# BUILDING CONSENSUS ON RESEARCH PRIORITIES IN ELDER MISTREATMENT

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United States Department of Justice, July 2015

#### **Abstract**

A survey of 26 leading U.S. elder abuse and financial exploitation researchers served as the basis for prioritizing critical knowledge gaps in the field. Three major themes emerged from this effort:

- (1) the need for psychometrically sound and consistent measurement;
- (2) research on strategies to prevent elder abuse and financial exploitation; and
- (3) the need for research on specific causes or risk factors as well as consequences for each type of abuse and exploitation.

The survey results provide evidence for a targeted national elder abuse and financial exploitation research agenda.

## BUILDING CONSENSUS ON RESEARCH PRIORITIES IN ELDER MISTREATMENT

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A survey of 26 leading U.S. researchers in the field of elder abuse and financial exploitation was conducted and served as the basis for prioritizing the most salient gaps in knowledge in the field. The survey indicates that of 18 Topics identified in the literature as research gaps, six are ranked as the most significant warranting immediate additional research. In order of their assessed importance, the rankings of these Topics are as follows:

Rank	Торіс	
1	Definitions & Measurement	
2.5*	2.5* Intervention Outcomes	
2.5*	Longitudinal Research	
4	Risk Factors	
5.5†	Adult Protective Services	
5.5†	Financial Exploitation	
	*Two Topics are tied for second place	

<sup>†</sup>Two topics are tied for fifth place

#### **INTRODUCTION & BACKGROUND**

The last decade of research in the field of elder mistreatment has produced a growing literature. (For the remainder of this brief, "elder mistreatment" is used to include the various forms of elder abuse and financial exploitation.) The growth in research in the field led to several important efforts to elaborate what the research community considers to be gaps in knowledge.<sup>1</sup> However, none of these efforts have resulted in a *prioritized* list evaluating which of the research knowledge gaps are most central and important for moving the field forward.

The United States Department of Justice (DoJ) undertook an effort to meet this prioritization need. Given limited available research funding, DoJ was interested in creating a clearer picture of research needed to facilitate progress in understanding and in addressing social

<sup>a</sup>National Research Council. (2003). Elder Mistreatment: Abuse, Neglect, and Exploitation in an Aging America. BJ Bonnie, RB Wallace, eds. Washington, DC: The National Academies Press. <sup>b</sup>The National Institute on Aging and the National Academies of Science. (2010). Expert Meeting on Research Issues in Elder Mistreatment and Abuse and Financial Fraud - See: <u>http://www.nia.nih.gov/about/events/2011/meeting-research-issues-elder-mistreatment-and-abuse-and-financial-fraud#sthash.W46xTKaU.dpuf</u> <sup>c</sup>Testimony before the U.S. Elder Justice Coordinating Council. (2012).

http://www.aoa.acl.gov/AoA\_Programs/Elder\_Rights/EJCC/Meetings/docs/EJCC%20Panel%204%20Adva ncing%20Reasearch.pdf

<sup>d</sup>U.S. Department of Justice. (2014). The Elder Justice Roadmap. Washington, DC: U.S. DoJ.

<sup>&</sup>lt;sup>1</sup> Examples of these efforts include:

problems represented by elder mistreatment. This brief provides information regarding those prioritized Topics based both upon the field's literature and the survey of expert researchers. It also provides the specific research questions and issues for advancing the field within each of the Topics.

#### FINDINGS

Three themes dominate the selected Topics and the research questions and issues most highly ranked.

First, several of the most frequently selected research questions concern the very basic need for psychometrically sound and consistent measurement of elder abuse and financial exploitation. The consensus of those sampled suggests that a definition and measurement gap exists within both the research community and the practice community. It may be argued that measurement consistency is not a topic for additional research. However, the creation of psychometrically valid and reliable definitions and measurement is a basic tenet of sound research. The literature currently yields wide variance in conceptual meanings and operational definitions both within and between each of these communities.

The United States Preventive Services Task Force (USPSTF) Recommendation Statement<sup>2</sup> that includes elder abuse reaches a similar conclusion. It states that there are "...varying definitions of abuse, a wide variety of mechanisms of elder abuse, no universal screening tools, wide-ranging risk factors, unclear guidance about whom to screen and what to do if abuse is identified ...." (p.481) The USPSTF goes on to amplify the critical need for psychometrically sound definitions and measures by pointing out the lack of accepted reference standards: "...development or validation of an accepted standard would allow more accurate assessment ... and allow instruments to be more readily compared with each other. The broad and inconsistent definitions of abuse pose challenges for creating screening instruments...." (p. 482).

The second theme concerns prevention. Sampled researchers selected research questions across the range of Topics dealing with interventions to prevent the reoccurrence (secondary prevention) of elder mistreatment. This is evident in items selected regarding the efficacy of Adult Protective Services and Intervention Outcomes (see below). Items dealing with the development of mechanisms measuring the "desirability" of outcomes and defining and measuring interventions impacting elder mistreatment were frequently selected. The development of such interventions is basic to social service practice regarding elder mistreatment. Although the research questions selected emphasize secondary prevention, lessons learned from such interventions will undoubtedly lead to interventions that prevent elder mistreatment from happening in the first place (primary prevention). Primary prevention represents a more difficult research problem since the identification of elders at risk of mistreatment requires an entirely different approach in identifying at risk populations. Evaluating the efficacy and effectiveness of these interventions constitutes a significant research need in the field. The USPSTF also concurs in the need for evidence-based interventions: "…studies are needed to determine the effectiveness of different post-screening interventions.

<sup>&</sup>lt;sup>2</sup> Moyer VA. (2013) Screening for intimate partner violence and abuse of elderly and vulnerable adults: U.S. Preventive Services Task Force Recommendation Statement. *Ann Intern Med* 158:478-486.

