U.S. Department of Justice
Office of Justice Programs
National Institute of Justice

National Institute of Justice

Elder Abuse Workshop

February 25-27, 2008
DoubleTree Hotel, Washington, DC

NCJ 242211

Elder Abuse Workshop

February 25-27, 2008
DoubleTree Hotel, Washington, DC

Table of Contents

Day One – February 25, 2008

I. Welcome and Introductions

- Marie-Therese (MT) Connolly, Fellow, Woodrow Wilson International Center for Scholars
- Thomas Feucht, Deputy Director for Research and Evaluation, NIJ

II. Measurement and Data: Measuring Prevalence and Incidence of Elder Abuse in the Community – Reports from Current or Recently Completed Research Projects

Introduction — Sid Stahl

Panels:

- Ron Acierno — Population-Based Assessment of Elder Mistreatment in Non-Institutionalized Adults
- Scott Beach — Testing Survey Methods for Collecting Data on the Prevalence of Elder Mistreatment
- Laura Mosqueda — Developmental Research on Elder Mistreatment Measurement
- Kate Wilbur — Toward a Better Understanding of Elder Mistreatment in Community Settings
- Larry Branch — Florida Elder Abuse Survey
- Lori Jervis — Exploring the Mistreatment of Native Elders

III. Measurement and Data: Screening Tool Development – Reports from Current Research Projects

Panels:

- Ken Conrad — Conceptualizing and Measuring Financial Exploitation and Psychological Abuse of Elderly Individuals
- Terry Fulmer — Primary Care Clinics for Estimating Prevalence and Incidence of Elder Abuse
- Yeates Conwell — Detection of Elder Mistreatment in the Aging Services Network

Discussant, Alex Crosby

Question/Answer/Comment Period

IV. Working Lunch – Measurement and Data: Working with Large Data Sets

Panels:

- Jim Robinson — Using Nursing Home MDS and OSCAR Information
- Erica Smith — The National Crime Victimization Survey (NCVS) and the National Incident-Based Reporting System (NIBRS)

- Wendy Verhoek-Offendahl — Evaluation of Data Linkage Methodology to Improve Estimates of Elder Mistreatment

Discussant, XinQi Dong

Question/Comment Period

V. Elder Abuse Forensics – Reports from Current or Recently Completed Research Projects

Panels:

- Laura Mosqueda — Bruising as a Forensic Marker of Elder Abuse
- Solomon Liao — A Multisite Study to Characterize Pressure Ulcers in Long-Term Care Under Best Practices
- Erik Lindbloom — Mandatory Reporting of Nursing Home Deaths: Markers for Mistreatment, Effect on Care, Quality and Generalizability
- Laura Mosqueda — People with Dementia as Witnesses to Emotional Events
- Nancy Knight — Whole-Body CT Imaging in Post-Mortem Detection of Elder Abuse and Neglect

Discussant, Judy Salerno

Discussion of Forensic Issues and Priorities in Future Research

Day Two — February 26, 2008

I. Abuse and Neglect in Long-Term Care (LTC)

Panels:

- Catherine Hawes — Detecting, Investigating and Resolving Elder Mistreatment in Residential LTC Facilities
- Catherine Hawes — Developing Prevalence Measures of Elder Abuse in Residential LTC Settings
- Mark Lach — Resident-on-Resident Elder Mistreatment
- Janne Swearengen — Identifying and Monitoring Abuse and Neglect in Long-Term Care Facilities
- Anne Montgomery, Lori Post, Susan Larsen — Research on Criminal Background Checks
    - Patient Safety and Abuse Prevention Act — Anne Montgomery
    - Centers for Medicare and Medicaid Services (CMS) Background Check Pilot Program Update — Susan Larsen
    - Information Communication Technology for the Prevention of Abuse, Neglect, and Exploitation in Long-Term Care Settings – Lori Post

Discussant, Nick Castle

Question/Answer/Comment Period

II. Laying the Foundation for Theoretical Model Development in Elder Mistreatment

Introduction — Laura Mosqueda

Panels:

- Joan Meier — Models of Domestic Violence
- Georgia Anetzberger — Caregiving: Primary Cause of Elder Abuse?
- Bonnie Brandl — Why Does Elder Abuse Occur and Persist?

Dialogue with Panel led by Laura Mosqueda

III. Challenges and Solutions in Conducting Elder Abuse Research

Discussion led by Sid Stahl on:

- Reporting and Certificates of Confidentiality
- Conference on Ethical Issues in Elder Abuse
- IRB Issues
- Cooperation/Partnering with Agencies
- Consent/Assent Issues

Day Three – February 27, 2008

I. The System Response to Elder Abuse – Reports from Current or Recently Completed Research Projects

Panels:

- Frederick Newman — Testing a Model of Elder Mistreatment and Barriers to Help Seeking
- Shelly Jackson — Financial Abuse of the Elderly Versus Other Forms of Elder Abuse – Assessing the Dynamics, Risk Factors and Society's Response
- Meghan Slipka — How Protective Behaviors and Risk Factors Affect the Course of Abuse Over Time
- Andy Klein — A Statewide Analysis of Elder Abuse of Older Women and the Criminal Justice Response in Rhode Island
- Lori Stiegel — A Multisite Assessment of Court-Focused Elder Abuse Initiatives
- Carmel Dyer — Factors That Impact the Determination by Medical Examiners of Elder Mistreatment as a Cause of Death in Older Persons

Discussant, Kathleen Quinn

Question/Answer/Comment Period

II. VISION Report

Discussed:

- Short-Term Research Priorities
- Long-Term Research Priorities
- Greatest Challenges
- What Help Do We Need From Federal Agencies and Others?

- Critical Research Priorities
- Ideas in a Box

III. Conversation with Potential Funders

Participants:

- Laura Giles, Archstone Foundation
- Gavin Kennedy, Assistant Secretary for Planning and Evaluation, HHS
- Carrie Mulford, National Institute of Justice, DOJ
- Meg Morrow, Office for Victims of Crime, DOJ
- Sid Stahl, National Institute on Aging, NIH, HHS
- Naomi Karp, AARP
- Alex Crosby, Centers for Disease Control, HHS
- Stephanie Whittier, Administration on Aging, HHS
- Andy Mao, Senior Counsel for Health Care Fraud and Elder Abuse, DOJ

Closing Remarks

Welcome and Introductions

Welcome — Marie-Therese (MT) Connolly, Fellow, Woodrow Wilson International Center for Scholars

Ms. Connolly welcomed the participants. Observing that many of the participants are grantees, she noted that the National Institute of Justice (NIJ), the National Institute on Aging (NIA), and the Archstone Foundation probably account for more than 90 percent of the grants awarded in the area of elder mistreatment.

Ms. Connolly introduced Mr. Thomas Feucht, Deputy Director for Research and Evaluation, NIJ. She recalled the first meeting ever on Elder Abuse Forensics in 2000 and the subsequent meeting four years later comprised of the first grantees in the elder abuse area, a gathering much smaller than the one today. She said that this meeting would not have been possible without the support of Mr. Feucht and his colleagues at NIJ who put great emphasis on how research translates into practice.

Opening Remarks — Thomas Feucht, Deputy Director for Research and Evaluation, NIJ

Mr. Feucht noted that it was a high moment for his agency to meet with the participants. He thanked Dr. Mulford and Ms. McNamee for their work in organizing this workshop, and he welcomed all the participants.

Mr. Feucht asked the participants to reflect on how to evaluate the quality, character and measure of a society. One of the most important measures of a society is how the most fortunate and best cared for see after and care for the least fortunate and most vulnerable—the poor, the sick, the very young and the very old. He suggested that the work of the participants on elder abuse and their continued commitment is a sign of the moral rectitude that we claim as this measure of the fortunate caring for the vulnerable, and he urged the group to hold this broad perspective as a hallmark of the measure of society.

NIJ, said Mr. Feucht, brings the perspective of two elements. The first is the rule of law—how laws are observed, sustained and supported, along with the notion of criminal action and legal remedies. This is a rich justice perspective and represents a powerful resource for caring for the vulnerable. The second element is the research perspective. This is a set of tools to bring to bear on the issues. It means that we are in the knowledge, learning and empirical evidence business. The connection between research on the one hand and policy on the other is something that NIJ always strives to support.

NIJ has an interest in why people do things. A fundamental question for NIJ is the "so what" question. We might know the relationship between things, but so what? How do we translate that empirical knowledge into policies and programs that will make a difference?

At NIJ there is a focus on data, evidence and measuring things accurately and reliably, and on being consistent with how others are measuring them. These theoretical frameworks help direct us to answer the right research questions in the right ways, and this is what we will be looking at over the next two days.

The NIJ research investment in elder abuse grants is middling compared with other portfolios. By the standard of hurt or lost lives, we must ask if we are satisfied with this level of investment. As a federal agency, NIJ faces difficult choices about where to place its resources. Meetings like this one matter all the more to illuminate the questions and the research most likely to make a difference in the lives of potential victims. We at NIJ are anxious for these conversations and for your insights. They are reality checks for us. For all of you who have worked as a researcher on a federally funded project, you are our ideas made real. This is important work. Thank you all for being here, for your attention, and for the work you do.

Introductions, Purpose and Charge — Ms. Connolly

Ms. Connolly asked all participants to introduce themselves and state where they were from. She asked the participants to bring forward their good ideas for research as the meeting progressed.

Measurement and Data: Measuring Prevalence and Incidence of Elder Abuse in the Community - Reports from Current or Recently Completed Research Projects

Introduction — Sid Stahl, NIA

In the first cohort of grantees, a grant by Dr. Mark Lachs, a geriatrician, for a very little bit of money looked at the New Haven Study and compared APS (adult protective services) reports — he found that death rates among those with confirmed cases of mistreatment were three times higher than those with no APS report. This was very dramatic. In 1999, wondering why so little on elder mistreatment was in the literature, I went to look at the science. It took very little time because there was so little research in elder mistreatment. We began talking with leaders in the field and learned that research on elder mistreatment was exquisitely difficult because so few people were working in this area. That is still true today — only 4/10 of 1 percent of NIA funding goes to elder mistreatment. We convinced the director of NIA to give $350,000 to the National Academy of Sciences to do the 2003 study — the result was "the Bible" that included measurement issues as well as prevalence and incidence issues.

Incidence and prevalence studies of elder abuse are still all over the map, and estimates range from ½ of 1 percent all the way to 10 percent. It's tough to create social policy if you are not sure

whether 200,000 or 4 million people need help. One reason that estimates vary so widely is measures. It is dangerous to have a single measure, but we are not sure what we are measuring.

We then got the director to award nine elder mistreatment grants on measurement at NIA, and another three measurement grants funded by NIJ are the basis of what will be covered this morning. The goals of the grants were to set the groundwork for national incidence and prevalence, but a barrier was the difficulty in defining elder mistreatment — financial, institutional, sexual, community-based — all have different risk factors. In addition, cultural diversity in the U.S. may defy our ability to come up with a single measure for elder abuse. So, let's not put all our eggs in one basket. There are multiple levels of data available to see if we can make reasonable estimates of elder mistreatment, and we may need ways other than surveys to obtain measures of incidence and prevalence of elder mistreatment in the U.S.

One objective is to seed the field with dynamic investigators. We need to get good people in other areas of research to join in the enterprise.

Panel Presentations:

Ron Acierno — Population-Based Assessment of Elder Mistreatment in Non-Institutionalized Adults

Goals:

- **NIA Study:** To demonstrate the feasibility of a method for epidemiological assessment of physical, sexual and emotional mistreatment of an elderly person who has a diminished capacity for self-care or self-protection perpetrated by someone in a position of trust.
- **NIJ Study**: To conduct a national epidemiological study of elder mistreatment, defined generally as physical, sexual, emotional, neglectful or financial mistreatment, using a multi-method assessment strategy with 4,500 randomly selected households.

