PARTICIPANT MANUAL

ADVANCED SERIES ON SELF NEGLECT

Legal, Ethical and Best Practice Issues ©

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

Curriculum Developer

Lisa Nerenberg, MSW, MA

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Academy for Professional Excellence- 6505 Alvarado Road, Suite 107
Tel. (619) 594-3546 Fax: (619) 594-1118 http://theacademy.sdsu.edu/programs/

ADVANCED MODULE 3 -2- 7/12/2010

Version 2
INTRODUCTION

THE ACADEMY FOR PROFESSIONAL EXCELLENCE

We are pleased to welcome you to the Advanced Series on Self Neglect, developed by Project MASTER, a program of the Academy for Professional Excellence.

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

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

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

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

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

Our partners include:

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

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

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

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

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

**Evaluation Consultants**
- James Coloma, Evaluation Consultant
- Jane Birdie, Evaluation Consultant
- Cynthia Parry, Evaluation Consultant
TRAINING GOALS AND OBJECTIVES

By the end of this training, participants will be able to:

- Explain APS’ authority to intervene in self neglect cases
- Identify state laws that apply to self neglect
- Describe basic principles of legal capacity
- Discuss ethical principles that apply in self neglect cases
- Describe “due diligence” and its application to APS practice in self neglect cases
- Work effectively with community partners
- Describe promising practices for handling self neglect cases
Legal, Ethical, and Practice Issues in Self Neglect

Presentation by Lisa Nerenberg

Blog: Prevent Elder Abuse
http://preventelderabuse.blogspot.com/
Web site: http://lisanerenberg.com/

Funded by the Archstone Foundation
WELCOME AND INTRODUCTIONS

TIME ALLOTTED: 15 minutes

Slide # 2

Evaluation Process

- All APS Training has 3 evaluation components:
  - Transfer of Learning Activity
  - Embedded Evaluation
  - Satisfaction Survey

Slide # 3

Developing an ID Code

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

Trainee ID Code: SMAL129

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ADVANCED MODULE 3  -7-  7/12/2010
Version 2
Learning Objectives

- Explain APS' authority to intervene in self neglect cases
- Identify state laws that apply to self neglect
- Describe basic principles of legal capacity
- Discuss ethical principles that apply to self neglect cases
- Describe "due diligence" and its application to APS practice in self neglect cases
- Work effectively with community partners
- Describe promising practices for handling self neglect cases
FORMS OF SELF NEGLCET

TIME ALLOTTED: 45 minutes

Slide # 5

Forms of Self Neglect Exercise

Slide # 6

Card 1: Capacity
Write 1-2 sentences about the client's mental capacity.
Slide # 7
Card 2: What’s at Risk
Write 1-2 sentences about what is at risk:
- To the client
- To family, neighbors, or other third parties
- To you or your agency

Slide # 8
Card 3: Legal / Ethical Concerns
Write 1-2 sentences about:
- Legal issues the case raises
- Ethical issues the case raises (to you or others)

Slide # 9
Card 4: Outcomes
Write 1-2 sentences about what you would like to happen.
Small Group Assignment

<table>
<thead>
<tr>
<th>Step 1</th>
<th>Step 2</th>
<th>Step 3</th>
<th>Step 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assign a &quot;scribe&quot; to take notes.</td>
<td>Assign a &quot;reporter.&quot;</td>
<td>Read through the cards.</td>
<td>Discuss cases, looking for common themes and variations</td>
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</tbody>
</table>

Assign a "scribe" to take notes. Assign a "reporter." Read through the cards. Discuss cases, looking for common themes and variations.
AUTHORITY TO INTERVENE IN SELF NEGLECT CASE

TIME ALLOTTED: 20 minutes

Slide # 11
Title XX Definition of Self Neglect
To receive Title XX Social Services Block Grant funds, states are "encouraged," but not required, to spend the funds to establish services to meet national goals, which include advocacy and services to adults who, "as a result of physical or mental limitations, are unable to act in their own behalf; are seriously limited in the management of their affairs; are neglected or exploited; or are living in unsafe or hazardous conditions.

Slide # 12
California’s Welfare and Institutions Code
Definition of Self Neglect
The failure of the elder or dependent adult to exercise a reasonable degree of care in providing for his/her own needs in such areas as personal hygiene, food, clothing, shelter, medical and mental health care, or avoiding health and safety hazards, malnutrition or dehydration.
Unbefriended & Unrepresented

People with diminished capacity who have not executed advance directives; who lack family, friends and others to serve as surrogates; and who need medical care or treatment that require consent (Karp & Wood, 2003).

Laws Pertaining to Self Neglect

Probate code
Penal code
W&I Code
Health and Safety code

Probate Code §1801. Conservatorship

Conservatorship: A mechanism by which courts appoint people to handle the affairs of individuals who are unable to protect themselves as the result of disability.