...good-quality randomized, controlled trials focusing on both screening and interventions are needed." (p.482)

The final theme is closely related to both definition and measurement consistency and the development and evaluation of interventions to prevent elder mistreatment. This pervasive theme relates to understanding the causes of specific forms of elder mistreatment and the consequences of these specific types of elder mistreatment. This objective is generally met through longitudinally designed research, although other methodologies such as propensity scoring are available. Cause-and-effect research is basic to the field. An elaboration of risk factors, both for victim and perpetrator, addresses this basic need for understanding circumstances that lead to specific types of elder mistreatment. The inverse of risk factors is also in need of additional research: what are the resilience factors that protect the majority of senior s from mistreatment. Modifiable risk and protective factors are important to eliminating causes of elder mistreatment and reducing its incidence.

### SPECIFIC RESEARCH QUESTIONS AND ISSUES

A total of 152 specific research questions and issues were abstracted from the extensive literature search and categorized into specific Topics. (See the following "Methods" section for detail on the procedures used and the sample of researchers.) The following set represents a summary of the specific research questions and issues for each of the six top ranked Topics.

#### **Definitions and Measurement**

- Develop comprehensive, consistent and widely accepted operational definitions for the various forms of elder mistreatment.
- Create psychometrically sound instruments to measure the various forms of elder mistreatment.

### Intervention Outcomes

- Develop research on conducting interventions addressing elder mistreatment and defining and measuring outcomes of these interventions.
- Conduct qualitative research on what victims of elder mistreatment consider to be successful and desirable outcomes of interventions.

### Longitudinal Research

- Research is needed on the phenomenology and clinical course of elder mistreatment including its etiology, nature, periodicity, variation, risk factors, triggers and consequences using longitudinal research designs.
- Conduct longitudinal research to separate causes from consequences.
- Conduct longitudinal research on the intersection of the changing dynamics between victim and perpetrator (i.e., the "trust relationship") and contextual factors (e.g., poverty, diminished capacity; substance abuse; mental illness).

#### **Risk Factors**

• Conduct research on the risk factors of victims and perpetrators that includes contextual factors (e.g., poverty; substance abuse; mental illness; diminished cognitive capacity;

functional impairments such as vision, hearing and mobility limitations; and other family issues).

• Conduct research on risk factor status among minority populations including cultural variation in how mistreatment is defined and perceived.

Adult Protective Services<sup>3</sup>

• Conduct research on each of the APS processes including triage, investigation, service planning and delivery to determine the efficacy and gaps in APS activities.

Financial Exploitation<sup>4</sup>

- Develop longitudinal studies targeting financial exploitation to determine risk factors, causality and consequences for elderly victims.
- Develop research on the relationship between financial exploitation and cognitive decline to determine the causal direction of these factors.

The following table presents the number of "votes" awarded each of the 18 Topics by the respondents.

8*	Adult Protective Services	5	Minorities & Vulnerable Populations
6	Cognitive Capacity	3	Multi-disciplinary Teams
3	Criminal Justice	5	National Database & Research Agenda
11	Definitions & Measurement	6	Prevalence/Incidence
8	Financial Exploitation	4	Prevention
5	Infrastructure & Funding	9	Risk Factors
10	Intervention Outcomes	4	Screening & Forensic Markers
3	IRB & HIPAA	4	Self-neglect
10	Longitudinal Research		
5	Long-term Care Facilities		*Number of times Topic selected

### **METHODS**

A list of 152 specific research questions and issues related to research was gleaned from an extensive literature review. These questions and issues were content analyzed and categorized into the 18 Topics listed above. Of necessity, some overlap exists between Topics and between specific questions and issues. It is impossible to create mutually exclusive Topics and mutually exclusive questions and issues. For example, Adult Protective Services deal with Financial Exploitation (two separate Topics). Overlap serves to highlight and amplify the necessity for multi-disciplinary research on elder mistreatment.

Once the 18 Topics and 152 specific questions and issues were compiled, they were sent to 26 leading researchers in the field. The group of 26 was selected based upon their outstanding publication histories as well as the opinion of individuals familiar with research literature in the

<sup>&</sup>lt;sup>3</sup> Only one research question or issue was selected by 1/3 of the respondents. (See Methods section for explanation.)

<sup>&</sup>lt;sup>4</sup> Only two research questions or issues were selected by 1/3 of the respondents. (See Methods section for explanation.)

field. Twenty two of the 26 researchers returned materials (85%). The respondents were asked to select five Topics they considered most significant for moving the field forward. Respondents were also asked to select the specific research questions and issues from the list of 152 that they assessed as meeting the same criterion. Respondents were free to select from any Topic areas and not just those five they felt were most critical for advancing the field.

Since two of the Topics were tied for fifth place, six Topic areas are presented in this analysis. For each of the six high priority Topics, research questions and issues selected by approximately 1/3 of the respondents are presented above. These research questions and issues were assessed as warranting the most immediate and necessary research attention. Appendix A presents all research questions and issues, by Topic. An explanation of the content of each of the 18 Topics as presented to the respondents is also found in Appendix A. The frequency with which research questions and issues were selected is also presented. The analysis is based upon these data. In addition, eleven of the 22 respondents made extensive comments on the Topics and specific research questions and issues. Appendix A includes the edited Topics, specific research questions and issues and more general comments made by the researcher respondents.

Sidney M. Stahl July 6, 2015 <Research Gaps MS.7.6.2015>

## Appendix A

## Topics, Research Questions and Issues and Respondent Comments and Suggestions

\*Number of times a specific Question or Issue was selected. Comments, suggestions and suggested edits by respondents are italicized.