NIJ Study Design:

- To implement a nationwide population-based study methodology validated by our prior research with younger populations and with a pilot sample of older adults.
- To augment this methodology with an alternative method of assessment of caretakers for those noninstitutionally based elders with significant cognitive impairment.
- To document prevalence and characteristics of other traumatic events that might interact with risk factors to increase or decrease the likelihood of experiencing mistreatment, including violent assault by strangers.
- To include measures of financial mistreatment, as well as measures of relevant risk factors for financial mistreatment.
- To use the knowledge gained about the scope, intensity and character of elder abuse, including risk and protective factors, to inform public policy and community-based interventions to reduce elder mistreatment and treat its negative effects.

Observations: An artificial distinction has been made between abuse and assault, which might be measured effectively using the same methodology. Cognitive status is conceptually important to the selection of mistreatment assessment methods. In considering models from other areas, the domestic violence model is more helpful and on point than the child abuse model. In order to avoid case identification failure, it is necessary to ask a certain type of question in a certain way: first a contextually orienting preface statement, then a behaviorally specific question. Feasibility data from a pilot study have shown: 1) explicit questions didn't really bother older participants, according to

their own report; 2) physical health barriers (e.g., hearing, fatigue) were not insurmountable; 3) participants felt that they were helping others by completing the survey; and 4) the victimization rates did not differ according to interview context. These findings inform the current NIA and NIJ studies. As a final, ethical note, screening for dementia in the two studies is critical; if the interviewer has the slightest concern, the interview is terminated.

Conclusions: After field testing, the first 200 interviews indicate:

- Only 14 calls lasted more than 25 minutes. Most of these were associated with a greater incidence of abuse.
- The call duration did not appear to vary greatly between adult and proxy interviews.
- Offering a $10 incentive did not appear to have any impact on response rates or call duration.
- The data appear to be very complete for those who participated. There was not a great degree of item nonresponse. The majority of those contacted who did not participate were screened out due to the lack of an elder adult in the home. Of the 1,610 records contacted, 1,136 were screened out or ineligible. Most of the call break-offs occurred during the introduction. There were very few break-offs once the interview began.

Scott Beach — Testing Survey Methods for Collecting Data on the Prevalence of Elder Mistreatment

Goals:

- Test the feasibility, acceptability and cost implications of survey methodologies for collecting self-report data on elder mistreatment.
- Test the reliability and validity of prevalence estimates derived from survey methodologies for collecting self-report data on elder mistreatment.
- Collect data regarding elder abuse from in-home elder service providers in order to: a) test feasibility, b) provide prevalence estimates to compare with the elder self-report data, c) incorporate data from severely cognitively impaired elders, and d) capture more severe forms of elder mistreatment.

Study design: Randomized experiment varying the mode of data collection and presence and absence of privacy-enhancing technology. Total n = 903 (called 35,000 numbers to get 900 participants; sample included moderately cognitively impaired participants). Four methods tested:

- Computer-assisted telephone interview (CATI), n = 228
- CATI/interactive voice response (IVR) hybrid telephone, n = 227
- Computer-assisted personal interviewing (CAPI) in person, n = 224
- CAPI/audio computer-assisted self-interviewing (A-CASI), n = 224

Observations: Elderly people are not as apt to hang up on interviewers, but there was some reluctance to use headphones. The definitions of abuse (financial, neglect, sexual) were very important and will continue to be refined. Very low prevalence was found for neglect and sexual abuse (less than 1 percent since turning age 60). The in-home provider survey was less successful because of resistance/reluctance to collaboration by directors at the Area Agency on Aging (AAA) level.

Tentative Conclusions:

- Direct victim surveys of elder abuse are feasible, although neglect and sexual abuse may require other approaches.
- Older adults are generally able and willing to use new privacy-enhancing survey technologies (A-CASI and IVR).
- A-CASI and IVR appear to increase reporting of psychological abuse.
- A-CASI also seems to increase reporting of financial abuse. Results are less clear for physical abuse.
- The feasibility and usefulness of in-home provider surveys is questionable.

Laura Mosqueda — Developmental Research on Elder Mistreatment Measurement

Goal: To develop a standardized measurement tool for evaluating elder abuse.

Study Design:

- Phase I (complete) **–** Define and operationalize five types of elder abuse (physical, psychological, sexual, financial and neglect) using a multidisciplinary advisory board.
- Phase II (complete) **–** Develop and field test the survey (Older Adults and Conflict Behaviors [OACB]) using focus groups (English and Spanish).
- Phase III (ongoing) **–** Recruit and enroll 250 participants ages 65+, either English- or Spanish-speaking, with cognitive impairment allowed when a caregiver is available. One-time home visit for interview, questionnaire and survey that is evaluated via LEAD Panel assessment (longitudinal, experts, all data).

Observations: Successful collaboration with APS with approximately 50 percent Mexican enrollment. Challenges include: 1) difficulty in recruiting participants with cognitive impairment *and* confirmed abuse, particularly in the Mexican-American population, and 2) getting LEAD Panel assessments that are timely and consistent.

Conclusions: None yet. Next steps include validating the survey/statistical analysis and disseminating results.

Kate Wilbur — Toward a Better Understanding of Elder Mistreatment in Community Settings

Goals:

- Enhance conceptual clarity through literature review and focus groups.
- Develop and test an instrument to measure abuse in diverse communities.
- Pilot the instrument using *promotores* as interviewers.

Study Design: Focus on elder abuse in diverse communities through door-to-door surveys using promotores (people who are knowledgeable about the culture, values and language of the population and can provide a culturally sensitive link and trusting relationship for those traditionally overlooked in research [e.g., immigrants, low-income and isolated individuals]).

Observations: The promotores model has been used in public health as a way to reach underserved populations. Highly diverse communities will be identified through the LA County Service Planning Areas (SPAs), and we will build on community structure by utilizing neighborhood councils to help recruit promotores. The challenges include inspiring trust so that participants are

willing to answer the door, and getting the right definitions so that our participants will know what we are talking about.

Conclusions: None yet. The study began in September 2007. The key question is whether this approach will work as a means to identify elder abuse in diverse communities and include people who might usually be left out of traditional surveys.

Larry Branch — Florida Elder Abuse Survey

Goal: To construct a self-report questionnaire that can correctly identify cases of elder abuse or neglect by a caregiver or exploitation as confirmed by APS field workers (i.e., our criterion) compared to other elders receiving home care services, but not identified as victims of elder mistreatment by case managers.

Study Design: Focus was on community residents who can self-report.

- Phase I – Shadowed Florida Elder Abuse Hotline to understand what information is used to designate a case as elder mistreatment.
- Phase II – Shadowed APS workers as they made their decision whether elder mistreatment was present or not.
- Phase III – Developed a questionnaire and conducted a survey with 26 confirmed cases of second-party elder abuse or neglect and 69 elder services clients who were not abused. Ten AAAs sent names of 168 clients to be interviewed, of those, 117 were contacted.

Observations: Age should not be used as a surrogate for vulnerability, and in considering the issue of "person of trust" we need to consider how long there has been a trust relationship — is the con man who promised house repairs a person of trust? Elder mistreatment is not equal to mistreatment of an elder (i.e., an elder who is a victim of crime). Elder mistreatment requires intentional actions that cause harm or a serious risk of harm. According to the National Research Council definition, an intentional act by a trusted advisor that caused unintended financial harm to a vulnerable elder (e.g., a financial advisor who intentionally sells a stock, resulting in a loss) meets the definition of abuse. We continue to argue that it does not.

Conclusions: The instrument was statistically significant with a sensitivity of 77 percent (identified 20 out of 26 known cases) and specificity of 42 percent (identified 44, 20 were confirmed, 24 were not). The instrument needs to be tightened to distinguish elder abuse from abuse of an elder. We still must define a set of risk factors so that we can get to a national prevalence rate.

Lori Jervis — Exploring the Mistreatment of Native Elders

Goal: To lay the groundwork for a pilot study of Native elder mistreatment to inform a set of recommendations for further examining the phenomenology and prevalence of Native elder mistreatment.

Study Design: Assemble a network of tribally diverse community experts with backgrounds in Native elder advocacy and abuse prevention/intervention and an interdisciplinary team of researchers to conduct developmental work on the phenomenology and prevalence of mistreatment among older American Indians/Alaska Natives.

Observations: The project has been under way for five months and the following themes have emerged: 1) elder abuse receives much less attention than child abuse or domestic violence in

Indian country; 2) there is no centralized mechanism for collecting data on elder abuse in Indian country; 3) criminal justice in this area is inadequate; 4) there is a need to know about more than prevalence – starting with prevalence is premature; 5) we need better definitions of elder abuse, including considering the issue of coerced caring for grandchildren; 6) existing measures need revision; and 7) there is a need for open-ended questions to provide qualitative perspective from elders, and participants must be treated in a culturally relevant manner.

Conclusions: The collaborative approach will ensure that scientific approaches are grounded in local realities. Next steps include measure modification and development, selection of data sites, a pilot study and development of recommendations.

Measurement and Data: Screening Tool Development - Reports from Current Research Projects

Panel Presentations:

Ken Conrad — Conceptualizing and Measuring Financial Exploitation and Psychological Abuse of Elderly Individuals

Goals:

- Conceptualize the financial exploitation and psychological abuse of elders and develop item banks that represent these constructs.
- Refine procedures for obtaining sensitive information concerning abuse in the community.
- Develop new items and refine existing items assessing financial exploitation and psychological abuse.
- Conduct a full-scale field test.
- Conduct Rasch (item response theory) analysis.

Study Design:

- Phase I (completed): Develop construct maps describing financial and psychological abuse and arrange the items in a hierarchical order from most severe to least severe. Develop concept maps for financial and psychological abuse and use these to develop questionnaires.
- Phase II (completed): Convene professional and consumer focus groups to establish face validity and ease of use, test the interpretation of questions and responses through cognitive interviews, and finalize the measures through review by the Survey Research Lab at the University of Chicago.
- Phase III (ongoing): Field-test the measures with 200 people with substantiated elder abuse by June 1, 2008. Rasch analysis of results will place items on rulers of severity based on input from clients and staff.

Observations: Measurement is important because measurement quality significantly affects both treatment delivery and research. The strength of concept mapping is that it enables a quantitative and objective analysis of items that were generated by 17 experts in the field of elder abuse. Measurement is the key to opening a field for scientific study. It is by using the items and the hierarchy developed in this study that behaviors can be located on rulers of severity to help with more precise prevalence measurements that lead to more appropriate interventions.

Conclusions: None yet.

Terry Fulmer — Primary Care Clinics for Estimating Prevalence and Incidence of Elder Abuse

Goals: Improve the health and well-being of older adults by detecting and treating elder mistreatment in the areas of physical abuse, psychological abuse and neglect by a person of trust. Primary goals of the study include:

- Estimate the prevalence of elder mistreatment.
- Estimate the six-month incidence of elder mistreatment.
- Compare standardized, valid, reliable instruments (EAI-R and HS-EAST) with a newly developed single-item screening question that was used with domestic violence and captured 51 percent with one item.

Study Design: Enroll 250 participants ages 65+ from primary care clinics who are willing to undergo initial screening and rescreening at six months using the above screening instruments. A-CASI technology will be employed.

Observations: Elder mistreatment is a potentially fatal public health problem that causes human suffering and preventable morbidity and mortality.

Conclusions: Preliminary data: 38 cases, one withdrawal, and 129 refusals. Top reasons for refusal include: not interested, not enough time, ineligible, and did not like the incentive ($10–15 gift card).

Yeates Conwell — Detection of Elder Mistreatment in the Aging Services Network

Goal: To develop a set of tools for the detection of elder mistreatment that is specifically designed for use in the aging services setting.

Study Design:

- Have instrument development panel develop a preliminary care management-based screening tool (CMEM) to identify elder mistreatment and vet the CMEM by using focus groups and cognitive interviews.
- Pilot test the preliminary CMEM tool on CM clients (n=13) and EAPP (Elder Abuse Prevention Program) clients weighted toward people identified as mistreated (n=27), and revise the tool based on pilot results.
- Establish the performance characteristics of the CMEM scale by comparison with LEAD Panel assessments on ES (Elder Source) clients (n=40) and EAPP clients (n=80).