A Conservatorship of person is for the handling of personal needs through the provision of medical care, food, clothing and shelter

A Conservatorship of estate is for the management of financial resources and assets
Slide # 16

**Why Conservatorship?**

Probate Courts appoint conservators when the following criteria are met:
- The proposed conservatee lacks sufficient mental capacity to manage his/her affairs
- The person is at risk
- Conservatorship can reduce risk

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Slide # 17

**Conservatorship may be needed when:**

- Severely impaired victims are unable to grasp the severity of their situation and refuse needed services
- Family members are quarreling over custody or assets
- Adult children want to claim inheritances, prematurely or influence their older family members to make new wills
- Less restrictive legal devices, such as durable powers of attorney or trusts, have been misused.

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Slide # 18

**Other California laws relating to self-neglect**

**Probate code**
- 1801: Conservatorship
- 2250: Temporary conservatorship
- 1250: Medical treatment for incapacitated persons
- 2950: Authorizes public guardians to freeze or seize assets when intending to file for conservatorship

**Welfare and Institutions code**
- 5150: Emergency, temporary basis to assess their need for psychiatric treatment or hospitalization
- 5170: Hospitalization in a psychiatric facility
- 15703-15705.40: "Protective custody" Health and Safety code
- 1488 (authorizes skilled nursing or intermediate care facilities to make medical decisions for incapacitated residents)

**Penal code**
- 597: Cruelty to animals
California Laws that May Apply in Self Neglect Cases.

<table>
<thead>
<tr>
<th>Situation</th>
<th>Statutes</th>
</tr>
</thead>
<tbody>
<tr>
<td>An adult appears to be a danger to him or her self or others, or gravely disabled as a result of mental illness.</td>
<td>Welfare and Institutions code §5150 permits police or mental health workers to remove individuals from their homes on an emergency, temporary basis to assess their need for psychiatric treatment or hospitalization. May lead to LPS conservatorship (Welfare and Institutions code §5350) if the person has a serious mental disorder or is impaired by chronic alcoholism and requires hospitalization in a psychiatric facility.</td>
</tr>
<tr>
<td>An adult is incapable of managing his or her financial and/or personal affairs and is at risk of abuse, neglect, exploitation or undue influence</td>
<td>Probate code §1801 provides for probate conservatorship, a process in which courts appoint individuals (conservators) to act on behalf of incapacitated persons (conservatees). After filing petitions for appointment, prospective conservators can file petitions for temporary conservatorship (Probate code §2250) which enables them to provide conservatees with immediate care for a limited time, pending the determination of the main petition.</td>
</tr>
<tr>
<td>An adult is unable to consent to needed medical treatment</td>
<td>Probate code Section §3200 allows for health and medical care providers, neighbors, friends and others to petition the court to order medical treatment and to select and discharge health care providers and institutions on behalf of the incapacitated person. Health and Safety code Section §1418.8 authorizes skilled nursing or intermediate care facilities to conduct interdisciplinary team reviews to make medical decisions for incapacitated residents who lack surrogates when physicians prescribe medical interventions that require informed consent.</td>
</tr>
<tr>
<td>An adult’s assets are in imminent jeopardy and the adult is believed to be incapable of protecting them</td>
<td><strong>Probate code §2950</strong> authorizes public guardians to freeze or seize the assets of persons who are incapacitated when the assets are believed to be in jeopardy and the PG intends to file for conservatorship.</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>§2952(^1) authorizes specially trained peace officers to issue declarations stating that there is probable cause to believe that a crime is being committed against an incapacitated person and that the person is in danger of losing his or her property. The declaration must be co-signed by local APS supervisors and sent to public guardians who may then take possession or control of the property.</td>
<td></td>
</tr>
<tr>
<td>A person’s home or residence is hazardous</td>
<td><strong>State and local fire, building, housing, and health codes</strong> address blight and safety hazards.</td>
</tr>
<tr>
<td>A person is a nuisance to others</td>
<td><strong>Penal code §370</strong> addresses acts or situations that are injurious, indecent, offensive or obstructive to neighborhoods, communities or others.</td>
</tr>
<tr>
<td>Pets are not being cared for properly</td>
<td><strong>Penal code §597</strong> addresses cruelty to animals. Failure to provide adequately for pets can result in the removal of animals. People convicted of cruelty to animals can be ordered into counseling.</td>
</tr>
</tbody>
</table>

\(^1\) This statute is being used in some California counties and not others.
Decision-Making Capacity and Consent

TIME ALLOCATED: 25 minutes

Slide # 19

Self Neglect and Diminished Capacity

Dyer et al. (2007) found that:
Of 500 self-neglecting elders, half scored poorly on mental health tests.

