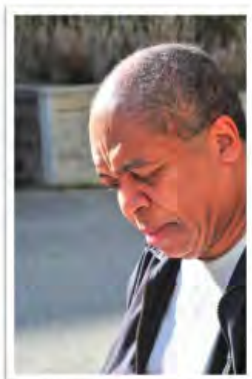
- Hospital Detox
- Medication and Therapy
- Counseling
- Self Help groups or Peer Support
- Harm Reduction

Treatment for Hoarding

- Forced clean-ups DON'T work for long-term solutions!
- Research is still pending:
 - Cognitive-Behavioral Therapy
 - Medications
 - Support groups
 - Harm Reduction

Interventions For Those Experiencing Self-Neglect

What factors determine appropriate interventions?



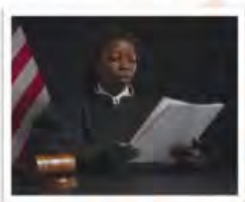
Types of Intervention



Support
Services



Mental Health
Treatment



Involuntary
Interventions

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. They then arrange for services and monitor them, responding to problems. Specifically, they:
 - Conduct comprehensive assessments of the older person's general health, mental capacity and ability to manage in the home and community
 - Develop "care plans," often in consultation with other professionals from several disciplines, for meeting clients' service needs
 - Arrange for needed services
 - Respond to problems or emergencies
 - Conduct routine re-assessments to detect changes in the person's health or ability to manage, and anticipate problems before they occur

- **Conservatorship.** A mechanism by which a court appoints a person to handle the financial and/or personal affairs of individuals who are unable to protect themselves as the result of disability. This is also called a guardianship in some states. States differ in whether they compartmentalize the duties of a conservator but they are often divided as follows:
 - **Conservatorship of person** refers to the handling of an individual's personal needs through the provision of medical care, food, clothing and shelter
 - **Conservatorship of estate** refers to the management of financial resources and assets
- **Counseling** may be needed to alleviate the immediate and long-term traumatic stress associated with abuse. Some groups address such issues as co-dependency depression and diminished self-esteem.
- **Daily Money Management (DMM).** Financial abuse frequently may occur when an older person has lost the ability to manage his or her finances. Arranging for trustworthy people to help can reduce this risk. The help may be informal, where the money manager simply helps the elder with simple tasks like paying bills or it may involve formal transfers of authority, including representative payeeship, power of attorney, or guardianship.
- **Emergency funds** may be needed for temporary caregivers, housing, food, rent, mortgage payments, shelter, transitional housing, transportation, utilities, new locks to secure clients' homes, attorney's fees, court filing fees, repairs, relocation costs, security deposits, respite care, and home modification. In cases of serious neglect, a one-time "deep cleaning service" may be needed to make the client's home habitable, thus preventing placement in a more restrictive environment.
- **Home delivered meal programs.** Programs deliver nutritious meals to older adults or adult dependents in their homes. Also called Meals on Wheels.
- **Friendly Visitor.** A number of senior organizations offer a friendly visitor or similar option where volunteers check in with designated people. This type of intervention can help promote social interaction, help build relationships and provides another pair of eyes to see how the client is doing and to contact APS if the person seems to be at risk again.
- **Mental health** assessments are often needed to determine if an older or dependent adult is capable of meeting his or her own basic needs, making decisions about services, offering testimony, and protecting him or herself against abuse. Assessments of alleged abusers' mental status are sometimes needed to determine if they pose a danger to others and are in need of treatment. Assessments range from simple exams that can be performed quickly by persons with minimal training to geriatric assessments, which involve multiple professionals performing a comprehensive battery of tests.

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

Social Support/ Supportive Services

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



Mental Health Treatment

- Crisis intervention
- Individual or group counseling for anxiety, depression, substance use, traumatic stress, hoarding, grief
- Medications



Involuntary Interventions

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



Activity- Working with Someone Experiencing Self-Neglect

Considering everything covered so far: definitions, indicators, decision-making ability, right to self-determination, various treatment, interventions and resources, answer the following questions in your groups:

- What should the APS professional take into consideration?
- What should they do next?
- What additional information should they gather?
- What interventions or techniques might be helpful?

Handout #11B – SELF-NEGLECT CASE STUDIES

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?)

Importance of Good Documentation

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



Partners When Working With People Experiencing Self-Neglect

- With whom can you partner with?