Observations: Work with the Aging Services Network (ASN) to develop a collaborative approach and innovative intervention for older adults with mental disorders. The research addresses the need to step across the boundaries between health and human services. Preliminary empirical work indicates that 30 percent of in-home adults have depressive episodes, some with suicidal ideation. The partnership with ASN in this research is to find a tool to help them detect and intervene more effectively in elder mistreatment with this high-risk population.

Conclusions: None yet.

Discussant, Alex Crosby

Dr. Crosby stated that the funding at the Centers for Disease Control and Prevention (CDC) is lower than middling, but there is much commitment from the CDC to go forward and convince the administrators to allocate resources to elder abuse. CDC does monitoring and surveillance as well as applied research, and this area could benefit from some of the CDC strategies.

Here is what Dr. Crosby said that he heard today:

There is a strong belief that this is a bigger problem than we have been able to measure so far. This pressures us to do more in measuring.

Our definition of elder abuse won't fit all of the disciplines involved in elder mistreatment, and this may offer us an opportunity for consistency. At CDC we know that public health often looks at something in a way very different from criminal justice, and in a way even more different from social services. We need a definition to give us the parameters.

How are we going to measure? How are we going to look at the validity and reliability of our instruments? How do victims define the problem? How do caregivers define it? As we are moving from how we define to how we measure, we need written, standardized definitions, as consistent as possible, across disciplines.

We can get to conceptual models if we understand our ultimate goals and the difference between interventions in the clinical and the community setting.

As we develop our elder mistreatment model, if we take existing models from family violence, we must do pilots to ensure that we are measuring what we think we are measuring.

We must take cultural, ethnic and geographic diversity into account — it will be a challenge to develop a definition of elder mistreatment that accounts for these issues.

We must take lessons from the fields of intimate partner violence and child mistreatment — these fields are decades ahead and can help us move our field ahead that much faster.

Question/Answer/Comment Period:

Dr. Stahl asked whether it is possible to look for a gold standard. **Dr. Conrad** replied there is no gold standard, but it is possible to develop good, valid measures for things like financial exploitation. One can put all the levels of severity on a yardstick or ruler and validate this as being a measure of this type of exploitation. **Dr. Mosqueda** suggested that a gold standard for research is necessary, but asked how this translates to policy issues. **Dr. Fred Newman** observed that it would be preferable to have a gold standard that was accepted across states and disciplines and it may well happen if funding for research continues, but it should be noted that to this day there are not gold standards of medical diagnoses across states, so we are no further behind than general medicine or psychiatry. **Ms. Quinn** suggested that there is no consistency among states because there are no incentives for legislators, as there is not enough evidence to present to them to make the case that this is a good idea. **Dr. Fulmer** stated that things must happen that either build on or refute theories. The momentum is to see what constructs continue to make sense. Busy clinicians are looking for one or two salient points to be made in the 10 minutes or so that they have with the patient. **Dr. Acierno** noted the difference in the approaches of clinicians and epidemiological researchers. Clinicians need to get information in a short time so they wish the gold standard to be

narrow, and then if they get an indication of abuse, go deeper. But epidemiologists want the opposite — to cast a wide net with no gold standard for specific questions, but instead have the leeway to ask enough questions to cover all elements and risk factors of the problem in a way that will capture everyone.

Ms. Jane Raymond called for more precision in terminology. She noted that caregivers provide care and suggested that there is a need to recognize that family members are not necessarily caregivers.

Dr. Maggie Baker referred to the unregulated adult family homes in Washington state and pointed out that although there is some overlap with nursing homes, there is a need to consider this population as well.

Working Lunch - Measurement and Data: Working with Large Data Sets

Panel Presentations:

Jim Robinson — Using Nursing Home MDS and OSCAR Information

The Center for Health Systems Research and Analysis (CHSRA) assists in nursing home monitoring and investigations by:

- Supporting OIG CIA (Office of Inspector General Corporate Integrity Agreements) monitoring by providing data analysis information to support quality monitors such as the Long Term Care Institute.
- Supporting IIG/DOJ/MFCU (Independent Inspector General/Department of Justice/Medicaid Fraud Control Units) investigations by providing OSCAR (Online Survey and Certification and Reporting System) data on deficiencies and QI (quality indicator)/QM (quality measure) outliers and identifying residents whose MDS (minimum data set) profiles suggest potential care problems.

CHSRA also analyzes data for nursing home corporations by identifying facilities and running deficiency and QI/QM data, and by comparing the corporation with a comparison group in the areas of number of health deficiencies; Health Deficiency Index, which is adjusted for state-to-state differences; percent of facilities with severe deficiencies; and Severe Deficiency Index, to name just four. For selected facilities, individual residents can be identified for review using MDS data.

Conclusion: OSCAR and MDS data are useful for exploratory problem identification and ongoing quality monitoring. It should be noted that QI is an indicator only; deficiency citations are subject to an appeals process.

Erica Smith — The National Crime Victimization Survey (NCVS) and the National Incident-Based Reporting System (NIBRS)

The two main sources of national-level data on crimes against older persons are NCVS and NIBRS.

NCVS is the nation's primary source of information on criminal victimization and represents an annual survey of 77,000 households comprising nearly 134,000 persons on the frequency, characterization and consequences of criminal victimization in the United States. The survey enables the Bureau of Justice Statistics (BJS) to estimate the likelihood of victimization by rape,

sexual assault, robbery, assault, theft, household burglary and motor vehicle theft for the population as a whole, as well as for certain segments of the population, including the elderly. The NCVS shows that older persons have lower violent crime rates and that although property crime rates are lower for older persons, they are disproportionately affected by property crime.

NIBRS includes detailed information from FBI (Federal Bureau of Investigation) administrative records collected by police departments on many categories of crime, including concurrent offenses, weapons, injury, location, property loss, and characteristics of the victims, offenders and arrestees. NIBRS shows that older persons account for a relatively small percentage of police-reported crime and reinforces the finding that older persons are disproportionately affected by property crime.

Both NCVS and NIBRS have distinct advantages for examining crimes against the elderly. NCVS contains information on both reported and unreported victimizations and offers direct access to victims. However, aggregating data on violence against the elderly over a number of years still does not always yield enough cases for a reliable analysis of the relationship between the victim and the perpetrator. Advantages of NIBRS include the ability to examine offender characteristics with greater validity and reliability, and the fact that the data are collected yearly. Although NIBRS data include enough cases involving older victims to analyze the victim-offender relationship, the numbers may not reflect the unwillingness of family members to report family.

In terms of limitations, NCVS allows for proxy interviews, which may be a problem if the abuse is occurring in the home by another household member. Also, interviews are not conducted on persons in institutional populations. NIBRS only covers crimes reported to the police, and then only from participating jurisdictions, so it is not truly a national survey.

Wendy Verhoek-Offendahl — Evaluation of Data Linkage Methodology to Improve Estimates of Elder Mistreatment

Goal: To apply linkage methodology to improve estimates of elder mistreatment.

Study Design:

- Develop, pilot test and evaluate the feasibility of data linkage methodology statewide that could be employed nationally to improve estimates of incidence and prevalence of elder mistreatment from existing sources.
- Assess and further elucidate risk factors for elder mistreatment that may be used to detect previously unrecognized cases.
- Develop standardized operational definitions that can be applied nationally for each type of elder mistreatment: physical abuse, sexual abuse, psychological abuse, neglect and financial exploitation.

Observations: Linkage of multiple data sources has been used to improve estimates of incidence and prevalence in public health surveillance of disease and more recently to improve estimates of intimate partner violence and child mistreatment. Such linkage methodology may be useful to gain estimates of elder mistreatment, which is an under-studied and underreported problem.

Conclusions: None yet. Progress to date includes:

- Central database development under way.
- Assembly of electronic data for 2006-2007 in progress.
- APS record abstraction for supplemental variables under way.

- Record abstraction at psychiatric hospital in pilot phase.
- Working group assembled to clarify case definition used by each data source.

Discussant, XinQi Dong

Dr. Dong explained that the human rights issue in China informed his interest in this area. After receiving his M.D. he felt that he had a deeper obligation to society and began working on domestic violence and gun control. Then he became committed to elder abuse.

Dr. Dong stated that Dr. Robinson did a wonderful job of describing OSCAR, which is a comprehensive source with great potential for linking. The QI and QM are markers for potential problems, but what needs to be explored is how predictive they are. As for MDS, in coming years MDS will be more clinically relevant and integrate more selected scales in terms of resident and family voices.

Ms. Smith presented on NIBRS — those data give us more information about offender characteristics as related to violent crime. NCVS gives a national representative sample, but we struggle with aggregate and proxy data and whether it is precise. The six-month intervals are good to minimize telescoping.

Dr. Verhoek-Offendahl's very ambitious work uses comprehensive, all-inclusive data sources. It is critical to have standard, operational definitions.

We often struggle with definitions. Right now we are looking at the tip of the iceberg. The question is whether the definition from the tip affects the base and can we capture the entire broad spectrum. Dr. Dong described his own work in Chicago with a population-based study using a biracial population. The goal is to get solid empirical data to look at how well measures predict adverse outcomes or consequences. We may find that mortality, for example, is an indicator of abuse. Data linkage is also an issue because minor differences in methods in linking can cause large variations. We must consider ways to deal with data linkage methods to minimize inconsistencies.

Question/Comment Period

Dr. Verhoek-Offendahl noted the availability of Link-Solv software for probabilistic linkage to find cut points. But because of the small numbers in Rhode Island it was necessary to use client identifiers. As many variables as possible are used for matching. **Ms. Smith** pointed out that BJS does not use linking, but it does have survey software that is available free that can be adapted to the victimization setting. **Dr. Robinson** noted that they have linked individuals with hospital records with some success and would welcome another data set with outcome information. **Dr. Acierno** asked if it is possible to get information on the top 5 percent of problems in nursing homes. **Dr. Robinson** replied that security considerations limit much of what can or cannot be done. He noted that he could access the Medicare comparison site and make comparisons at the facility level. In terms of linking with CDC or other health databases, there is a potential for linkage, but it is technically much harder than it might appear.

Dr. Catherine Hawes, referring to Dr. Dong's comment that if certain numbers indicated a change in mortality, that might be the gold standard, asked why mortality should be the standard. A person might instead be scared, and we would be under-recognizing the impact of psychological violence. **Dr. Dong** agreed that there should be multiple domains to measure instrument performance.

In response to a question, **Ms. Smith** stated that she did not know why it was so costly to add questions to surveys. She noted that they run a supplement in partnership with the **National Center for Health Statistics** to see how to capture yearly information while bringing the cost down. It might be possible to look at a core group of questions and do a modular run around those.

Dr. Stahl, in summarizing the panel, said that he is intrigued by the possibility of using secondary data through data linkages with major data sources specifically addressing elder abuse. He noted the difficulty in adding on to surveys. Citing as an example the longitudinal Heath and Retirement Survey, Dr. Stahl said that even if he could convince a grantee to write a module to add questions, there would be concern about jeopardizing the survey with questions on a topic as sensitive as elder mistreatment. Overall, he concluded, the methodologies are very impressive.

Elder Abuse Forensics - Reports from Current or Recently Completed Research Projects

Panel Presentations:

Laura Mosqueda — Bruising as a Forensic Marker of Elder Abuse

Goal: Working in partnership with APS, document the bruises of elders who have been physically abused.

Study Design: Study population to include 100 adults, ages 65 and older, alleging physical abuse within six weeks. Cognitive impairment is allowed when a caregiver/surrogate is available. One-time home visit assessment, including documentation of all physical markers of abuse, will be conducted. Data will be subject to LEAD Panel assessment to determine the presence (or absence) and severity of abuse.

Observations: An earlier study described bruises associated with abuse and those that were not. Findings showed that 90 percent of accidental bruises were on the extremities, none on neck, ears or genitals. Only 20 percent of persons with accidental bruises knew how they got them. It is important to make a distinction between accidental and inflicted bruising to ensure that caregivers are not unfairly accused of abuse, to get guidelines for suspicious bruising to improve reporting, and to give health care providers parameters for evaluating bruising in the elderly.