Slide # 20

Functional vs legal capacity

- Functional, or clinical, capacity is determined by clinicians based on clinical judgments
- Legal capacity is a threshold requirement, imposed by societies, that is required for particular activities, actions, or decisions.
- Denotes legal status that may remove rights to self determination or transfer of authority to others.
Legal capacity judgments

Based on:

- Clinical judgments
- Statute
- Case law
- Principles of justice

Capacity is collection of skills, that includes:

- Memory
- Logic
- The ability to calculate
- Executive function

Criteria for Specific Actions or Decisions

- To make medical decisions
- To execute advance directives
  (for health or finances)
- To execute a will
  (testamentary)
- To contract
- To give gifts (donative)
Slide # 24

Capacity Declarations for conservatorship

Form GC-335
- May be filed as an attachment to the Petition for Appointment of Conservator
- Must be completed by
  - Psychiatrist
  - Psychologist
  - Geriatric physician
  - Palliative medicine physician
  - Family doctor

Slide # 25

Deficits in Mental Functioning

Must be supported by evidence of deficits in at least one of the following mental functions
1. Alertness and attention
2. Information processing
3. Thought processes
4. Ability to modulate mood and affect

Slide # 26

Filling out Capacity Declarations

- Problems
- Failure to fill out
Capacity Declaration: GC335

To keep other people from seeing what you entered on your form, please press the Clear This Form button at the end of the form when finished.

Name and Address

Must mark A, B, or C

Must be dated

If B. must check boxes

Signature!

Include # of pages

ADVANCED MODULE 3  -20-  7/12/2010
CONSERVATORSHIP OF THE □ PERSON □ ESTATE OF (Name): □
□ CONSERVATEE □ PROPOSED CONSERVATEE □ CASE NUMBER:

6. EVALUATION OF (PROPOSED) CONSERVATEE’S MENTAL FUNCTIONS

Note to practitioner: This form is not a rating scale. It is intended to assist you in recording your impressions of the (proposed) conservatee’s mental abilities. Where appropriate, you may refer to scores on standardized rating instruments.

(Instructions for items 6A–6C): Check the appropriate designation as follows: a = no apparent impairment; b = moderate impairment; c = major impairment; d = so impaired as to be incapable of being assessed; e = I have no opinion.)

A. Alertness and attention

(1) Levels of arousal (lethargic, responds only to vigorous and persistent stimulation, stupor)
   a □ b □ c □ d □ e □

(2) Orientation (types of orientation impaired)
   a □ b □ c □ d □ e □
   Person □
   a □ b □ c □ d □ e □
   Time (day, date, month, season, year) □
   a □ b □ c □ d □ e □
   Place (address, town, state) □
   a □ b □ c □ d □ e □
   Situation (“Why am I here?”) □

(3) Ability to attend and concentrate (give detailed answers from memory; mental ability required to thread a needle)
   a □ b □ c □ d □ e □

B. Information processing. Ability to:

(1) Remember (ability to remember a question before answering; to recall names, relatives, past presidents, and events of the past 24 hours)
   i. Short-term memory □
      a □ b □ c □ d □ e □
   ii. Long-term memory □
      a □ b □ c □ d □ e □
   iii. Immediate recall □
      a □ b □ c □ d □ e □

(2) Understand and communicate either verbally or otherwise (deficits reflected by inability to comprehend questions, follow instructions, use words correctly, or name objects; use of nonsense words)
   a □ b □ c □ d □ e □

(3) Recognize familiar objects and persons (deficits reflected by inability to recognize familiar faces, objects, etc.)
   a □ b □ c □ d □ e □

(4) Understand and appreciate quantities (deficits reflected by inability to perform simple calculations)
   a □ b □ c □ d □ e □

(5) Reason using abstract concepts (deficits reflected by inability to grasp abstract aspects of his or her situation or to interpret idiomatic expressions or proverbs)
   a □ b □ c □ d □ e □

(6) Plan, organize, and carry out actions (assuming physical ability) in one’s own rational self-interest (deficits reflected by inability to break complex tasks down into simple steps and carry them out)
   a □ b □ c □ d □ e □

(7) Reason logically
   a □ b □ c □ d □ e □

C. Thought disorders

(1) Severely disorganized thinking (rambling thoughts; nonsensical, incoherent, or nonlinear thinking)
   a □ b □ c □ d □ e □

(2) Hallucinations (auditory, visual, olfactory)
   a □ b □ c □ d □ e □

(3) Delusions (demonstrably false belief maintained without or against reason or evidence)
   a □ b □ c □ d □ e □

(4) Uncontrollable or intrusive thoughts (unwanted compulsive thoughts, compulsive behavior).
   a □ b □ c □ d □ e □

(Continued on next page)

CAPACITY DECLARATION—CONSERVATORSHIP

Page 2 of 3
### Legal, Ethical, and Best Practice Issues

#### Participant Manual

**CONSERVATORSHIP OF THE** [ ] PERSON [ ] ESTATE OF (Name): [ ] CASE NUMBER:
- CONSERVATEE [ ] PROPOSED CONSERVATEE

6. (continued)

**D. Ability to modulate mood and affect.** The (proposed) conservatee [ ] has [ ] does NOT have a pervasive and persistent or recurrent emotional state that appears inappropriate in degree to his or her circumstances. (If so, complete remainder of item 6D.) I have no opinion. (Instructions for item 6D: Check the degree of impairment of each inappropriate mood state if any as follows: a = mildly inappropriate, b = moderately inappropriate, c = severely inappropriate.)