<u>ADULT PROTECTIVE SERVICES</u>: includes research on Adult Protective Services (APS) to determine their role in investigation, substantiation, and mitigation of elder mistreatment. Research on various APS activities and agency interactions with other related services is included.

uger	icy interactions with other related services is included.
3*	Research is needed on the issue of caseness or "case identification" so that there is a universal understanding and identification of substantiated elder mistreatment.
5	Conduct research on the efficacy and effectiveness of adult protective services interventions by comparing outcomes in cases in which services were provided and those in which eligible recipients declined offered services.
5	Survey APS agencies for their intervention programs by type of elder mistreatment, codify these remediation measures (e.g., institutionalization; "foster" homes; safe houses; removal of perpetrators) and evaluate them for efficacy, effectiveness and cost.
2	Encourage research using existing APS administrative and case data to make improvements in data by finding common elements between agencies/states to encourage the improvement of generated data. ( <i>NOTE: several respondents questioned the wisdom of pursuing this question since the "data are seriously flawed."</i> )
4	Conduct research on elders' accounts of suspected and substantiated cases and the perceptions and self- definitions of seniors regarding their own security.
7	Conduct research on each of the APS processes including triage, investigation, service planning and delivery to determine the efficacy and gaps in APS activities.
3	In a limited geo-political setting, create a comprehensive database by linking different data sources (e.g., APS; local crime reports; law enforcement like the FBI National Incident Based Reporting System; medical records; forensic labs) to build a comprehensive model of elder mistreatment in a given setting.
4	Conduct research on the efficacy, quality and cost-effectiveness of APS responders to elder mistreatment.
4	Research is needed on how decision making capacity is assessed in the field by APS.
4	Conduct research evaluating the outcomes for the abused elder of APS identified interventions.
1	Conduct research to identify and verify the source of gaps between self-reported elder mistreatment and the incidence of cases substantiated by APS.
5	Develop consistent screening tools that are valid, reliable and generalizable across a number of race/ethnic- specific groups that can be used by APS.
2	Conduct systems level research to determine the applicability of safety audits used in domestic violence to determine if the social service network is adequately meeting the needs of the abused elder.
	Research is needed on how APS workers assess financial capacity and vulnerability to exploitation in their elderly clients.
	Develop risk assessment instruments, particularly for high risk situations, that guide APS decision making and interventions and potentially reduce the revolving door clients.
	Conduct research on alternative models to APS, comparing effectiveness of the new/modified system to standard care.
	What is the impact of self-determination on intervention in and the outcome of cases of elder mistreatment in both the APS and Criminal Justice systems?

**<u>COGNITIVE CAPACITY</u>**: includes research on developing or validating measures of cognitive capacity for use in all aspects of elder mistreatment research and practice. The purpose of this research is to provide frontline workers with the ability to assess cognitive capacity as it relates to screening, assessment and the disposition of elder mistreatment cases. Additionally, the roles of cognitive capacity as a risk factor and as an outcome of elder mistreatment are addressed.

3	Examine the National Institute of Health's Cognition Battery Toolbox
	(http://www.nihtoolbox.org/Pages/default.aspx) for its applicability to the various types of elder mistreatment
	and for use in the field by Adult Protective Services, law enforcement, and legal professionals.
4	Conduct measurement-related research on the feasibility, reliability and validity of incorporating cognitively
	impaired individuals into elder mistreatment incidence and prevalence studies.
5	Conduct research on the role of cognitive capacity as a risk factor for various forms of elder mistreatment using
	longitudinal studies or other research approaches to determine the causal link between cognitive capacity and
	elder mistreatment.
2	Examine the role of executive and cognitive dysfunction in abused elders who may not be able to make a self-
	preserving decision to extricate themselves from an abusive situation.
4	Provide Institutional Review Boards (IRBs) with guidance on the conduct of research with cognitively impaired
	participants and with appropriate responses by the researcher to evidence of mistreatment.
2	Research is needed on the ability of older persons with cognitive and functional impairment to provide accurate
	evidence regarding case identification in research, clinical settings and in legal settings especially in light of the
	impact of emotion upon memory.
1	Design and evaluate models for community-dwelling settings that can include cognitively impaired victims of
	elder mistreatment among their residents.
5	Determine what normal cognitive aging, prodromal dementia states (e.g., MCI) and which characteristic
	symptoms and which stages of dementia place the older person at greater risk for different types of elder
	mistreatment.
1	Study spousal dyads of older persons and parent/adult-child dyads where cognitive incapacity in one or both
	dyadic members increases the probability of elder mistreatment.
6	Conduct intervention research on enhancing caregiving skills to avoid elder mistreatment especially among
	cognitively impaired elders.
4	Conduct longitudinal research on the relationship between financial exploitation and changes in cognitive
	capacity to determine the causal direction.
	Conduct longitudinal research on the relationship of physical abuse and cognition over the course of a
	dementing illness.
	Conduct research on the when persons with dementia experience neglect and the reasons for that neglect.
Cor	<u>nment</u> : Evaluation of cognitive capacity should be subordinate to, and targeted towards, assessment of elderly
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clients' decisional capacity regarding their finances and personal and physical welfare. <u>Comment</u>: Regarding the introductory paragraph, one respondent questions the underlying assumption that "The purpose of this research is to provide frontline workers with the ability to assess cognitive capacity," saying that it is unlikely that this will be helpful.

<u>Comment</u>: My read of the cognitive capacity instruments (NIH's website and literature reviews) indicates that we're quite close to a pretty good instrument, but we need a little more work on development in either sensitivity or specificity, and then to ensure that the instrument is valid in the context of APS using it. So that's where I would put my limited dollars since almost all APS caseworkers do some type of cognitive assessment of alleged victim.

**<u>CRIMINAL JUSTICE</u>**: Includes research that addresses the criminal justice system's efforts to reduce the incidence of elder mistreatment. Also included are examinations of the criminal justice system's practices and organization at various levels as a deterrent to elder mistreatment.