Conclusions: None yet. Preliminary data on 59 participants shows:

- Bruises with accidental or unknown causes were more likely to be on the extremities, while inflicted bruises were more likely to be on the head and/or trunk.
- The size of an inflicted bruise was greater than an accidental bruise, which could indicate that a larger bruise on head or trunk has clinical relevance.

Solomon Liao — A Multisite Study to Characterize Pressure Ulcers in Long-Term Care Under Best Practices

Goal: To determine whether pressure ulcers can occur with good care, characterize full-thickness pressure ulcers in terms of who will get them, and establish best care practices.

Study Design:

- Select top-performing skilled nursing facilities (SNFs) with no citations for pressure ulcers for the past 12 months and conduct an on-site facility evaluation to confirm the quality of the institution.
- Conduct a one-time assessment of pressure ulcers on residents, including measurements of ulcer characteristics, digital photos and medical record review.
- Present all information except current wound characteristics to LEAD Panel, which will determine quality of care.

Observations: Challenges have included: 1) IRB (institutional review board) issues regarding a) protecting the facility and staff and b) mandatory reporting, and 2) difficulty in recruiting facilities because of low prevalence of ulcers and facility concern about oversight and discovery with a study funded by the DOJ.

Conclusions: None yet.

Erik Lindbloom — Mandatory Reporting of Nursing Home Deaths: Markers for Mistreatment, Effect on Care, Quality and Generalizability

Goals:

- Further elucidate markers for elder mistreatment.
- Identify whether or not the reporting law (all nursing home deaths must be reported in Pulaski County, Arkansas) has had an effect on the quality of nursing home care in Pulaski County.
- Explore possible generalizability to other counties.

Study Design:

- Review death investigation records for the 3,175 reported deaths, including discussions with family members in 18.8 percent of cases (596).
- Note presence of pressure sores.
- Document factors associated with cases referred for further investigation, which includes dissatisfied family members, presence of pressure ulcers and race.
- Review MDS linkage data for predictors of referral to the attorney general.
- Review autopsy case series, n=20.
- Survey Arkansas coroners.

Observations: A previous project explored the details of death investigations suspicious for mistreatment. Since 1999, in Pulaski County, more than 3,000 nursing home deaths have been investigated and more than 100 cases referred to the Arkansas Attorney General's office on suspicion of abuse or neglect.

Conclusions:

- Some factors were elucidated that were associated with a higher suspicion of mistreatment among investigators.
- Discrepancies were found in autopsies, underscoring the importance of autopsies in death investigations.

- No evidence was found for care improvement as a result of the reporting law, but the study was limited by the use of retrospective and self-reported data (MDS).
- The coroner survey outlined formidable barriers to generalizing such investigations to other locations.

Laura Mosqueda — People with Dementia as Witnesses to Emotional Events

Goals: To determine whether there is a subset of persons with dementia who are reliable witnesses to emotional events and, if so, to determine what are the measurable characteristics.

Study Design:

- Start-up (in progress) — Meet with industry experts to refine study design and instrumentation.
- Phase 2: Recruit 100 dementia dyads (i.e., people with dementia and a reliable informant) and controls for a one-time home visit during which separate interviews will be conducted with each member of the dyad to assess variables such as confabulation, mental status, disease stage, awareness and attention. Outcomes assessment will be audio recorded, and reliable emotional memory will be assessed based on unanimous inter-rater agreement.
- Phase 2: Recruit 10 participants from the population to represent the two polar groups: five older adults with reliable emotional memory and five without. These participants will undergo an MRI (magnetic resonance imaging) protocol to assess amygdalar volume and undergo salivary cortisol assays to test the hypotheses that an ADRD (Alzheimer's disease or a related dementia) patient with reliable emotional memory will have significantly greater amygdalar volume and normal patterns of daytime salivary cortisol levels.

Observations: Clinical experience shows that people with dementia can recall emotional events. A previous study showed that 47.3 percent of the demented older adults in the study had experienced one or more types of abuse. Judges know very little about cognitive changes in older adults, and there is little understanding of dementia.

Conclusions: None yet.

Nancy Knight — Whole-Body CT Imaging in Post-Mortem Detection of Elder Abuse and Neglect

Goals:

- Phase 1: To determine whether a noninvasive protocol (examination by a forensic pathologist for evidence of external injuries and whole-body CT [computed tomography] scan evaluated by a radiologist for internal injuries) is a sensitive/accurate method for detection or exclusion of abuse and/or neglect in elder individuals.
- Phase 2: To determine whether the optimized version of the CT protocol will obviate the need for complete autopsy in some percentage of suspected elder abuse cases.
- Phase 3: To determine to what extent the CT will provide a time- and cost-efficient model for rapid investigation of suspected elder abuse and neglect.
- To prepare a database of freely available images and descriptive technical reports that will facilitate replication of this scanning protocol.

Study Design:

- Phase 1: N=30 decedents ages 65+ in whom residential care abuse/neglect is suspected. Compare sensitivity, specificity and accuracy of whole-body CT for indications of abuse/neglect with autopsy findings by CME (chief medical examiner).
- Phase 2: N=50 decedents ages 65+ in whom residential care abuse/neglect is suspected. Assess relative duration and cost of noninvasive imaging protocol and autopsy, and number of autopsies avoided or facilitated by imaging.
- Phase 3: Assess/report: 1) sensitivity, specificity and accuracy of CT, 2) quantitative and subjective results on effect of addition of this protocol to OCME's (Office of the Chief Medical Examiner) routine processing of elder deaths, 3) additional analysis of specific demographics (e.g., sex, type and location of injury), and 4) limitations and challenges of this forensic imaging approach.

Observations: Recent studies suggest a major role for high-resolution 3-dimensional CT and MRI in the forensic investigation of death. However, autopsy by CT imaging has some limitations, including the inability to evaluate all pathologies, unfamiliarity of many forensic pathologists with CT and MRI, lack of widespread access to scanners and no data demonstrating the potential for cost-effectiveness. An additional consideration is the minimally invasive ultrasound-guided autopsy (MIUGA), which offers service where consent for a full autopsy is refused and is an option for autopsy where hazardous infectious agents are suspected.

Conclusions: None yet from this study. Early experience with other studies suggests that autopsy by CT imaging showed promise as a sensitive tool for detection of major injuries and cause of death after accidental blunt trauma and drowning. In non-accidental traumatic death, CT can be a valuable adjunct to mandatory autopsy and may shorten autopsy time.

Discussant, Judy Salerno

Dr. Salerno stated that she was not commenting as a researcher in making this summary. Each presentation reminded her of a clinical case that was confounding. She recalled taking her own crying child to the hospital as a young mother and being grateful for the very thorough examination that found encephalitis from a pertussis vaccination. It showed her the importance of doing proper fact-finding to protect people.

It has been said that there is hard science and then there is really hard science. In this field it is necessary to think innovatively and creatively to get data. Bruising and pressure ulcers are clues to mistreatment but are not hard evidence. While it is clearly important to try to link presentation and clinical signs to elder mistreatment, as clinicians we must think about risk factors and prospectively identify patients at risk for mistreatment. For clinicians, the question is when to act and report — a decision that is not easy with sick patients. The picture becomes even more complicated with patients with dementia, particularly because there are different types and degrees of dementia. Some types involve memory loss, others cognitive impairment — and sometimes there is cognitive impairment without dementia. There are great stresses to caregiving and things become invisible because they happen behind closed doors. There has been little science in this area, but we must look at risk factors and think in terms of how the patient presents.

We are looking at the interface of health and a social system of care and are not doing a good job of straddling the divide. We need a more interdisciplinary approach. Today we are trying to understand how widespread elder mistreatment is, but we can be hopeful because the unknown is

not unknowable. Clinical protocols may allow us to identify things that make us suspect elder mistreatment — and pressure ulcers may not be such an indicator.

The big issue is dependency, because people depend on family members to care for them. Perhaps we need to engage caregivers more in the dialogue — they will tell us. As a teacher, I also think about trainees. We have not taught our young health trainees to ask the right questions, sometimes even the most rudimentary ones.

We need a broader use of home evaluation. The home care workers are the boots on the ground — they have built the trust with the family and with that can come increased information. These relationships need to be developed — they are not one-shot deals.

The data don't seem to support more reporting from nursing homes to the medical examiner, but we have a long way to go in evaluating these data. We should think more about unannounced visits in institutional care settings. We need to see things as they really are.

Discussion of Forensics Issues and Priorities in Future Research

Detective Cherie Hill thanked the panel from a law enforcement perspective, noting that studies such as theirs affect the way she and other law enforcement officials do their jobs.

Dr. Hawes asked **Dr. Lindbloom** whether he considered staffing in his study. **Dr. Lindbloom** replied that the study looked at facility and individual levels, but did not identify any links other than those presented in his talk. He noted that because of the large amount of data, the study used a P value of .0001. **Dr. Mosqueda** asked **Dr. Knight** whether her forensic pathologists had training in geriatrics. **Dr. Knight** stated that a gerontologist is working with her group to address pertinent areas that would require more study in that area. She agreed that many medical examiners do not have a geriatric focus. **Dr. Mosqueda** asked whether **Dr. Knight's** team considers elder abuse when the cause of death does not indicate clear evidence of elder abuse. **Dr. Knight** replied that her team does document old fractures and other traumas that could indicate prior abuse.

Dr. Hawes recounted two incidents in which medical examiners were aware of events that should have raised a red flag, but they declined to act: one in which two deaths occurred from smothering due to mattress placement near bed bars, and the other that involved seven deaths in six months from falls with no injury other than head trauma. Both were very unusual occurrences, but neither generated official reports. She expressed a deep concern about the lack of investigation of these incidents and asked that participants consider the constraints of confidentiality versus the responsibility to report such unusual and disturbing incidents. A participant noted that in the case of ongoing studies funded by the NIH (National Institutes of Health), investigators are required to report adverse events on a regular basis. **Dr. Hawes** responded that there are confidentiality constraints that prohibit reporting and argued that the balance between these constraints and the welfare of the elderly participants who are part of the research study must be considered.

Dr. Carrie Mulford brought up misuse of medications as a form of abuse and asked whether this is being captured in any studies.

- **Dr. Lindbloom** said that his studies looked at medication and toxicity screens.
- **Dr. Maggie Baker** reported on a pilot study that touched on medications.
- A participant noted that more chemical restraints were used in the long-term care setting if the patient was difficult.

- **Dr. Verhoek-Offendahl** raised a concern that in the elder community when a caregiver is not giving medications, this kind of medical neglect does not seem to get the same attention as with child mistreatment.

Dr. Salerno asked **Dr. Branch** about the difference between intended and unintended harm in the elder mistreatment setting. **Dr. Branch** replied that caregivers' intentional acts with unintended consequences, such as leaving an elderly person home alone for too long a time, should be included as elder abuse. The participants discussed the line between clinical abuse, negligence and malpractice, noting that although legal issues such as civil versus criminal prosecution and levels of proof and intentionality inform this discussion, some areas do overlap. The issue of distinguishing between nursing facility staff that is not properly trained and staff that simply makes a mistake was raised. **Ms. Erica Smith** suggested that it was critical to have definitions of malpractice and lack of training, but that it is hard to capture the nuances to arrive at a standardized definition. A participant suggested that this is where intent (e.g., "I knew that if I didn't do X, Y would happen") must be used broadly to tease out actions that are unintentional mistakes. Other participants agreed that it can sometimes be difficult to determine when a person has crossed the line into criminal negligence. **Ms. Connolly** suggested that this is an area that requires data collection across disciplines.

The participants discussed the comment made in an earlier presentation that caregivers, when asked, will tell that they are abusing. **Dr. Acierno** pointed out that this generally refers to anonymous reporting and that domestic violence literature indicated that proxies would admit to abuse when reporting is anonymous. **Dr. Alex Crosby** noted that sexual violence perpetrators are the exception to this, as they do not report abuse, even anonymously. **Dr. Mosqueda** stated that she routinely asks family caregivers questions such as "Do you ever get to the point that you hit?", and they do admit to this.