<table>
<thead>
<tr>
<th>Anger</th>
<th>Joy</th>
<th>Euphoria</th>
<th>Anger</th>
<th>Joy</th>
<th>Euphoria</th>
</tr>
</thead>
<tbody>
<tr>
<td>a</td>
<td>b</td>
<td>c</td>
<td>a</td>
<td>b</td>
<td>c</td>
</tr>
<tr>
<td>a</td>
<td>b</td>
<td>c</td>
<td>a</td>
<td>b</td>
<td>c</td>
</tr>
</tbody>
</table>

**E. The (proposed) conservatee's periods of impairment from the deficits indicated in items 6A–6D.**

1. [ ] do NOT vary substantially in frequency, severity, or duration.
2. [ ] do vary substantially in frequency, severity, or duration (explain; continue on Attachment 6E if necessary):

<table>
<thead>
<tr>
<th>Signatures:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

**F. (Optional) Other information regarding my evaluation of the (proposed) conservatee's mental function (e.g., diagnosis, symptomatology, and other impressions) is [ ] stated below [ ] stated in Attachment 6F.**

This is the opportunity to indicate any environmental or social factors that compound the mental capacity issues.

### Ability to Consent to Medical Treatment

7. Based on the information above, it is my opinion that the (proposed) conservatee:

a. [ ] has the capacity to give informed consent to any form of medical treatment. This opinion is limited to medical consent capacity.

b. [ ] lacks the capacity to give informed consent to any form of medical treatment because he or she is either (1) unable to respond knowingly and intelligently regarding medical treatment or (2) unable to participate in a treatment decision by means of a rational thought process, or both. The deficits in the mental functions described in item 6 above significantly impair the (proposed) conservatee's ability to understand and appreciate the consequences of medical decisions. This opinion is limited to medical consent capacity.

(Declarant must initial here if item 7b applies: _ _)  

Number of pages attached: _ _  

I declare under penalty of perjury under the laws of the State of California that the foregoing is true and correct.  

Date: _ _

(TYPE OR PRINT NAME)  

(SIGNATURE OF DECLARANT)

**Capacity Declaration—Conservatorship**

Page 3 of 3

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**ADVANCED MODULE 3**  

-22-  

7/12/2010

Version 2
Slide # 27

Consent

Requires that the consenting person:

1. Possesses the mental capacity to make an intelligent choice whether to do something proposed by another person.
2. Is acting freely and voluntarily and not under the influence of threats, force or duress.
3. Has knowledge of the true nature of the act or transaction involved.
4. Merely being passive does not amount to consent; requires free will and positive cooperation to act.

Slide # 28

Principles of Legal Decision-Making Capacity

1. No single standard
2. Normal adults are presumed to have capacity.
4. Diagnosis does not constitute incapacity.
5. Cognitive impairment does not constitute incapacity.
6. The more significant the decision, the higher the level of capacity needed.
### Criteria for Specific Actions or Decisions

<table>
<thead>
<tr>
<th>Decision or Action</th>
<th>Criteria</th>
</tr>
</thead>
</table>
| Capacity to make medical decisions or execute advance health care directives | The patient must have the ability to:  
  - Understand the medical problem  
  - Understand the proposed treatment  
  - Understand alternatives to the proposed treatment  
  - Understand and appreciate the foreseeable benefits and risks of the treatment and of postponing or refusing it.  
  - Communicate decisions |
| Capacity to execute a will (testamentary) | The person must:  
  - Have the ability to describe what a will is  
  - Have the ability to describe a basic plan for distributing their assets to heirs  
  - Know the nature and extent of his or her bounty  
  - Be able to identify or recognize potential heirs and beneficiaries |
| Capacity to contract | The person must be able to understand the nature and consequences of the transaction. |
| Capacity to give gifts (donative) | The person must have an intelligent perception and understanding of the dispositions made of property and the person and objects one desires shall be the recipients of one's bounty |
| Capacity to create or revoke a power of attorney | Traditionally based on the capacity to contract although some courts have held that the standard is similar to that for making a will. APA-ABA |
| Triggers for taking protective action |  
  - The existence of diminished capacity  
  - A risk of substantial harm  
  - An inability to act adequately in one's own interest (includes that ability to withstand undue influence) |
| Probate conservatorship | California courts use capacity declarations, which can be filled out by doctors, psychologists and religious healing practitioner address the following elements of executive function  
  - Alertness and attention  
  - Information processing.  
  - Thought disorders  
  - Ability to modulate mood and affect. |

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2 Recommended for lawyers under the American Bar Association's Model Rules of Professional Conduct.
ETHICAL AND CULTURAL ISSUES

Slide # 29

<table>
<thead>
<tr>
<th>Ethical Principles</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autonomy</td>
<td>The right of individuals to make decisions for themselves that are voluntary and intentional, and not the results of coercion, duress or undue influence.</td>
</tr>
<tr>
<td>Least restrictive alternatives.</td>
<td>Options that are least restrictive of incapacitated persons' autonomy, independence, and freedom of choice.</td>
</tr>
<tr>
<td>Beneficence</td>
<td>&quot;Doing good for others&quot; or promoting their welfare. When clients cannot make decisions for themselves, workers must act in their best interest.</td>
</tr>
<tr>
<td>Justice</td>
<td>The fair and equitable distribution of benefits and burdens. Workers must balance the needs of self-neglecting clients against those of other clients.</td>
</tr>
<tr>
<td>Nonmaleficence</td>
<td>&quot;Do no harm.&quot;</td>
</tr>
<tr>
<td>Privacy</td>
<td>People's right to control information about themselves.</td>
</tr>
</tbody>
</table>
Code of Ethics
© NAPSA 2004

Adult Protective Services Ethical Principles and Best Practice Guidelines

*Dedicated to the memory of Rosalie Wolf*

**Adult Protective Services** are those services provided to older people and people with disabilities who are, or are in danger of being mistreated or neglected, are unable to protect themselves, and have no one to assist them.