7	Examine the efficacy of criminal justice interventions such as prosecution within specific socioeconomic,
	race/ethnic and gender communities as a response to elder mistreatment.
1	Examine outcomes of the ability of elder mistreatment victims to provide evidence and testimony in cases
	brought to trial and contrast that with other fields of violence (e.g., child abuse; intimate partner violence).
3	Conduct research on the ability of elders to provide accurate testimony at various levels of cognition based
	upon Gerontological research indicating the negative impact of emotion upon memory.
4	Examine the consequences of legal interventions in cases of self-neglect to determine the social, and
	economic and ethical costs of that intervention.
2	Conduct research on "hand-offs" between APS or the Ombudsman and the criminal justice system levels
	including police, prosecution, judicial hearings, and guardianship to determine system flow and barriers in the
	adjudication of elder mistreatment.
4	Conduct qualitative research from the perspective of the elder victim on the consequences of legal interventions
	involving the prosecution of a trusted others.

4	Conduct research on the efficacy of criminal background checks for new employees in institutional settings to	
	determine its impact upon making elders safer in these settings.	
1	Research is needed on the impact of various state public policy initiatives such as increasing the number of	
	prosecuted cases and whether these initiatives serve as a deterrent.	
	Determine the prevalence of elder abuse prosecution.	
	Research is needed to understand the magnitude of neglect including those who are neglected to death.	
	Validated tools are needed for coroners/medical examiners for when to take custody and how to distinguish	
	forensic markers from "normal" aging.	
	Research is needed on the usefulness and outcomes of "elder courts."	
	Research is needed on the usefulness of forensic center types of teams for the criminal justice system.	
	Research is needed on defining the role of a geriatrician across all aspects of a criminal elder abuse matter	
	(e.g., assisting with diagnosis/determination of criminal neglect; preparing for prosecution; their role as a	
	witness; their partnership with a medical examiner).	
	Conduct additional research on perpetrators (e.g., criminal background checks; arrest and conviction records;	
	gun ownership; the possibility of groups of perpetrators).	

<u>Comment</u>: There is a need to clarify the confusing idea that what constitutes elder mistreatment from a public health or social services perspective is different when compared to a criminal justice perspective since not all elder mistreatment reaches the threshold of a criminal offense.

**DEFINITIONS & MEASUREMENT**: includes research that establishes standardized definitions and measurement across all areas of elder mistreatment. It is important to assure reasonable measurement and definitional agreement between researchers and practitioners. Without such agreement, it is difficult to compare studies, establish assurance of comparability of practices or communicate between researchers, practitioners and those responsible for enforcing legal requirements in the field.

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14	Develop comprehensive, consistent and widely accepted operational definitions and validated and standardized measurement for the various forms of elder mistreatment for use by both the research and practice
	communities. ( <i>NOTE: two reviewers and this author feel that this is not a useful question since definitions of</i>
	necessity often differ between the two communities. Practitioners have different needs than researchers. The
	creation of standardized measures, etc., within each community was however felt to be an important goal.)
5	Conduct research on the measurement of the prevalence of elder abuse among people with diminished
5	cognitive capacity.
7	Create "gold standard" measures for each type of elder mistreatment to determine the presence or absence of
/	
	elder mistreatment using a "LEAD standard" (Longitudinal, Experts, All Data). (NOTE: one respondent noted
	that this is expensive and fairly difficult to do well; every study would need to have adequate funding for LEAD
10	panels if this is the "gold standard.")
10	Develop research on defining and measuring outcomes of interventions addressing elder mistreatment.
2	Compare various versions of the widely accepted Conflict Tactics Scale to determine its applicability to
	various types of elder mistreatment.
5	Develop consistent elder mistreatment surveillance & screening measures for use in institutional settings.
4	Use the National Library of Medicine's linguistic expertise related to the "Unified Medical Language System"
	to create federally shared taxonomy, nomenclature and measurement of elder mistreatment. (Note:
	communication with a CDC colleague indicates that their work on a shared taxonomy is due to be published in
	early 2015.)
5	For the most prevalent minority groups, conduct research to define the culture-specific construct of elder
	mistreatment for each group.
5	Conduct research that compares the various states' APS reporting systems for their definitions of confirmed
	elder mistreatment cases.
8	Create a consistent, unified Adult Protective Services reporting system across the US based upon uniform
	definitions and measurement.
Con	ment: There is a need for some greater [clarity] and delineation around the concept of elder abuse

*Comment:* There is a need for some greater [clarity] and delineation around the concept of elder abuse.

**<u>FINANCIAL EXPLOITATION</u>**: Includes research on financial exploitation in various institutional settings. Financial exploitation appears to be the most prevalent form of elder mistreatment and is growing in frequency and severity. The involvement of various financial institutions (e.g., banks; financial investment companies) is appropriate. In addition, research on the integration of cognitive capacity as it relates to financial exploitation is recommended.

Conduct research that estimates the costs and consequences of elder financial exploitation for the victim,
families and society.
Conduct research in conjunction with the financial industry that focuses upon financial fraud detection and
prevention.
Develop longitudinal studies targeting financial exploitation to determine risk factors, causality and
consequences for elder victims.
Develop research by working with financial institutions such as banks and fiduciary agents to evaluate the
utility of financial flow monitoring for vulnerable elders as a means of detecting financial exploitation.
Conduct research on the efficacy of monitoring financial transactions of seniors in Durable Power of Attorney
or Medical Power of Attorney relationships for untoward money transfers as a possible indicator of financial exploitation.
Conduct research on older and younger financial exploitation victims to determine if there is commonality
between these groups to detect risk factors and create preventive interventions.
Develop research on the relationship between financial exploitation, psychiatric factors in later life (e.g.,
depression; anxiety; loneliness; loss of support networks) and cognitive decline to determine the causal
direction of these factors.
Develop research that uses existing bank technology to determine early warning indicators of the possibility of
financial exploitation.
Conduct research that uses a combination of self-reported financial exploitation, financial flow monitoring,
monitoring of financial transactions, and existing bank technology to obtain more comprehensive estimates of prevalence and determine validity of the methods.
<i>Explore prevalence, risk factors, causality and consequences of financial exploitation with various racial/ethnic sub-groups.</i>
Conduct neuroscientific studies of cognitive aging and cognitive disorders of aging to determine what are early
declines in financial skills and judgment that presage diminished financial capacity and increased vulnerability
to exploitation.
Conduct research on the effectiveness of interventions designed to inoculate older adults against financial exploitation.
Design, create and evaluate preventive interventions for persons assisting elders with financial affairs, both
formally and informally, regarding what are considered acceptable actions vs what constitutes financial exploitation.