Ms. Kathleen Quinn asked whether, in the context of trying to define elder abuse, which is harm to the older person, the issue was being clouded by mixing in the accountability of the perpetrator regarding whether his or her actions were intentional or resulted in unintended consequences. A participant suggested that the reporting of the abuse remains the same, but the distinctions about the perpetrator affect the type of intervention that is required. **Ms. Quinn** stated that this assumes that the person receiving the report is trained and has the tools to make such judgments, which may not be true in all cases.

Dr. Georgia Anetzberger asked whether putting emphasis on the evident signs of abuse, such as pressure sores and bruising, causes people to ignore or miss the more subtle signs of abuse. **Dr. Mosqueda** stated that this question was a great cautionary note and that clinicians and others must resist the temptation to latch on only to the obvious signs. However, she added that if everyone would even just be aware of the obvious things, we would be way ahead of where we are right now because so much of the obvious is missed.

Detective Hill recounted a case in which a grandson injured his elderly grandmother's wrist by roughly taking the TV remote control from her. Both the grandmother and family members lied about the cause of her injury to protect the grandson. Ultimately, the nature of the injury made it clear her story was false, and the grandson confessed. **Detective Hill** noted that this case demonstrated the importance of looking at the whole picture. **Dr. Branch** contended that this was not a case of elder abuse because it was not done by the caregiver, but rather was an example of abuse of an elder. **Dr. Acierno** suggested that this is a good example of why one should measure an event and decide what it was afterward. **Ms. Jane Raymond** asked **Dr. Branch** for more clarification about how he defined elder abuse in the context of whether it was perpetrated by the caregiver, wondering whether he looked at it as incident specific. **Dr. Branch** replied that he was

assuming in this case that the grandson was not in a caregiving relationship, and thus the grandson's actions constituted assault, which was a crime against the elderly, not elder abuse. **Dr. Branch** noted that the line is not always easy to draw, recounting that caseworkers have mentioned how difficult cases of psychological abuse can be to define where, for example, a couple may have gone for years with one partner being psychologically abusive, and then when the abused partner becomes frail, at what point does this become elder psychological abuse?

Dr. Kerry Burnight noted that over the past eight years, as knowledge in this field has been accumulating, it has come in more of a piecemeal fashion as if adding pieces of a puzzle, rather than in a more systematic, building block way. She stated that she did not consider this a problem because the body of knowledge was indeed expanding.

Dr. Solomon Liao suggested that a valuable area of future research would be end-of-life care, because the elderly are such a vulnerable population. He cited as an example of an area where there is no research is the issue of non-administration of pain medications, thus allowing an elderly dying person to suffer needlessly.

Ms. Connolly adjourned the meeting at 5:00 p.m.

Abuse and Neglect in Long-Term Care

Panel Presentations

Catherine Hawes — Detecting, Investigating and Resolving Elder Mistreatment in Residential LTC Facilities

Goals: To identify systems for detecting, investigating and resolving abuse after it is reported. Primary goals:

- Describe abuse reporting laws in all states.
- Conduct telephone survey of all "first responder" agencies.
- Conduct seven in-depth case studies.
- Identify smart practices.

Study Design: Focus on all types of residential care facilities (RCF).

Observations: This is hard research to do because colleagues don't want to talk to you about it. You need to think about how to support your staff during field studies. Some assume this elder population can self-report and protect themselves, but that is not true. This is a vulnerable population. Understaffing and inadequate training are major causes of abuse, but there is also a failure of political will to get proper regulations in place. The same problems persist and policy is not moving forward.

Conclusions: Preliminary findings:

- Problems with detection and investigations: there is little outreach and flawed intake with limited regulatory systems in most states.
- A growing problem is sex offenders, prisoners and people with persistent and severe mental illness who are placed in RCFs with frail elders.
- Practices and policies are dysfunctional, with underfunding of agencies and a lack of awareness of the views of field staff.

- Problems with detection and resolution: there is a difference in focus between APS and licensure that does not converge to the benefit of residents, and a limited and perplexing role of APS in several states. Police cooperation is variable, and prosecution is a major problem due to a failure to understand the residents and the setting, and a tendency to discount testimony in cases of people with dementia.
- There are some smart practices, including: 1) registries for all health care personnel, 2) criminal background checks for staff, 3) involvement of Attorney General's Medicaid Fraud Control Unit, and 4) ombudspersons.

Catherine Hawes — Developing Prevalence Measures of Elder Abuse in Residential LTC Settings

Goal: To develop and test methods of generating estimates of the prevalence of elder mistreatment in LTC settings and assess the feasibility and challenges involved in conducting a national study by:

- Developing valid operational definitions of elder mistreatment.
- Developing and testing the utility of various methods for estimating prevalence.
- Identifying potential resident, facility and staff risk factors for abuse.
- Using the findings to identify obstacles, recommend strategies and assess the feasibility of conducting a national prevalence study of elder mistreatment in LTC facilities.

Study Design:

- Test the definition in focus groups and individual interviews with 120 residents and 55 facility staff in two nursing homes and two RCFs.
- Test alternative methods for estimating abuse prevalence and determine which produces the most comprehensive reports of elder mistreatment through interviews with 780 cognitively intact residents and a randomized, anonymous sample of more than 350 direct-care staff on multiple shifts.

Conclusions: None yet.

Mark Lach — Resident-on-Resident Elder Mistreatment

Unexpected findings from a previous study: After completion of a large, community-based, longitudinal study to understand the epidemiology of police contact with community-dwelling older adults, some unexpected findings were:

- A substantial number (747) of the 2,322 participants were placed in nursing homes over the 13-year follow-up.
- Many police contacts with participants occurred *after* they were placed in the long-term care facility.
- These were overwhelmingly situations in which the police were called to intercede in resident-on-resident aggression.

Scope of the problem: Resident-on-resident elder mistreatment (RREM) is defined as negative and aggressive physical, sexual or verbal interactions between long-term care residents that would be construed as unwelcome by the recipient in a community setting and that have high potential to cause physical or psychological distress. There is little in the literature about RREM, but indirectly the literature indicates that behavior disturbances, such as those associated with dementia, are notorious provocateurs, and when patients with behavior disturbances and disinhibitions are commingled, it is asking for trouble. Clinical experience supports this observation as do two pilot

studies that provide evidence for the phenomenon of RREM. Resident-on-resident elder mistreatment may be the most prevalent form of elder mistreatment, either inside or outside nursing homes.

Methodological challenges to studying RREM:

- Official reporting systems are subject to massive underreporting of cases, and there are nonstandard policies and practices across states.
- Resident informants (aggressors and victims) are often cognitively impaired, have visual and hearing impairments, and have incentives not to be truthful.
- Staff informants may avoid aggressive residents, and RREM often occurs and escalates specifically because staff is absent.
- Events may be ephemeral, infrequent or hidden.
- Researchers may be obligated to report events that they witness.

Next Steps:

- Need a prevalence study of RREM.
- Need to drill down on the range of various behaviors that constitute RREM.
- Need evidence-based intervention strategies to prevent RREM or at least avert poor outcomes if RREM cannot be prevented.

Janne Swearengen — Identifying and Monitoring Abuse and Neglect in Long-Term Care Facilities

Question: How do you evaluate whether poor care has become abuse or neglect?

Answer: Utilize available data to come to an informed conclusion.

Use of Data:

- Quality Indicator/Quality Measure (QI/QM) Data: QI/QM facility reports can identify facilities with very high rates of problem conditions in residents. QI/QM resident-level reports can identify residents with a specific clinical or functional problem or condition and identify patterns of problems in a single resident or across residents.
- Deficiency Data: Can indicate various citation levels (G,H,I,J,K,L) to identify substandard care, actual harm or immediate jeopardy.
- Observation and Interview Data: Observe resident care, appearance, staff-to-resident and staff-to-staff interaction. Interview resident, staff, family.

Putting It Together:

- Knowing how to interpret available data can lead to the identification of possible abuse or neglect.
- Intense and in-depth investigation can determine whether abuse and harm or neglect and harm have occurred.

Anne Montgomery, Lori Post, Susan Larsen — Research on Criminal Background Checks

I. Patient Safety and Abuse Prevention Act — Anne Montgomery

Improved screening of long-term care workers is needed to exclude individuals with abusive backgrounds. The Patient Safety and Abuse Prevention Act would be a good start in taking a proactive approach to screen out predators. In 2003, Congress authorized a three-year pilot study of background checks. States taking grant money were required to make improvements in background check systems and streamline the process among different state agencies, including doing more detailed checks. The study showed that although no single check worked, a multifaceted approach is effective. A total of 7,200 individuals were identified out of 200,000 checks. There is solid bipartisan support for the Act, which is endorsed by 41 states, numerous state attorneys general, and Medicaid Fraud Control Units. The bill is currently in committee in the House and Senate. More research is needed on costs and benefits of well-designed screening systems.

II. Centers for Medicare and Medicaid Services (CMS) Background Check Pilot Program Update – Susan Larsen

Program Purpose: To identify efficient, effective and economical procedures for conducting background checks. The pilot period ran from January 2005 to September 2007. The data are now being analyzed by an independent evaluator.

Study Design: CMS selected seven states to participate in the pilot. States could establish their own background check programs but had to meet specific requirements of the study. Most states built in sustainability to be able to continue the programs.

Pilot State Comments:

- All states agreed that conducting thorough background checks helps improve health care workforce quality.
- All states expressed concerns about the high cost of conducting state and FBI fingerprint-based background checks.

Lessons Learned/Best Practices:

- Begin with an incremental approach – first complete low-cost/fast turn-around checks and only spend money for expensive fingerprint-based checks for those applicants who clear the initial search.
- Capture and submit fingerprints electronically.
- Rap-back background check systems can improve effectiveness, efficiencies and cost.
- Background check time exemptions – some states reestablished exemptions after the pilot and do not require a new fingerprint-based check each time an employee changes jobs.
- Unintended consequences – when developing check processes be aware of potential unintended effects in reduced health care work force.

Three states delivered innovative, culturally sensitive and effective abuse prevention training programs.

III. Information Communication Technology for the Prevention of Abuse, Neglect, and Exploitation in Long-Term Care Settings - Lori Post

Problem: As more vulnerable elders require long-term care, there is no standardized system across agencies for preventing abuse, neglect and exploitation in long-term care facilities.

Partial Solution: Use information communication technology to standardize systems.

To answer the question of cost-effectiveness, a pilot study was conducted to make an economic analysis of abuse, neglect and exploitation.

Goal: Conduct a cost/benefit analysis for developing, maintaining and staffing the Michigan Program for Background Checks.

Study Design: Establish estimates of: 1) crime costs; 2) cost savings from crime prevention; 3) cost savings from training prevention, hierarchical system and system record retention; and 4) costs of developing, maintaining and staffing background check program and performing cost-benefit analysis.

Conclusion:

- Total savings from crime prevention efforts: $48,050,316.
- Total cost of instituting background check program: $9,568,707.
- Cost benefit for first year: $38,481,609.

Discussant, Nick Castle

Dr. Castle noted that there is very little in the literature on this topic, which is a developing area.

In terms of the institutional component, why do we find abuse? Staffing issues certainly contribute in an environment where staff workers earn $7/hour, work long and difficult hours, are often minorities, have stresses of their own at home, and then get abused by the residents. This fosters professional burnout, which leads to high turnover, which makes it necessary to bring in agency staff workers who don't have a relationship with the residents. This in turn leads to absenteeism and inadequate staffing — now we have a recipe for abuse. Solving the staff issue is a necessary first step, but it does not address the entire problem.

Another problem is the lack of definition of elder mistreatment. Where do you set the bar, low enough to use the definition as a screen? We have differences between QI and QM — what is this used for? There is a Web site where you can look up deficiency information, so if you bring up abuse, nursing homes don't want to talk about it. Terminology is also a problem — abuse, neglect, mistreatment, maltreatment — we are on a slippery slope and soon may be calling it "not being so nice to the elderly."