**Interventions provided by Adult Protective Services** include, but are not limited to, receiving reports of adult abuse, exploitation or neglect, investigating these reports, case planning, monitoring and evaluation. In addition to casework services, Adult Protection may provide or arrange for the provision of medical, social, economic, legal, housing, law enforcement or other protective, emergency or supportive services.

**Values**

*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 people and people with disabilities who are victims of abuse, exploitation or neglect 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 some of these rights have been restricted by court action.
- Adults have the right to make decisions that do not conform with societal norms as long as these decisions do not harm others.
- Adults are presumed to have decision-making capacity unless a court adjudicates otherwise.
- 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 your 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—community based services rather than institutionally based services whenever possible.
- 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.
Hierarchy of Approaches to Surrogate Decision-Making.

Even when people cannot express preferences, their autonomy should be respected to the extent possible. The following hierarchy of approaches applies:

- Honor preferences that the person has expressed in the past. These can be determined by consulting clients' records and people who know them. It should be noted, however, that past preferences may need to be re-considered. For example, it may no longer be advisable for a client who consumed alcohol in moderation in the past to continue in do so in light of illnesses, medications, etc.

- If preferences are not known, surrogates should use "substituted judgment." This means that decisions should be based on what the person would have wanted or preferred. This approach requires substantial information about clients' views and wishes.

- When there is insufficient information on which to base substituted judgment, surrogates must decide based on their judgment about what would be in the "best interest" of the patient. Estimates of best interest are based on what a rational, normal person would prefer, not just on what the surrogate prefers.

- In cases in which physicians, surrogates, other family members, service providers, or other legitimately involved persons disagree about what is in the person's best interest, parties should be encouraged and provided with opportunities to meet to exchange information and views.

- In cases where agreement cannot be reached, interested parties should consult ethics committees if available. Other options include multidisciplinary elder abuse teams or other problem-solving groups.

- When a surrogate or physician is acting against the expressed preferences or best interest of the patient and consultation with an institutional ethics committee fails to bring a resolution of the disagreement, the courts can be consulted to order treatment or appoint a conservator.
Cultural Variables
Do all cultural groups share the same values?

Small Group Assignment

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<td>Read through the case.</td>
<td>Answer the questions</td>
</tr>
</tbody>
</table>
Case 1: Mrs. Alvarez

Mrs. Alvarez is 92 years old and lives alone in an apartment. She has 10 cats and her home is filthy and infested with fleas, lice, cockroaches and flies. Neighbors have called the police to complain about the odor. On several occasions, neighbors and the facility’s manager have made reports to APS. Each time APS has investigated, they have found Mrs. Alvarez to be marginally capable of making decisions. Recently, the management sent her an eviction notice stating that if she does not clean up the apartment immediately and get rid of the cats, she will be evicted. She wants to stay in the apartment.

Questions for small group

- What interventions should be considered? What are the benefits, risks and limitations of each?
- What interventions should be tried first and why?
- How would you evaluate Mrs. Alvarez’ decision-making capacity and ability to consent to services?
- What ethical issues does the case raise?
- What is APS’ role in this case?
Case 2 Mr. Smith

Mr. Smith suffers from severe diabetes. After his wife died four years ago, he stopped following the regimen for diabetics his doctor prescribed. He eats mostly snack foods, is overweight, and refuses to monitor or have others monitor his blood sugar level. He has repeatedly been referred to APS but refuses services and has been assessed as marginally able to make decisions. APS has kept his case open and continued to check in with him occasionally. Those working with him are unsure of whether his lack of self-care is due to apathy, depression or because he doesn’t understand what needs to be done.

As a result of the uncontrolled diabetes, Mr. Smith developed edema and lesions in his left leg. He was recently admitted to the hospital with a gangrenous foot and his doctors are recommending amputation. Mr. Smith is refusing to give consent and his physician does not believe he understand the risks.

Questions for group

- What interventions should be considered? What are the benefits and drawbacks of each?
- What interventions should be tried first and why?
- What factors and criteria should be considered in determining whether Mr. Smith has legal decision-making capacity?
- What ethical issues do the case raise?
Case 3: Mrs. Wells

Mrs. Wells is 78 years old. At 76 she began losing her vision as a result of glaucoma. She is now totally blind in one eye and almost blind in the other. She has become increasingly depressed and started drinking heavily. She is unable or unwilling to take medication that her doctor prescribed for the glaucoma and has refused assistance from a home health agency to assist with the administration of the medication. She has also refused training to help her adapt to her blindness and offers of assistance from the Department for the Visually Handicapped. As a result, She has not learned how to manage her finances. Six months ago, she agreed to have a personal care attendant several times a week to shop for her. The attendant fills out the checks and has Mrs. Wells sign them.