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 assault).
- Fearfulness, distrust
- Hallucinations
- Alertness
- Flat affect
- Agitation and anxiety

Indications of Capacity and Consent

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

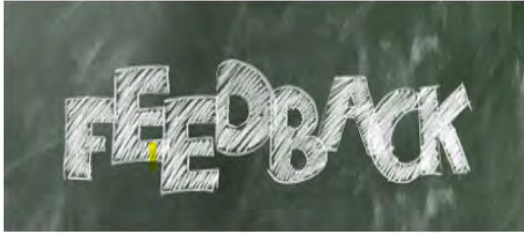
Handout #13 – Community Partners in Self-Neglect Cases

Professional, entity or group	<i>Role in self-neglect cases</i>
Mental Health professionals, including county geriatric mental health program personnel or professionals in private practice (geriatric psychologists, psychiatrists, etc.)	<ul style="list-style-type: none"> • <i>Can assess clients' mental status</i> • <i>Can arrange for psychiatric hospitalization under W&I Code §5150.</i> • <i>Can diagnose and treat depression and other mental conditions</i>
Geriatric physicians and nurses	<ul style="list-style-type: none"> • <i>Can diagnose, assess and treat medical conditions</i> • <i>Can complete medical declarations (doctors) for conservatorship</i> • <i>Can review medical records and distinguish injuries from effects of aging and disease</i>
Conservators, including private professionals	<ul style="list-style-type: none"> • <i>Can file for and provide conservatorship services</i>
Public Guardians	<ul style="list-style-type: none"> • <i>Can file for and provide conservatorship services</i>
Clergy	<ul style="list-style-type: none"> • <i>Can provide emotional and spiritual support to clients</i> • <i>Can provide or arrange for informal support services</i>
Local law enforcement, including police and sheriffs	<ul style="list-style-type: none"> • <i>Can assist with well-being checks, psychiatric hospitalizations, protective custody, freezing assets</i>
Animal Welfare Organizations (municipal animal care and control) agencies, humane societies, SPCAs and rescue organizations	<ul style="list-style-type: none"> • <i>Can provide information and assist with finding homes for animals</i> • <i>Can make home visits to check on the welfare of the animals in the home</i>
Ethics Committees (most are convened by hospitals and nursing homes)	<ul style="list-style-type: none"> • <i>Can identify and address ethical issues raised in self-neglect cases</i>
Multidisciplinary teams, including elder abuse multidisciplinary teams and death review teams	<ul style="list-style-type: none"> • <i>Can provide suggestions for interventions</i> • <i>Provides a "checks and balances" to ensure that all multiple options and points of view are considered</i> • <i>Can ensure that workers' actions reflect community standards of practice</i>

Review: Learning Objectives

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

Please Complete Your Evaluations



THANK YOU FOR THE
WORK THAT YOU DO!

Thank You!

Academy
for Professional
Excellence



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 <https://www.youtube.com/watch?v=RBCo4UBOliU&list=PLTkfyRcpER10MW7Qe40B8mJGXEcBCD719&index=2>
- Acierno, R., Hernandez-Tejada, M., (2018). Protection Through Connection: Social Support as a Key Intervention & Prevention Component in Elder Abuse [PowerPoint slides]. Retrieved from <https://eldermistreatment.usc.edu/education/usc-tamkin-international-symposium-on-elder-abuse/presenter-slides/>.
- Administration for Community Living. (2021). *Adult Maltreatment Report 2021*, National Adult Maltreatment Reporting System. Retrieved from <https://namrs.acl.gov/Data/Adult-Maltreatment-Reports/2021-Adult-Maltreatment-Report.aspx>
- Adult Protective Services Technical Assistance Resource Center (APS TARC). (2020). Capacity screening in Adult Protective Services: Guidance and resources. Administration for Community Living. <https://apstarc.acl.gov/getattachment/Education/Briefs/CapacityScreeningBrief.pdf.aspx?lang=en-US> 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. <http://epublications.marquette.edu/cgi/viewcontent.cgi?article=1284&context=mulr>
- 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 substantiation 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 community-dwelling 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-harm-reduction/>.
- Karp, N., & Wood, E. (2003). *Incapacitated and alone: Health care decision-making 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-in-treating-compulsive-hoarding.php>. Accessed April 14, 2009.
- Mayo Clinic Feb. 3rd 2018- <https://www.mayoclinic.org/diseases-conditions/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? TM

www.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*. 19(3):137-42.

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

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.

This page is intentionally left blank.

OUR WHY: **REVOLUTIONIZE
THE WAY PEOPLE
WORK TO ENSURE
THE WORLD IS A
HEALTHIER PLACE.**



theacademy.sdsu.edu

6505 Alvarado Road, Suite 107; San Diego, CA 92120 (619) 594-3546