Dr. Castle stated that in his patient safety work he didn't see much about errors of omission or commission. Instead, the issues were scope and standardization. As to scope, how do you measure it in, for example, financial abuse? If a resident makes $10/month and you steal $1 you have stolen 10 percent of his income, even though you only took a dollar. How do we deal with standardization when residents' rights vary from state to state?

As to estimating prevalence, it is very difficult to get the right number of items for residents to comprehend the question. We ask nursing aides if they have ever seen, suspected or been told

about abuse. With an N of 2,000, the data certainly show that abuse is occurring. Dr. Castle noted that he has personally walked in on an abuse situation that was clearly about to happen. He noted that his own children can push him to the limit — that is when he goes out to walk the dog. But how does a nursing aide take a "time-out?" What is a best practice here? We don't know yet.

Question/Answer/Comment Period

Dr. Maggie Baker asked the panel to comment on the incidence of sexual abuse in residential settings, specifically whether they think the numbers are higher than estimated. **Dr. Lachs** stated that hypersexual behavior in people with dementia is extremely common and reported often by nurses. Such residents will often impose themselves on many other residents, and most of this type of behavior in the long-term care setting is done by residents themselves, not sexual predators on staff. **Ms. Swearengen** added that residents' reports of sexual molestation are sometimes discounted by staff due to the belief that the residents are mentally or cognitively impaired. This raises the question of what kind of policies and procedures the facility has in place to respond to such resident concerns. **Dr. Hawes** reported that staff will sometimes normalize the sexual event, saying the resident did it to herself. This is not logical, but it is not always easy in this setting to discern what is normal sexual expression and what it not, which is why it is essential to have enough staff to observe and prevent problems.

Ms. Kathleen Quinn asked whether other states are developing background check programs. **Ms. Larsen** stated that not many other states, outside of those in the pilot, are doing it. **Ms. Montgomery** added that background checks are not within the scope of the legislation, and she opined that it is not clear that legislators would consider that part of the solution.

Ms. Fran Henry observed that currently the framework that drives elder maltreatment funding seems to come from the criminal justice area. She asked whether it would be valuable to come at the problem from a different perspective and frame the issue in terms of rights and responsibilities. **Dr. Hawes** suggested that this concept might not be grasped by a population in which two-thirds are cognitively impaired. **Dr. Lachs** stated that it is a constant struggle to decide how to frame the issue from a funding perspective and that in light of resident-to-resident abuse, framing the issue from an educational rather than punitive standpoint merited thought. **Dr. Lachs** added that epidemiologists direct resources according to attributable risks and opined that the risk in the long-term care setting is most likely living among violent residents, not violent staff. He said that if there were data to indicate this risk, it would drive the area to focus resources. **Dr. Ron Acierno** stressed the importance of focusing on the events first and defining the issue after getting accurate numbers. If the numbers demonstrate that the majority of cases are coming from resident-on-resident abuse, those data can be used to justify allocation of resources to that area. **Dr. Hawes**, noting the idea of cost-effectiveness, suggested that it is hard to reform the system where costs and benefits go differentially across settings and agencies. She added that staff-on-resident abuse does indeed exist, not necessarily because the staff person has a criminal background, but because the staff person is overly stressed. **Dr. Acierno** suggested that even without staff-to-resident abuse, resident-on-resident abuse might still account for a significant percentage of overall abuse.

Dr. Georgia Anetzberger stated that she and others in her local community had looked at the Patient Safety and Abuse Prevention Act and felt that they could not support it because: 1) it was based more on horror stories than reality, 2) it fostered a pervasive unwillingness to hire people with *any* sort of criminal background due to a fear of liability, and 3) a concern that over time the definition of criminal background could broaden to a greater application than warranted. **Ms. Montgomery** replied that the basis for the act is not horror stories but documented abusive staff and serial offenders, and it is necessary to ensure that they do not harm residents. The Act is a proven, non-costly intervention, and there is a moral responsibility to take action to keep those with

certain criminal backgrounds out of the system. Resident-to-resident abuse is not implicated in the screening and is certainly a part of the larger picture, but the Act provides an opportunity to solve one area of the abuse problem as it relates to serial offenders. **Ms. Naomi Karp** asked whether there were any outcome data or before/after studies indicating that background checks lead to less abuse. **Dr. Post** said that efforts are being made to trace incident reports to licensing agencies, but it is too early to tell about outcomes. **Ms. Larsen** stated that CMS is looking at this aspect, too. She noted that it appears that heightened awareness leads to more accurate reporting and therefore incident reports actually increase. She added that through a centralized process to oversee all incident reports, a criminal background check was conducted on accused caregivers and a criminal background was rarely found.

Dr. Laura Mosqueda asked that the participants consider that neglect is more of a problem than abuse. **Dr. Pamela Teaster** suggested resident-on-resident and staff-on-resident abuse have the same effect on the victim. **Dr. Post** disagreed, saying that there is a greater negative impact on the victim when the abuser is someone the victim trusted. **Ms. Jane Raymond** asked whether anyone is studying family or other outsider abuse on residents. **Dr. Lachs** said that he has not planned to look at this, and he suggested the closest thing that he has seen in focus groups is in the situation of roommates where one resident has a lot of visitors and the other has none. This seems to provoke ill will that can lead to aggression. **Dr. Hawes** noted that in her research she is studying what happens to residents by asking residents themselves and staff. The issue may well be, in the case of abuse, that if the resident feels unsafe in the place where he or she lives, then the problem is not so much who is doing the abusing as the fact that it is occurring. The same is true of neglect, which leads to suffering that is just as painful for the resident. A part of the solution might be working on facility responsibility for various conflict situations. **Dr. Lachs** agreed that this is a big tent, and whether it is resident-on-resident or staff-on-resident, resources must be allocated.

Laying the Foundation for Theoretical Model Development in Elder Mistreatment

Introduction — Dr. Laura Mosqueda

Dr. Laura Mosqueda introduced the discussion by asking why elder mistreatment occurs and suggesting that the way we think about this will determine our interventions and intervention strategies. It is a complex issue and we must be respectful of, but not overwhelmed by, the complexity. One question is whether the issue can be broken down into studyable components. If it is too simplistic we will miss the interacting factors, but it is worth considering whether we can get a testable hypothesis that allows us to design testable interventions. Might there be a relatively small number of models that account for 80 percent of abuse? We have heard about a number of factors: caregiver stress, entitlement thinking, cycle of family violence, caregiver revenge and greed, mental health challenges, abuse-waiting-to-happen issues—is it possible that abuse might largely be a by-product of one of these factors? First, with this panel, let's explore how models have been used in other fields, particularly domestic violence.

Panel Presentations:

Joan Meier—Models of Domestic Violence

In attempting to develop a model for elder abuse, it might be helpful to consider the models of domestic violence. In terms of history, the patriarchal roots of society led to the Doctrine of Coverture under which women lost their separate legal identity once they were married. This doctrine dominated thought and action for centuries and was only overtly rejected in 1910. Even as recently as 20 years ago, police would not arrest in domestic violence cases, deeming them private

matters. It is not that people were not aware of the problem, it was just that society let it go underground because grappling with trauma is so excruciating. This notion of behavior being excruciatingly painful may have some resonance in elder abuse. In the 1960s, the women's movement surfaced awareness of the prevalence of violence against women. A key point is that it is necessary that a community acknowledge the reality of the horrors—that allows us to come to grips with it.

Given this history, it may seem obvious that domestic violence is related to gender inequality and is a function of male domination, but there are many alternate theories to this feminist perspective, including that women are hooked on abusive relationships in a self-destructive way, that it is really a mutual dysfunction relationship, or increasingly the notion that women are violent, too (and there is some empirical evidence of this). A new model has been advanced by Michael Johnson to try to resolve the tension between the feminist perspective and the nonfeminist view. He posits that perhaps both are right and that there is both intimate terrorism (feminist paradigm) and situational couple violence that is less controlling and less terrorizing. The model allows for the notion of women's violent resistance in response to intimate terrorism and possibly even mutual violent control. This theory has engendered much debate and sparked the fear that if Johnson's model gains wide acceptance, we'll never be able to protect women in court.

Final thoughts: Models are both useful and double-edged. The feminist view was critical to making social and legal changes regarding the abuse of women, but now we see some pushback. How does this relate to elder abuse? Perhaps what is needed is less a model and more a political movement to generate concern, attention and action. On the other hand, perhaps a model or political analysis is essential to such an awakening or movement. In terms of a political movement for elder abuse, consciousness must be raised about how abysmally western society treats older people, and this will entail political and ideological challenges to western social norms regarding the lack of respect for elders. It will take a cultural change of awareness for people to realize that elders are *us*. We will all be there someday, and we are doing this to us.

Georgia Anetzberger—Caregiving: Primary Cause of Elder Abuse?

Calling herself a practitioner first and researcher second, Dr. Anetzberger noted that caregiver stress (CS) and burden has been advanced as the explanation for elder abuse. Believing that the explanation is more complex, Dr. Anetzberger developed an explanatory model for elder abuse that:

- Recognizes the problem as complex and having a variety of forms, perpetrators and victims.
- Reflects the research to date.
- Can incorporate various theories.
- Suggests intervention strategies to inform the practitioner.
- Supports interdisciplinary cooperation for effective treatment.

The model consists of five interrelated components that lead to abuse:

1. Cultural context of social values and norms—e.g., right now our society has a love affair with violence and ageism.
2. Perpetrator characteristics (primary consideration)—e.g., substance abuse, financial dependence.
3. Victim characteristics (secondary consideration)—e.g., Alzheimer's, other dementias, social isolation.

4. Context for victim-perpetrator interaction—e.g., caregiver, guardian/ward, intimate relationship.
5. Context for abuse occurrence—such triggers as the perpetrator has unrealistic expectations or the victim exhibits troublesome behavior.

Useful interventions to prevent or treat elder abuse will vary by model component:

- Cultural context of social values and norms—e.g., intervention is to just say no to caregiving because it is not a good role for you.
- Perpetrator characteristics—e.g., perpetrator may have problems such as substance abuse or mental retardation and need intervention himself/herself.
- Victim characteristics—e.g., victim may benefit from geriatric assessment.
- Context for victim-perpetrator interaction—e.g., a support program through an agency of the Older American Act to help the caregiver relieve some stress.
- Context for abuse occurrence—e.g., perpetrator may benefit from anger management.

Bonnie Brandl—Why Does Elder Abuse Occur and Persist?

Ms. Brandl noted that her focus is as a person working in the field who does training and talks to elders—she is not a researcher. From comments she hears in the field it appears that this is an intergenerational problem and that giving care is very stressful, leading to elder abuse due to caregiver stress.

Who are the victims? They are persons ages 60 and older, not necessarily vulnerable, who are in an ongoing relationship with an expectation of trust that they want to maintain. They are harmed both accidentally by well-intentioned caregivers or intentionally, either through contact with persons with physical or mental health conditions that manifest themselves in aggressive or inappropriate behavior, or by being abused. Elder abuse appears to occur from a sense of entitlement that is often very much about greed. It persists, as is illustrated by the Abuse in Later Life Wheel, for complicated reasons, but at the center is power and control. One concern is that if an abuser really has an entitlement mentality, intervention to address his/her anger management or substance abuse issues may not be sufficient.

The notion of caregiver stress came from asking abusers why they do it, with their answer being "I'm stressed." Many abusers will tell the truth, but others blame the victim and manipulate. Another fact about caregiver stress is that it leads to more self-destructive behavior. Most caregivers are not abusive to other people as a result of caregiver stress.