The attendant recently came to the bank and attempted to close out the account, which contained $15,000. The bank employee refused, stating that the attendant had no authority to do so. The attendant claimed that she had Mrs. Well’s permission and asked the bank employee for a power of attorney form, stating that would return with Mrs. Well’s signature. The employee contacted APS and a worker went out to investigate. Mrs. Wells did not seem to understand how much money she had or that she was at risk of being exploited. When asked what Mrs. Wells wanted to do about the situation, she stated “Let’s just wait and see.”

Questions for small group

- What interventions should be considered? What are the benefits and drawbacks of each?
- What interventions should be tried first and why?
- What factors and criteria should be considered in determining whether Mrs. Wells has legal decision-making capacity?
- What is APS’ role in this case?
Case 4. Mr. Chambers

Mr. Chambers, who is 92 years old, is frail and emaciated. He lives alone and has managed marginally for several years. He pays bills sporadically but is occasionally without electricity and food. He has two children who live out of state from whom he is estranged.

He recently suffered a stroke and was brought to the emergency room and hospitalized for approximately a week. He wants to go home but the hospital discharge team feels that he is unsafe at home and can no longer live independently. They have recommended nursing home placement but the county’s nursing home refused to accept him because he has no “responsible party.” The hospital is claiming that the costs of the unnecessary hospitalization will impact other patients. The public guardian has refused to take the case because Mr. Chambers is not at imminent risk.

Questions for small group

- What interventions should be considered? What are the benefits and drawbacks of each?
- What interventions should be tried first and why?
- What factors and criteria should be considered in determining whether Mr. Smith has legal decision-making capacity?
- What ethical issues do the case raise?
- What is APS’ role in this case?
CAREGIVING SYSTEMS

TIME ALLOCATED: 25 minutes

Slide # 33

Mr. Nobody (40 minutes)

- Interventions
- Examples of due diligence

Slide # 34

Caregiving systems

Neglect and Self-Neglect as the Absence or Breakdown of Caregiving Systems *

Absent or “broken” caregiving systems

1. Overwhelmed Caregiving Systems
2. The Dysfunctional Caregiving System
3. The Self Interested Caregiver
4. The Elder Alone
5. Elders who Refuse Care
Neglect and Self-Neglect as the Absence or Breakdown of Caregiving Systems*

Types of Neglect and Self-Neglect

A. Overwhelmed Caregiving Systems

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

B. The Dysfunctional Caregiving System

1. Definition: A caregiving system is in place but the dynamics between caregivers, or between caregivers and older person are characterized by dysfunction.
2. Examples:
   a) The older person is difficult and alienates others - choreworkers quit or the older person fires them.
   b) Family members are estranged.
   c) Feuding families. You may have sibling feuding with each other or with the older person.
   d) Alcoholic families.
3. Prognosis: Not good unless “tolerant outsiders” (people who are not involved in the conflict) can be found.
4. Promising Approaches: The likelihood of success improves if feuding family members are kept involved (so that they won’t sabotage treatment plans), but are not in control. Guardianship can be very helpful to shift responsibility away from people who are enmeshed in the conflict.
C. The Self Interested Caregiver

1. Definition: Someone has responsibility for providing but the care is inadequate because the caregiver is really just in it for the money.
2. Examples:
   a) Caregiver is being paid or stands to inherit.
   b) But they’re really just concerned or preoccupation with their own interests.
   c) Accounted for the fewest number of cases
3. Prognosis: Interventions are relatively simple if caregivers were removed as responsible parties.

D. The Elder Alone

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

E. Elders who Refuse Care

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

DUE DILIGENCE DEFINED

TIME ALLOTTED: 30 minutes

Slide # 36

Due Diligence Defined

- The level of care or judgment that reasonable and prudent parties would be expected to exercise in given situations to avoid harming themselves or others.
- Following ethical standards
- Going above and beyond

Slide # 37

Due Diligence in APS Practice (Duke, 2003)

An APS worker exercising due diligence:

- Determines the causes of bruises and other injuries.
- Knows the client’s lifestyle and preferences.
- Takes all appropriate action in the pursuit of the client’s safety and well-being.
- Follows all reasonable leads.
- Knows all applicable state and local policy and procedures.
Following Policies and Procedures

Workers must follow:
- Legal mandates and applicable laws
- Agency policies and procedures, including:
  - Chains of command
  - Eligibility criteria (with respect to self neglect cases)
  - Appeals process (e.g., if they disagree with supervisors)
  - Confidentiality
  - Record keeping

Complying with Accepted Community Standards

- Present cases at community problem-solving forums, such as multidisciplinary teams, geriatric mental health teams, and ethics committees
- Stay apprised of current literature on self neglect
- Stay apprised of community resources and training opportunities