**<u>INFRASTRUCTURE & FUNDING</u>**: Includes research and advocacy for the creation of a research infrastructure with a reasonable and sustained funding line. To move the field of elder mistreatment forward, adequate arrangements and organizations must be in place for both research personnel development and the assurance of research career support.

4	Create an infrastructure consisting of multiple university based sources for cultivating and mentoring a cadre of elder justice researchers.
0	Develop and test system-wide mechanisms for assuring the adequate servicing of elder abuse victims by applying the safety audit model used in domestic violence to elder abuse.
9	Develop adequate long-term funding commitments for research on elder mistreatment by relevant federal, state, and private agencies to support research careers and to develop the next generation of investigators.
5	Develop training programs for <i>required</i> use in undergraduate and graduate social service programs, nursing and medical schools, law enforcement and the legal professionals for the recognition and treatment of elder mistreatment.
6	Create one or two federal funding foci for elder mistreatment research in agencies with expertise in funding strong research rather than spreading research funds around multiple federal agencies. ( <i>Comment: If it were possible to have required joint efforts among agencies to fund topics of mutual interest that might be a better way to go so that many agencies share responsibility/ownership of this topic.</i>
	Develop long-term funding commitment so that longitudinal studies may be conducted and that determination can be made to separate risk factors from associated factors.

**INTERVENTION OUTCOMES**: includes research on the outcomes or consequences of elder mistreatment. Strong research evidence is available about proximate and longer-term mortality as a consequence of various forms of elder mistreatment. However, too little is known about other outcomes such as nursing home placement, long-term financial burden or the physical or psychological impact of having experienced various forms of elder mistreatment.

6			
	inter-relationship of these different harms, their natural history, their severity and their clinical course.		
10	Conduct qualitative research on what victims of elder mistreatment consider to be successful and desirable		
	outcomes of interventions.		
9	Develop a body of longitudinal research on the clinical course, antecedents, and outcomes of various types of		
	elder mistreatment.		
5	Develop research comparing outcomes using similar types and severity of elder mistreatment in which services		
	were provided and those in which eligible recipients declined offered services.		
7	Conduct longitudinally designed research to separate causes or risk factors of specific types of elder		
	mistreatment from their outcomes.		
0	Develop research within relatively "closed" health systems (e.g., the Veterans Administration Health System;		
	the Indian Health Service; the state of Hawaii) to document the clinical and social consequences of elder		
	mistreatment.		
	Conduct research on the outcomes/consequences for the perpetrator in both criminal and non-criminal cases.		

**IRB & HIPAA:** perceived issues related to Institutional Review Board (IRB) clearance for the ethical conduct of research on elder mistreatment and Health Insurance Portability and Accountability Act (HIPPA) rules regarding the sharing of information. Although not strictly an issue warranting research, IRB and HIPPA adherence are viewed as barriers to the conduct of research and the effective treatment of elder mistreatment victims. Researchers and practitioners have called for a review of these rules and their subsequent dissemination.

7	Codify techniques for promulgating guidance, as required by the Elder Justice Act, to assist IRBs, researchers and multidisciplinary teams navigate abuse, cognitive capacity, consent and human subjects' protection issues in elder abuse research.
3	Given inconsistencies among IRBs, provide guidance on conditions under which research can proceed with cognitively impaired participants and appropriate responses to evidence of mistreatment elicited during research.
3	Create special oversight IRB models when elder mistreatment is involved through the participation of community members, especially in light of cognitive impairment.
5	Convene a panel in conjunction with the U.S. Department of Health and Human Services's Office for Human Research Protections (OHRP) to explore HIPPA issues as they relate to the unique area of elder mistreatment.
5	Explore mechanisms for educating professionals regarding the sharing of information across health care delivery, social service and law enforcement systems regarding the nature and extent of HIPPA's perceived restrictions on information sharing.

**LONGITUDINAL RESEARCH**: Includes research on the course of elder mistreatment from pre-mistreatment through the event to the consequences of mistreatment. Often, the risk factors for mistreatment may be similar to the consequences of that mistreatment (e.g., cognitive impairment; social isolation). It is therefore necessary to more clearly understand the natural history or sequencing of mistreatment events.

	e clearly understand the natural instory of sequeneing of misucatinent events.
13	Research is needed on the phenomenology and clinical course of elder mistreatment including the nature,
	periodicity, variation, triggers and outcomes using longitudinal research designs so as to separate causes from
	outcomes.
2	Conduct research using a "clinical course" model of the natural history of elder mistreatment (e.g., lead time
	prior to manifestation; active signs and symptoms; periods of remission; critical points of intensive or acute
	mistreatment; consequences of the mistreatment).
2	Conduct research on the natural history of elder mistreatment to determine if there are periods in which the
	elder mistreatment may resolve on its own, intensify and/or stabilize.
5	Explore if elder mistreatment has a natural progression where one form of abuse leads to another specific form
	with some stochastic probability level.
8	Add an elder mistreatment module to extant, population-based, large-scale, longitudinal studies of older
	persons (e.g., the Health and Retirement Survey) for prospective research on elder mistreatment's natural