Where does caregiver stress lead us in terms of intervention? Here is an example:

I am in the field investigating a physical abuse case with a couple in their 70s. He answers the door and says his wife is sleeping, but he will talk. He says he loves her, that she is the most important person in his life, that she can't care for herself, or him, or the house, that it happened just this one time. For this case we can do things to help if it is caregiver stress. Now picture the exact same scenario but instead of 70, the caregiver is 22. If I believe that it is caregiver stress then I act in an interventional way; that is fine if it really is caregiver stress. But if it is not, he will awaken her and scream at her and say that the social worker thinks he's right and needs respite. In this case I have encouraged his negative behavior.

The point is that not all frameworks, not all models, get us to victim safety.

Dialogue with Panel

Dr. Mosqueda asked the panelist to comment on the notion of a "time-out" for staff to counter abusive feelings or impulses. **Ms. Brandl** noted that establishing an ongoing relationship does not always play out in the facility setting, but that this issue implicates a mindset about how to act in stressful situations, and people generally find another outlet as opposed to abuse. **Dr. Anetzberger** suggested that taking a "time-out" in the facility setting is complicated by regulations and staff shortages. **Dr. Mosqueda**, noting that the panel had pointed to power and control issues, not simply caregiver stress as causing abuse, asked them to consider the certified nurse assistants/aides (CNAs) making $7/hour in a very stressful situation—what is leading them to be abusive if not caregiver stress? **Dr. Anetzberger** stated that this is a complicated matter with many variables: a cultural context that might involve racism, CNAs who may lack empathy and are stretched to the limit in other ways, staff shortages that undermine continuity of care, and often demented residents. In this context we ask a CNA to assist an individual who spits at her, pulls her hair, and we expect her to do nothing. We need to take a systematic look at this issue. **Ms. Brandl** added that the abuse might be driven by power and control for people who want to dominate these frail people. **Ms. Lori Stiegel** suggested that, no matter what factors were causing the problem, the issue should be addressed through staff training. **Dr. Pamela Teaster** recounted an experience where a CNA did not even have enough food, let alone being faced with child care and transportation issues. She wondered whether, for people in the situation of having their own very difficult lifestyle, training can actually address the abuse problem when personal problems run so deep. **Ms. Brandl** suggested that volunteers can help be the eyes and ears in the facility, as she found with her own mother who, as a volunteer, was able to make suggestions about things that she had witnessed in the facility. **Dr. XinQi Dong** referred to a body of literature comparing caregiving skills for a particular population, such as Alzheimer patients, with the caregiver's own issues. He suggested that it would be interesting to focus on skills by comparing caregiving skills with caregiver stress and burden to see how much the problem of abuse might be due to one or the other.

Dr. Ron Acierno suggested that there is a danger in the early stages of research in allowing too much theory or too much politics to intrude, because these can drive the questions instead of the other way around. He stressed the need in the early phase of the study to look at the component pieces first and find the extent of the problem by getting the numbers. He wondered whether stress data were dismissed because caregiver stress did not fit the model. **Ms. Brandl** replied that in her work of training people who are on the front lines there is a need for immediate answers. **Dr. Kerry Burnight** agreed that people in abuse situations need to have their problem addressed now, so it is important to have practical tools on the table even as the research goes forward. **Ms. Meier** felt that models could be helpful in peeling away layers, but she noted from her perspective as someone outside the field of elder abuse that it seems very clear that many things—not just one thing—are going on. The problem is that there is not yet widespread sentiment that elder abuse is unacceptable. We discount the worth of nursing aides' service so there is a social willingness to ignore the fact that they make $7/hour for very difficult work. The greater need is for a movement to coalesce around elder abuse, as happened for domestic violence when women latched on to the domestic violence problem, moved it forward into social consciousness, and thereby gained money and support for the fight. **Dr. Ken Conrad** stated that articulating the best theory is essential in directing the study of elder abuse, rather than letting the numbers guide the study. He noted that science involves developing a hypothesis and testing it; the same must be true for elder abuse where the theory guides the data collection. **Dr. Shelly Jackson** agreed that science is the world of competing ideas and it is valuable to get as many theories as possible and test them all. **Ms. Erica Smith** suggested that theory testing and hypothesis testing should be separate from data collection. Knowing what one wants to test will guide the instrument used, and this could be a barrier to capturing all the data. Today's discussion has been illuminating in asking how much

abuse is attributable to caregiver stress versus power and control. It would be interesting if we could explain 80 percent of abuse with one theory, but we can't do that by choosing one perspective over another. **Dr. Jeffrey Hall** commented that the application of theory depends on the character of the situation. What is needed is a multilevel approach with all theories on the table. **Dr. Solomon Liao** suggested that it is not so important to get the model correct as it is to have a unifying model. He expressed surprise that the mutual control model in domestic violence was not more accepted, saying that mutual control and dependency is more common than power and control. **Ms. Meier** stated that there is so much going on that it will be difficult to develop a model for elder abuse. There is more need for a movement based on how we devalue older people. She found the mutual control model inherently contradictory because the way power and control works in the domestic violence field is if one side has the power, the other side doesn't. **Dr. Liao** suggested that there are issues of mutual control in end-of-life decisions, with dying persons sometimes accepting treatment based on their desire to please family members and doctors. **Ms. Meier** suggested that these issues were different from the notion of mutual control that she was describing. The power and control to which she was referring, she posited, could not be mutual because it was about non-normal levels of control that approached the pathological.

Ms. Lori Stiegel suggested that in the effort to quantify elder abuse with the goal of getting more research money, there has not been a universal definition of elder abuse. Perhaps instead of trying for a universal definition, we should produce a definition that works for quantifying the issue and not be concerned that it does not necessarily drive theory or what the practitioners do. **Dr. Anetzberger** asserted that we have to have definitions in order to collect the numbers. The problem is that the definition of elder abuse keeps expanding, and so it is harder and harder to do prevalence studies. There is a need to contain the definition. **Dr. Wendy Verhoek-Offendahl** stated that it was premature to try to nail down a definition at this time. There is still much that is unclear, and if we keep data collection simple and collect variables carefully, we can restrict our definition but get a better idea of who are the victims, the perpetrators and the trusted others. We need to evaluate what we have and get a better understanding of what we are seeing. If we came up with a definition now, **Dr. Wilbur** observed, she was not sure that much of the data that she has at this time would even fit it. **Dr. Dong** asserted that writing a grant without a theory or hypothesis would be "suicidal," but he cautioned that there is still a need to be open to a broader scope. We need the numbers and must have a theory to guide us, but still must be willing to adjust the theory as the numbers come in. What would be very valuable is a rigorously designed, national, population-based study. **Dr. Scott Cunningham** suggested that theory must be involved at the front end, such as exploring whether the domestic violence model applies to elder abuse and, if so, incorporating the relevant portions in terms of victim safety, harm, law enforcement and increased risk of early death. Theory must also be involved at the back end, which is where methodology is implicated in terms of qualitative approaches and early interventions. **Dr. Fred Newman** stated that every time we go out and collect data an implicit theory is there. The question is: is the theory testable and deniable? He differed with Dr. Cunningham that a lot of qualitative things are going on preceding the collection of data. **Dr. Conrad** asserted that theory is how things work, so practitioners want theory. When we hand them a ruler to measure psychological abuse we are handing them a tool based on theory. **Dr. Sid Stahl** stated that we don't do research without theory with a practical background behind it. He urged everyone to forget about closure for a definition. The key is to bring people to share theoretical structure and research issues that make sense to those in the trenches. **Dr. Acierno** clarified his point, noting that theory is necessary but there should not be too much theory. It is better to assume as little as possible to minimize how much theory gets in the way of asking critical extra questions. It is better to minimize the theory and the politics and maximize the description of the event. Scientists should not be the ones doing the political movement.

Dr. Kate Wilbur suggested that the outcome must be victim safety. She said that her focus groups have shown that elders are afraid to acknowledge abuse because they fear that they will be sent to a facility. The question is what does it mean to be safer, and given the fear of the facility, is safer better? **Ms. Brandl** noted that the word "safety" means many different things, and there must be a balance between safety and protection in terms of how we view rights taken away in the name of safety. This may be different from domestic violence where, if there is a power and control imbalance, you restore power to the victim so she regains control. **Ms. Jane Raymond** noted the work in her state in trying to bring older battered women into the APS universe, sparking questions about whether these victims need services different from elder abuse victims. It was noted that there are differences among states in handling these cases. In some states it is felt that it is dangerous to contact perpetrators, so it is not required. The focus is on the victim with no identification of the perpetrator. Other states focus on the perpetrator and are driven by perpetrator rights. **Dr. Anetzberger** responded about the interface between elder abuse and battered women, noting that previously none of her state's shelters were accessible to the handicapped and now they are. These nuances are important. **Dr. Post** stated that the women's movement had neglected older women. Older women were excluded from the Violence Against Women Act, which applies to ages 18-65. Abuse is abuse, but older women face additional challenges, including stereotyping, lack of access to shelters, different types of abuse against elders, cultural bias against divorce and the onset of dementia in their partners. **Ms. Janice Green** noted that the Office on Violence Against Women has a program for older women, but the challenge is adapting outreach and the definitions of success and safety, which are geared to younger women, to the older population. It is not a matter of not being willing to help older women, but of not helping because we are not responding properly to their needs. We might say, "we serve everyone," but we are not really serving older women because they are not calling themselves "battered." How you define whom you are working with defines how you do outreach. We need information from researchers to help us develop things like training programs for law enforcement officials who respond to elder abuse. **Ms. Brenda Uekert** noted the divide between social science theory and law enforcement practice in elder abuse, noting that it is not likely that the basic law enforcement response is going to change. **Ms. Page Ulrey** noted that her office is engaged in a massive training effort to combat the denial of elder abuse in the courts and by law enforcement.

Dr. Jerry Silverman discussed the political movements around domestic violence and child abuse. He noted that the issue of child abuse had an early history of supporters but was mainly driven in the early 1950s by doctors. He asked who represents or advocates for battered children and suggested that there is not a strong constituency for that. Domestic violence has a constituency, although it only goes so far. The question is where will the constituency for elder abuse come from? Who will speak out for vulnerable elders? **Ms. Fran Henry** agreed, noting that battered women themselves came forward. There has not been the same advocacy for child abuse because it is hard for the victims to come forward, just as it is hard for elder abuse victims to come forward. It behooves the professionals in the field to take a stand. **Ms. Kathleen Quinn** suggested that the AARP consider taking up this cause.

Dr. Mosqueda informed the participants about an organization that she and Dr. Burnight are starting in California called ElderPeace, which will bring together victims of elder abuse, family members, and those outraged by elder abuse with professionals in the field to generate an outraged public to advocate effectively. Drs. Mosqueda and Burnight also propose to write a white paper outlining the theories and models for elder abuse and devise testable hypotheses so that we can stop reinventing the wheel. They invited all participants to e-mail them with comments and ideas.

Challenges and Solutions in Conducting Elder Abuse Research

Introduction

Dr. Sid Stahl introduced the discussion by outlining some of the issues that he has seen affect grantees:

- Certificate of Confidentiality: Grantees should consider this for the protection it gives from reporting what is typically required to be reported.
- Obtaining IRB approval: IRBs are not as familiar with this type of research and consequently the process can be time-consuming.
- Multiple IRBs: Often research involves multiple agencies with multiple IRBs, each with its own set of rules. Be prepared for this process.
- Study section reviews: Not all study section reviewers see the innovative nature of the research.
- Writing the grant: Choose your words carefully. The words "descriptive" and "exploratory" can be the kiss of death with some funders.
- Qualitative research: Research in elder mistreatment is in its earliest stages, and consequently qualitative research and mixed methodologies are being used. NIA and NIH do have interest and have funded qualitative research.
- Cultural differences in elder mistreatment: There is a desperate need for research in this area. It is hard to do, but it is essential.
- Co-funders: It is very difficult to find co-funders for elder mistreatment research, except for DOJ and the Archstone Foundation. That is a problem because co-funders can help make up for budget shortages.