Documentation

In Legal Proceedings:
- Demonstrate the need for conservatorship
- Keep an abusive or otherwise inappropriate relative from being appointed as conservator or guardian
- Provide the basis for protective orders
- May be used as evidence in criminal cases
- May be requested when workers or their agencies are being sued
- When workers’ conduct is questioned by licensing boards or professional associations
Slide # 41

What to Document: Capacity and Consent

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

Slide # 42

Preferences, Values, and Lifestyles

Client’s (or others’) statements about:
- Treatment and service preferences
- Indicators of clients’ wishes and preferences (e.g. advance directives or statements to others like “I never want to live like a vegetable”)
- Values
- Life-style

Slide # 43

What to Document: Workers’ Actions

- Actions taken by workers
- Reasons for actions not taken
- Indicators that workers followed their agencies’ chains of command, such as consulting with supervisors, following rules concerning documentation, etc.
Documentation

While good documentation is an essential part of APS practice, it is especially critical in self neglect cases for the following reasons:

- APS may be involved with clients continuously or repeatedly over long periods. Good documentation can ensure continuity of care by providing a record of developments and agencies' involvement in cases, which can be accessed by substitute or newly-assigned workers, supervisors and others.
- Documentation collected over time provides a “baseline,” which can alert workers to changes in clients' health, cognitive status, conditions or circumstances over time.
- There is a tendency for workers to document what they do, not what they don’t do. It is particularly important in self neglect cases for them to documents actions they did not take (options that were proposed and refused)
- Documentation of self neglect is likely to be used in legal proceedings.

Documentation may be needed in self neglect cases to:

- Demonstrate the need for conservatorship
- Keep an abusive or otherwise inappropriate relative from being appointed as conservator or guardian
- Provide the basis for protective orders
- May be used as evidence in criminal cases
- May be requested when workers or their agencies are being sued
- When workers’ conduct is questioned by licensing boards or professional associations

The following should be documented:

Physical signs and symptoms
The following physical signs and symptoms of self neglect can be documented using photographs, descriptions, and body maps, which are drawings of the front, sides, and back of a human figure:

- Bruises and other injuries (photographs, descriptions and body maps, which are drawings of the front, sides, and back of a human figure, can be used to describe injuries)
- Pressure ulcers
- Weight loss
- Dental problems
- Deteriorated or dilapidated living conditions, filth, pest infestations
- Signs of hoarding and cluttering
- Adequacy of facilities. Are there hazards or dangers, adequate heating, etc.
- Evidence of medication mismanagement, non compliance, etc.
- Adequate clothing and assistance devices
- Evidence of alcohol or substance abuse
Behavioral Signs and Symptoms
- Lethargy
- Depression
- Signs of post traumatic stress disorder (PTSD) including withdrawal, hyper-vigilance and fear
- Patient’s demeanor (the patient is crying, shaking, angry, agitated, upset, calm, or happy.
- Sexual “acting out” (may be a sign of sexual assault).
- Fearfulness, distrust
- Hallucinations
- Alertness
- Flat affect
- Agitation and anxiety

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

Indicators of Clients’ Preferences, Values and Lifestyles
Indicators of preferences, values and lifestyles can be documented by recording clients’ (or others’) statements about:
- Their treatment and service preferences
- Their wishes and preferences as told to others or as indicated in advance directives
- Values
- Life-style

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

TIME ALLOTTED: 15 minutes

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Slide # 44

Partners

Agencies and Disciplines Involved in Self Neglect Cases
- Mental health professionals (geriatric psychologists, psychiatrists, etc.)
- Geriatric physicians and nurses
- Civil attorneys
- Conservators, including private professionals and agencies
- Public Guardians
- Probate court Investigators
- Case managers
- Clergy
- Local law enforcement, including police and sheriffs
- Animal welfare organizations (humane societies and rescue organizations)
- Ethics Committees
- Multidisciplinary teams
- Support services

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Slide # 45

Promising Practices

- Ethics committees
- Code enforcement task forces
- Hoarding treatment programs
- Programs to increase number of conservator
Best Practices in Self Neglect

- The Santa Clara County (California) Medical Association, working with a multidisciplinary team, developed a protocol entitled, “Medical Decision Making for the Unbefriended,” which has been distributed to all acute care hospitals in the county. They have also developed protocols for “do not resuscitate (DNR)” orders and the delivery of futile medical care.

- To encourage family members to serve as conservators, Contra Costa County has a conservatorship workshop where family members who want to serve or who are currently serving as conservators can get help.

- Santa Clara County has a medical ethics committee that routinely reviews cases involving elders with diminished mental capacity who need medical treatment and lack surrogates. The group was, in one case, granted Probate Code §3200 powers to make medical decisions for an “unbefriended” elder.

- San Francisco APS has developed a referral panel of private professional conservators. To be included on the panel, conservators must agree to provide occasional pro bono services.

- Several courts in California have started self-help conservatorship clinics, which permit families and friends of incapacitated elders to file for conservatorship without the assistance of lawyers.