	history.
5	Develop theory-driven, qualitative longitudinal research to explore the changing dynamics of elder people's
	relationships and the risk for mistreatment.
7	Conduct longitudinal research on the intersection of the changing dynamics between victim and perpetrator
	(i.e., the "trust relationship"), and contextual factors (e.g., poverty; diminished capacity; substance abuse;
	mental illness) and intergenerational solidarity.
3	Test specific behavioral and social science theories (e.g., power; conflict; life course) to determine their
	applicability to various forms of elder mistreatment.
5	Conduct research on both victims and perpetrators including on a specific aspects of elder mistreatment
	explicitly integrating multiple conceptual frameworks (e.g., behavioral, social, neurological, and medical
	sciences) using mixed methods and research.
	Conduct research on family cycles of violence: if you were abused as a child are you more likely to be abused
	as an elder? More likely to be abusive to an elder? More likely to be abusive specifically to the person who
	abused you? Utilize information from ACES to understand type/extent of child abuse and consequences.

**LONG-TERM CARE FACILITIES**: Includes research on elder mistreatment which takes place in long-term care facilities. Research on elder mistreatment in institutional settings is "all but uncharacterized." Research is recommended on risk factors and remediation programs in the range of specific types of facilities for this extremely fragile and potentially vulnerable population.

5	Conduct population-based research on elder mistreatment in institutional settings, including hospitals, skilled
	nursing facilities, long-term care and assisted living facilities.
4	Conduct research on the prevalence and incidence of elder mistreatment in institutional settings. for comparison
	with similar data from community and population based studies. (Note: the comparison would be difficult
	because differences between community and institutional populations.)
2	Create new methods to assess incidence and prevalence in institutional settings using biomarkers as well as
	psychological and family-generated indicators.
5	Conduct evaluative research on the Ombudsman Program to determine its efficacy and value (i.e., effect/cost)
	in long-term care settings as a mechanism for <i>detecting and</i> preventing elder mistreatment.
3	Examine different types of long-term care settings (e.g., Skilled Nursing Facilities; custodial nursing homes;
	dementia units; assisted living facilities) for unique elder mistreatment risk factors associated with each setting.
	Examine risk factors for abuse at the institutional level (e.g., staffing ratios; for-profit status; level of
	involvement of medical director and/or DO; type and adequacy of staff training) as well as at the individual
	level (e.g., characteristics of the abuser and victim).

**<u>MINORITIES & VULNERABLE POPULATIONS</u>**: includes research addressing the unique problems of elder mistreatment in vulnerable and minority populations. Cultural differences and perceptions often confound the ability to recognize and to intervene in cases of elder mistreatment. Further, the role of specific physical disabilities has an unknown relationship to elder mistreatment. (Note that diminished cognitive capacity is treated separately and elsewhere in this manuscript.)

3	Conduct research on how functional impairments such as vision, hearing and mobility limitations impact vulnerability and add to the risk of victimization of specific types of elder mistreatment.
3	Conduct qualitative research on elder mistreatment and its related risk factors among minority populations including cultural variations in how mistreatment is defined and perceived by specific race/ethnic groups <i>and the LGBT community</i> .
5	Conduct qualitative or Community-based Participatory Research exploring cultural norms, expectations and linguistic complexities related to the perception, determinants, and impact of elder abuse in diverse communities.
2	Research is warranted that determines the barriers to reporting elder mistreatment and help-seeking behaviors in specific ethnic/racial groups.
1	Explore the need and feasibility of over-sampling specific ethnic and racial minorities in future population- based studies of elder mistreatment.

<u>MULTI-DISCIPLINARY TEAMS</u>: includes research on the composition and outcomes of team approaches to elder mistreatment. The growing literature in this field suggests that Multi-disciplinary Teams are an effective mechanism for successfully handling cases of elder mistreatment. However, little solid research exists upon which

to base that assertion. Research is needed on the preventive and remediated consequences of using multidisciplinary teams.

uist	cipinary teams.
2	Conduct a nationwide study of extant multi-disciplinary teams to determine composition and processes of these
	Teams and catalogue outcomes that these teams are attempting to accomplish.
1	Conduct a multi-site examination of the efficacy of Multi-disciplinary Teams to determine best practices for the
	operation of these Teams.
2	Conduct an examination of the economic cost of a Multi-disciplinary Team including the cost incurred in
	running a Team and the estimated cost savings to local, state and federal entities.
5	Using the relatively controlled and procedurally recorded environment of multi-disciplinary teams, test specific
	interventions to determine the intervention components that lead to "successful" outcomes.
0	Conduct research using the multi-disciplinary mix represented multi-disciplinary teams to determine the nature
	of the interaction between perpetrator and victim leading to elder mistreatment.
2	Codify and combine the potentially extensive data sets necessarily collected by Multi-disciplinary Teams across
	the U.S. to examine specific "Big Data"-like questions.
8	Conduct research on Multidisciplinary Teams' outcomes to determine what makes these Teams appear "more
	effective" than standard APS handling if these Teams bring value (effect/cost) or are more effective than
	standard APS intervention for of elder mistreatment.
	Define "successful outcomes" and provide that definition as a tool for all MDTs to use.

**<u>NATIONAL DATABASE AND RESEARCH AGENDA</u>**: includes the creation of an open, publically available database for use by researchers, practitioners and policy makers. Such a database is necessary to maximize the integration of data and improve the delivery of services to abused elders.

mitt	Egration of data and improve the derivery of services to abused enders.
3	Create an open but encrypted database by integrating extant records systems (e.g., arrest and conviction
	records; family violence data; APS records; law enforcement like the FBI's National Incident Based Reporting
	System; medical records; forensic labs; and disciplinary problems in the military) to determine if elder
	mistreatment is committed by the same individuals who have multiple social problems leading to their presence
	in various data bases.
2	Create an encrypted national data system based upon a victim-centered methodology vs. an aggregate
	methodology where links can be made between case reports and the victim's identity.
6	Create a national database that includes sufficient sociodemographic information to facilitate research on
	correlates, causes and consequences of the elder mistreatment event.
3	Conduct a meta-analysis on specific elder mistreatment topics (e.g., prevention; APS; risk factors) to determine
	topic-specific state-of-the-science progress.
5	Create and sustain a longitudinally designed national incidence/prevalence survey with a surveillance sub-
	sample of known elder mistreatment cases.