- San Francisco’s Code Enforcement Task Force responds to reports of homes that are hazardous to occupants and neighbors as a result of deterioration, garbage piling up, multiple animals, pest infestations, drug activity, etc. Members represent city attorneys; police, fire, and health departments, building inspectors, and planning departments. Although their primary goal is to make owners take responsibility for upkeep, team members also work with APS and other social service providers to address the needs of occupants, which often include self neglecting elders. The team may exert pressure or provide leverage to get self neglecting elders to improve their residences to avoid eviction or lawsuits or to comply with court orders. Upon receiving reports, members inspect the premises, record code violations, inform owners, suggest corrections, and set a deadline for making repairs.

- In Los Angeles County, the Departments of Aging, Housing, Animal Services, and Mental Health work together to address the needs of residents who hoard. The county
organized the Hoarding Task Force, a multidisciplinary team that meets monthly to discuss cases and sponsors an annual conference, which teaches supportive counseling techniques for working with elderly hoarders and informs participants of available resources. A needs assessment is currently being conducted.

- Humboldt County uses a team approach that pairs APS workers and public health nurses (PHN). The PHNs are funded by SPMP (Skilled Professional Medical Personnel), TCM (Targeted Case Management) and APS allocation. They have observed that PHN’s are often better able than APS workers to gain access in self neglect situations. The nurses make safety and medical assessments, encourage clients to seek medical care, and provide liaison with hospitals and physicians’ staff. They are further integrating a mental health clinician into the team.

- Geriatric Evaluation Networks Encompassing Services, Information and Support (GENESIS) is a partnership between Los Angeles’ Department of Mental Health and the Department of Community and Senior Services/Adult Protective to provide mobile health and mental health support for frail homebound elders. The agencies coordinate their activities through interagency agreements, use of shared assessment protocols, clinical case conferences, joint planning, and disposition. The program has been particularly effective in helping victims of elder abuse who have mental health problems. GENESIS' mobile, "trans/multidisciplinary" teams are each composed of a licensed clinical social worker and registered nurse who conduct joint in-home visits to provide mental health assessments, crisis stabilization, short-term treatment, and linkage to needed services. In addition, GENESIS has on staff a geriatric internist, nurse practitioner, and gerontologist. In 1999, GENESIS signed a formal memorandum of understanding (MOU) with Adult Protective Services to provide assessment to older adults, who APS believes may have a mental health issue that puts them at risk.

**Resources**

- Bibliography on Self-neglect. The Clearinghouse on Abuse and Neglect of the Elderly (CANE), maintains a collection of publications and elder abuse and neglect for the National Center on Elder Abuse. CANE has produced an annotated bibliography on self neglect, which is available on-line: http://www.elderabusecenter.org/default.cfm?p=cane_neglect.cfm

- A Day in the Life of Adult Protective Services. This in-depth report produced by the California Welfare Directors’ Association describes calls made to Adult Protective Services in one 24 hour period. Synopsis of the calls, data, and recommendations and recommendation. The original report and updates are available online at http://www.cwda.org/publications/adult.php

• Animal Hoarding: Structuring Interdisciplinary Responses to Help People, Animals and Communities at Risk. This publication was produced in 2006 by the Hoarding of Animals Research Consortium (HARC), which is affiliated with Tufts University Veterinary School and the Massachusetts chapter of the Society for the Prevention of Cruelty to Animals. It is available on-line at: www.tufts.edu/vet/cfal/hoarding.


Websites

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<th>Websites</th>
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<td>California Attorney General’s Office</td>
<td><a href="http://caag.state.ca.us/">http://caag.state.ca.us/</a></td>
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<td>California Courts Self Help Center</td>
<td><a href="http://www.courtinfo.ca.gov/selfhelp/">http://www.courtinfo.ca.gov/selfhelp/</a></td>
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<td>California Department of Aging</td>
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<td>Consortium for Research in Elder Self-Neglect (CREST) led by Baylor College of Medicine</td>
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Research

The Consortium for Research in Self-Neglect of Texas (CREST) is an interdisciplinary collaboration led by the Texas Elder Mistreatment Institute, Baylor College of Medicine, that is attempting to establish a case definition for self-neglect and strategies for prevention and intervention. They are looking at relationships among self-neglect and executive dysfunction, alcohol abuse, hoarding behavior, and nutrition and are attempting to develop risk and severity assessment tools for self-neglect. The team has developed a instrument, the KELS Test, for Substantiating self neglect. See www.bcm.edu/crest/?PMID=4143 and www.bcm.edu/crest/?PMID=0.
The Leonard Schanfield Research Institute, Council for Jewish Elderly; in collaboration with the University of Illinois-Chicago, is refining and testing a client assessment instrument for detecting risk or signs of self-neglect in community-dwelling elders. Specific objectives of the project, which is funded by the Retirement Research Foundation, are to identify and rank key risk indicators for self neglect. Ten clusters of risk factors have emerged: mental health assessment; hoarding; infection control; medical health issues; level of cooperation (compliance/adherence); emotional assessment; social/cultural issues; and financial issues.
REFERENCES