**PREVALENCE/INCIDENCE**: includes research to determine the prevalence and/or incidence of elder mistreatment locally and/or nationally. Research is needed to gather population-based information about the occurrence of elder mistreatment. Longitudinal research is also suggested that follows a population over time to determine changes in incidence and/or prevalence.

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2	Conduct a national incidence and prevalence study to measure all types of elder abuse.
3	Conduct a sufficiently large national incidence and prevalence study such that state-specific incidence and
	prevalence estimates can be established.
2	Conduct local or small area incidence and prevalence studies.
3	On a local level, determine the feasibility of enhancing survey-acquired information by applying record linkage
	techniques to administratively gathered data (e.g., APS; law enforcement; FBI National Incident Based
	Reporting System; medical records; forensic labs).
0	Conduct small scale local incidence and prevalence studies to compensate for the larger surveys (e.g., National
	Health Interview Survey; National Nursing Home Survey) inability to determine incidence and prevalence of
	low probability events such as elder mistreatment.
6	Add incidence and prevalence research as supplements to extant surveys such as the Health and Retirement
	Study (HRS) or various Department of Justice funded surveys.
3	Conduct research to determine sensitive, valid and reliable methods of assessing elder mistreatment in
	population surveys that include frail and cognitively impaired adults.
2	Develop new methods to assess incidence and prevalence of elder mistreatment in institutional settings such as

	assisted living facilities and nursing homes.
6	Establish consistent working definitions for each type of elder mistreatment to facilitate cross-walk
	comparisons of incidence and prevalence in future research.
1	Develop small scale qualitative studies to determine prevalence and incidence of elder mistreatment by
	triangulating multiple sources of data to establish benchmarks of how elder mistreatment is presented to social
	agencies such as APS.
	Conduct research to determine the prevalence and incidence of polyvictimization.

**<u>PREVENTION</u>**: includes research that creates or evaluates efforts to prevent elder mistreatment (primary prevention) and/or research creating programs or efforts to prevent the reoccurrence *or early detection* of elder mistreatment (secondary prevention). Although randomized controlled trials (RCTs) are typically the methodology used, other methodologies (e.g., propensity scoring) should be included.

3	Create a catalogue and taxonomy of programs used by Adult Protective Services (APS) that address primary and secondary prevention.
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4	Conduct research to determine the effectiveness of specific APS interventions used to address primary and/or
	secondary prevention in elder abuse.
3	Study the impact of criminal justice interventions that address prevention.
2	Conduct a meta-analysis to determine the effect of interventions in other fields such as child abuse and
	domestic violence that have demonstrable impact upon primary and secondary prevention.
5	Conduct research on the efficacy of Multidisciplinary Teams (MDTs) as an intervention to reduce the
5	reoccurrence of elder mistreatment.
0	Research is needed on the preventive impact of reporting practices by comparing states with and without
	mandated reporting.
2	Conduct research on preventive interventions that maximize the likelihood of keeping elders in their own
	homes.
4	Analyze known and modifiable risk factors that are indicative of a high probability of elder mistreatment so that
	they can be translated into prevention strategies.
4	Design, create and evaluate community interventions that sustain social support networks to prevent elder
	mistreatment and enhance resilience.
3	Design, create and evaluate preventive interventions for Resident-on-Resident elder mistreatment. (NOTE: one
5	respondent does not consider this to be elder mistreatment.)
1	
1	Design, create and evaluate community-based interventions that address primary prevention of elder
	mistreatment such as public service and public awareness messages that are positive regarding the value of
	older adults, and model healthy relationships.
	Design, create and evaluate preventive interventions for enhancing caregiving skills (e.g., education regarding
	what caregivers can expect in terms of increasing caregiving demands over time as the elder ages/declines;
	typical social and physical comfort care needs of elders), acceptable and unacceptable caregiving techniques,
	and future planning for alternative placement once the level of care required exceeds what the caregiver feels
	able to manage with supports.
	Design, create and evaluate preventive interventions involving use of elder mediation to assist families and
	older adults resolve conflicts, make care and attendant decisions (e.g.; regarding property; driving) and
	address elder mistreatment that is occurring but does not reach the threshold for criminal justice intervention.
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**<u>RISK FACTORS</u>**: includes research that clarifies risk factors specific to the victim, the perpetrator(s) and their interaction for each of the types of elder mistreatment. The identification and measurement of modifiable risk factors is especially important. Research on this topic should include risk factors that have a high probability of being predictive of elder mistreatment and for which preventive interventions can be introduced. The risk factor literature is limited and inconsistent thus restricting our ability to screen, provide a rationale for prevention programs and hinders the ability to develop public policy initiatives.

7	Conduct research that creates operational definitions and validated and standardized measurement of risk
	factors associated with the various types of elder mistreatment.
8	Conduct longitudinal research on the characteristic risk factors of victims and perpetrators that includes
	contextual factors (e.g., poverty; substance abuse; mental illness; functional impairments such as vision, hearing
	and mobility limitations; and other family issues).
3	Conduct theory-driven longitudinal research exploring the changing dynamics of older people's relationships

	and its interaction with the risk of elder mistreatment.
8	Conduct research on risk factor status among minority populations including cultural variation in how
	mistreatment is defined and perceived.
7	Conduct research on the role of personal and contextual factors for both potential victims and perpetrators that
	are protective of the various types of elder mistreatment.
7	Conduct research on risk and protective factors for elder mistreatment in institutional settings.
3	Determine what normal cognitive aging, prodromal dementia states (e.g., MCI) and which characteristic
	symptoms and which stages of dementia place older persons at greater risk of different types of elder
	mistreatment.
2	Examine how the various stages of dementia impact the probability of elder mistreatment by the caregiver and
	inversely, by the dementia victim upon the caregiver.
2	Conduct research on self-neglect from a social problem perspective where risk factors have contextual or
	societal origins (e.g., poverty; access to medical care), psychological origins within the individual and origins in
	his/her potential caregivers and determine the extent to which these risk factors are the same as those for
	various forms of elder mistreatment and may predispose someone self-neglecting to elder mistreatment.
5	Risk factor research is needed that includes the co-occurrence of different abuse types (i.e., polyvictimization)
	to determine the potential sequencing of various types of elder abuse.
2	Conduct research to determine if risk factors for elder mistreatment are the inverse of protective factors so that
	protective factors can be enhanced in an effort to prevent elder mistreatment.
5	Consider conducting research on the effectiveness of social well-being indicators (e.g., social network
	embeddedness; the extent of various types of social support; loneliness; social participation) as protective
	factors.
8	Conduct research that results in the creation of risk factor profiles for different types of elder mistreatment.
2	Extend research on the biological linkages with, and biomarkers of, elder mistreatment such as the link between
	self-neglect and low levels of Vitamin D.
6	Create profiles of financial exploitation victims, their perpetrators and the interaction between the two to
	determine risk factors specific to various forms of financial exploitation.
6	Conduct applied research on enhancing informal caregiving skills, <i>including education of caregivers regarding</i>
	changing needs over time, as a mechanism for avoiding elder mistreatment especially among cognitively
	impaired elders.
2	Examine extant large-scale caregiving-related data sets (e.g., REACH; the Health and Retirement Study; the
	N.Y.U. and Minnesota Counseling Programs) for the availability of evidence of elder mistreatment.
2	Examine the link between informal caregiving as a risk factor for each type of elder mistreatment, separately.
	Conduct research to achieve a clearer understanding of risk factors for perpetration and victimization, effective
	interventions and outcomes involving family members vs "other" trusted others.

**SCREENING AND FORENSIC MARKERS**: Includes research on determining specific markers for various forms of elder mistreatment. Research on screening and forensic markers needs to further examine, identify and verify physical markers for physical abuse as well as specific psychological and social markers for all forms of elder mistreatment. Valid screening measures are needed at all professional levels (e.g., APS; physicians; law enforcement). In addition, the development of screening measures suggestive of elder mistreatment for use by community non-professionals (e.g., Meals-on-Wheels drivers) needs research attention. Case identification can have momentous consequences for the victims and for those with false-positive and false-negative conclusions.

nav	e momentous consequences for the victums and for those with faise-positive and faise-negative conclusions.
6	Conduct research to validate existing screening tools and forensic markers as indicative of elder mistreatment
	and for use in different settings (e.g., physicians' offices; institutional settings).
3	Conduct research on how best to create a "menu" of validated and sensitive screening measures for use in the
	multiple contexts in which elder mistreatment is likely to be detected.
3	Research is needed to extend forensic markers of physical elder mistreatment by including behavioral,
	environmental, physical and financial markers.
4	Conduct additional research on physical markers of elder mistreatment (e.g., bruises; pressure sores; fractures;
	burns; and abrasions) to distinguish preventable and unavoidable signs from those that are intentional or
	avoidable using child abuse as a model (e.g., retinal hemorrhage; subdural hematomas; rib and long bone
	fractures).
2	Conduct research that stochastically creates the predictive value of various clinical findings as indicators of
	elder mistreatment.

functional capacity; susceptibility to
al and social service professionals.
to establish screening benchmarks
ence between self-reported elder
logical screening for elder
rally-occurring illness and trauma.
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bitation in the banking and financial
revents or escalates elder
ce may have a deleterious impact
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<u>SELF-NEGLECT</u>: Includes research on the outcomes or consequences of elder self-neglect and on the precipitating factors associated with this syndrome. Research on the distinction between self-neglect and neglect by a trusted other is included here. Although self-neglect is often not considered a form of elder mistreatment, its consequences are often similar to those of neglect by a trusted other.

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4	Research needs to determine if self-neglect is an unique syndrome or if self-neglect risk factors and outcomes
	are sufficiently similar to other forms of elder mistreatment such that self-neglect may be considered a separate
	category of abuse.
4	Explore the relationship between self-neglect and other forms of elder mistreatment to determine if they occur
	serially or if there are causal relationships between them.
3	Qualitative research is needed to conceptualize self-neglect and neglect by others to determine the role of
	"justice" in these types of elder mistreatment.
2	The causes of self-neglect need to be examined as a multi-level phenomenon using risk factors with origins at
	the societal level (e.g., poverty; access to medical care), the psychological level, and the interpersonal level
	(e.g., the availability of caregivers).
0	Examine ethical issues of intervening in self-neglect cases where the individual is cognitively and physically
	competent and choses to live in physical surroundings that pose danger to only the elder (e.g., hoarders; owners
	of large numbers of pets).
	Examine the utility of behavioral, social and environmental interventions in self-neglect cases to increase self-
	care management and social connection/support networks.
	Measure the severity and types of lack of cognitive capacity in self neglect.

<u>Comment</u>: Self-neglect is clearly important and needs to be studied. However, it is not elder abuse and should not be categorized as such. The fact that APS includes this issue within their purview does not make it elder abuse.

#### General Comments:

- 1. Many of the Topics and Research Questions and Issues can't be done "without ... case definition."
- 2. There needs to be a separate Topic for "Conceptual/Theory." It is currently imbedded in Longitudinal Research.