Question/Answer/Comment Period

Reporting and Certificates of Confidentiality

Dr. Lori Jervis brought up a concern about mandatory reporting. **Dr. Fred Newman** stated that in his Miami project they do not collect names or enough information to identify the participant, including not requiring the participant to give an accurate name. If, at the end of the data collection, the participant wants to go to APS, forms are available. Dr. Newman stressed the importance of getting the Certificate of Confidentiality and maintaining a steady collaboration with the IRB on this issue. **Dr. Stahl** recommended that Dr. Jervis confer with her IRB about her reporting concerns.

Ms. Catherine McNamee explained that researchers who accept DOJ funding are bound by the DOJ privilege requirements and that Certificates of Confidentiality do not apply. The researchers must maintain the confidentiality of identifying information, and if elder abuse is discovered they cannot report it. Researchers are only allowed to report in cases of immediate harm to the participant or others. Researchers are allowed to provide help to the participant by giving help-seeking information, counseling referrals and phone numbers. As DOJ has gotten involved with elder abuse research, other alternatives have been developed, such as allowing researchers to seek approval from the IRB and NIJ for a second informed consent form to get consent for reporting suspected abuse discovered during an interview. **Dr. Solomon Liao**, who has been involved in alternative consent, stated that although his research involves going into the best facilities and therefore does not expect to find abuse to report, there was an ethical problem with not being able to report if necessary. Moreover, the IRB said that one cannot consent someone to do what you are required by law to do. Our solution was to use a form separate from the research informed consent

form stating that researchers are mandated reporters and allowed to do so. Interestingly, the facilities were more concerned about this than the participants or their families. Dr. Liao felt confident that the participants understood what they were signing because in California they use a process of evaluation of capacity to consent. **Dr. Larry Branch** reported that his university gets 60 percent of its funding from NIH, and the IRB follows the NIH standards regardless of whether his funding is from NIJ. His approach is to emphasize that his interviewers are not trained professionals and therefore are not subject to the same professional reporting requirements. They do make available the abuse hotline number. **Dr. Carrie Mulford** added that if an IRB tells an NIJ-funded researcher that a Certificate of Confidentiality is needed, the researcher will be told to inform the IRB that it is not required. **Dr. Ron Acierno** noted that even though a researcher has federal protection from reporting, researchers who are clinicians stand to lose their licenses and could be sued. Because participants in his studies are identified by phone number and address, Dr. Acierno reviewed the three-step process his researchers use: 1) see if the participants will report if they think it will happen again, 2) see if a non-offending person is available, and 3) make the report on the basis of imminent harm to self or others. His group follows state law regarding violence reporting. **Dr. Alex Crosby** stated that in the CDC epidemiological studies they are gathering historical information from the past 12 months, so the abuse is not necessarily ongoing from their standpoint.

Conference on Ethical Issues in Elder Abuse

Dr. Liao asked Dr. Stahl about the possibility or feasibility of sponsoring a conference on ethical issues in elder abuse. **Dr. Stahl** stated that this might be done through an NIA R13 conference grant. He urged anyone interested in being the PI (principal investigator) to apply. He agreed that there is a great need to educate IRBs in this area and suggested that NIJ might be interested in cosponsoring such a conference.

IRB Issues

Dr. Pam Teaster asked about the IRB process when one is working in multiple states. **Dr. Shelly Jackson** replied that the process is laborious in multistate research because of having to deal with multiple IRBs. She noted that for one study it took her 18 months to gain approval.

Dr. Acierno noted that when an IRB seems to consider research a problem, a good question to pose is, "Is the situation better or worse because of the research?" Most often it is better because now the participants have received information about reporting and that means that the situation is improved.

Cooperation/Partnering with Agencies

Dr. Scott Beach described his efforts to get help from AAA directors to provide names of persons for his researchers to call for an in-home provider survey. The county director sent a letter of support for this approach, and incentives ($50 to directors, $5 to interviewees) were offered. After funding for the project was received, the researchers encountered resistance from the directors that revolved around mandatory reporting, as the researchers are non-mandatory reporters. Despite explanations that this was an anonymous project that was separate from APS with aggregated statistics, it was difficult to gain cooperation. The event data collected could have been helpful to the AAA with training, but because there was not full support, only 500 surveys were sent and about 200 responses were received. **Ms. Stephanie Whittier**, with AOA (Administration on Aging), stated that although she was not sure that her office could have been of help, it would have been worth calling. She noted that training caseworkers is a high priority because of the responsibility to

be sure that people are safe. People often misunderstand mandatory reporting issues, and she offered the help of her office in trying to intercede and make them feel more comfortable. **Dr. Beach** noted that they did their work in an adjacent county with no problem and that the positive response was, "our voices are never heard."

Dr. Laura Mosqueda stated that she counts on APS to help with case finding, and the caseworkers will do so (engage in case finding) when reassured about confidentiality. The real problem has been with the state and university lawyers, who can significantly delay projects. **Ms. Lori Stiegel** suggested that rather than blame the lawyers, tell funders that if they want research done that involves using APS workers, they should think about allowing a sufficient time frame to write the proposal.

Dr. Jackson reported having difficulty getting cooperation from caseworkers. **Dr. Mosqueda** replied that she had good results and routinely gives caseworkers Starbucks cards because it is important to thank them and try to keep the workload associated with the research request as low for them as possible. **Dr. Jackson** noted that in Virginia she is not allowed to give APS workers any compensation, even of a token variety. **Dr. Georgia Anetzberger** reported no difficulty with APS workers and asked Ms. Quinn about the effect of the NAPSA (National Adult Protective Services Association) committee on research. **Ms. Quinn** replied that so far there had only been two calls, so there is nothing to report. **Dr. Mosqueda** stressed the importance of involving the caseworkers in the formulation of the research and making sure that the results are presented to them so that they understand the relevance of the research and realize that their contribution is critical, not just something that is more work for them. **Ms. Quinn** agreed and suggested coming up with an official policy for this support. She noted that APS is so fragmented that often everything depends on the local supervisor. She added that we train APS workers so much about confidentiality that they forget they can ask for a client's permission to refer them to a program. **Ms. Connolly** suggested that because APS workers can be so helpful in research, it is important to make clear to them what can be accomplished through research and how it can help them do their jobs. **Dr. Teaster** noted that sometimes the results of the research are not good news for APS workers, so it is necessary to give back beyond just the published article. **Ms. Whittier** agreed with being cognizant of the effect of the research on the APS workers. **Dr. Mosqueda** cautioned that we can't not do research just because it might result in bad news. Such research needs to be done sensitively, and if there is bad news, it must be communicated as supportively as possible. Researchers cannot shrink from this responsibility.

Consent/Assent Issues

Dr. Teaster recounted a study in which she interviewed truly adjudicated incapacitated persons. She wondered what might be the best strategies in this situation. In her national study she got the consent of a public guardian to interview the participant, and she also wrote an assent for the participant. One of her concerns was whether for incapacitated persons who crave company, the interview itself implicated coercion because the interviewer was providing company. **Dr. Madelyn Iris** observed that the interviewer must constantly assess assent during the interview of mentally incapacitated persons, despite the fact that they signed the form, and evaluate by the participants' actions as well as their words whether they are no longer assenting to the process. When that happens, the interviewer must be responsive to this and walk away.

Dr. Nina Kohn asked how much reliance should be put on the guardian's consent, especially if it is not in the best interest of the ward. She stated that she would be concerned about research based only on the guardian's consent. **Dr. Kate Wilbur** noted that one could consent a ward or conservatee to see if they understand. They have a right to participate in research and have their voices heard. **Ms. Naomi Karp** noted a preference for the combination of consent from the

guardian and assent from the ward. She suggested that there should be a more limited form of guardianship because some people who have guardians are still capable of making decisions.

Dr. Crosby commented on situations where research functions as an intervention, recalling that while doing focus groups on youth suicide, his researchers found that engaging youths in this conversation brought suicide to the surface and allowed for public and community discussion to address the issue in a more effective way.

The meeting was adjourned at 5:00 p.m.

The System Response to Elder Abuse - Reports from Current or Recently Completed Research Projects

Panel Presentations:

Frederick Newman — Testing a Model of Elder Mistreatment and Barriers to Help Seeking

Goals:

- To test the full structural equation model.
- To test factor invariance by type of abuse, ethnicity, age clusters and first-order interactions.
- To hold community workshops on a coordinated community plan.

Study Design: A total of 450 women of varying ethnicities individually completing a three-part survey on barriers and types of abuse, conflict tactics scale and demographics. Follow up with unstructured interviews with nine victims who sought help and nine who did not. Analysis includes unified coding strategy, individual coding and constant comparison method, results confirmed by multiple groups and respondents.

Observations: The people the study focuses on are not in the system. If anything we code is not in two or more people or in two or more groups, it is not included.

Conclusions: In relation to the Barriers to Help Seeking model we will look at covariance structure as to how these things relate to each other and across groups. This is more in the area of preventive intervention. We will work with authorities in the community to see if the results of the study can help them. We are working at the statistical and change level.

Shelly Jackson — Financial Abuse of the Elderly Versus Other Forms of Elder Abuse - Assessing the Dynamics, Risk Factors and Society's Response

Goals:

- Compare risk factors associated with various forms of elder mistreatment.
- Compare the outcomes of the various forms of elder abuse.
- Compare the elder person's and caseworker's perceptions of the case.
- Consider whether the current APS model is an appropriate way of responding to financial exploitation.

Study Design:

- Conduct triangulated interviews [APS caseworker (N = 240); elder (N = 240); caregiver, residential partner or other (N = 120)].
- Use four types of cases [financial (n = 60), physical (n = 60), neglect by other (n = 60), hybrid (n = 60)].
- Eligibility - incident (not necessarily substantiated, but not invalidated) occurred within last 18 months to an elderly person over the age of 59 who was living in his or her home at the time, and the APS investigation is closed.

Observations: All participants will be asked about the incident during the interview. The APS response and outcome will be noted and all caseworkers will be asked about their opinion and experience. The IRB required that the interview be limited to 90 minutes, but the investigators have discretion to continue longer if the elder person seems to want to extend the interview. The elder person and the caregiver each receive $75 compensation; we are not allowed to compensate APS workers. Virginia APS indicators of financial exploitation will be used. Lawyers will use the Lawyer Assessment of Capacity to evaluate whether the volunteer has the capacity to be interviewed. Data collection will take 18 months.

Conclusions: None yet.

Meghan Slipka — How Protective Behaviors and Risk Factors Affect the Course of Abuse Over Time

Goals:

- To determine the proportion of cases in which abuse escalates, maintains or desists.
- To determine the risk factors associated with the onset of abuse and its persistence.
- To determine which victims receive assistance from police and other service providers and why.
- To determine how reporting abuse and/or other protective measures taken by victims affect the course of the abuse.

Study Design: Population is either elderly victims for whom the Chicago Police Department's elder abuse unit responded to a call or elderly residents in Chicago overall. Sampling strategy includes extensive telephone interviews of 150 elders who have filed a police complaint, and 150 victims and 150 non-victims in the general population of Chicago.

Observations: The victim survey is moving slowly.

Conclusions: None yet. The non-victim community sample is complete. There are 30 complete interviews from the community victim sample and 30 complete interviews from the police sample. The six-month follow-up surveys will begin in the next few months.

Andy Klein — A Statewide Analysis of Elder Abuse of Older Women and the Criminal Justice Response in Rhode Island

Observations: Women were classified as "older" (50-59) or "elder" (60+). Women who are 60 and older can use APS, not just law enforcement.

Conclusions: Some of the results included:

- In Rhode Island, a greater percentage of whites were victimized.

- The suspects were 90 percent intimate partners for younger women, 30 percent intimate partners for older women, with the rest family members, and they were all family members for elder women.
- Victim relationship — a finding that the abuser was a relative was significantly higher for 60+ victims.
- The profile of the family member suspected of abuse versus the intimate partner suspect indicates that those suspected of abusing elder women are younger male members of the family with a criminal history.
- The incidence of calling the police was not related to the age of the victim.
- Within two years, 23 percent were re-victimized, but not necessarily by the same suspect.
- Family member abusers were more likely to be back in court for re-abuse than were intimate-partner abusers.
- Referrals - police made very few referrals to the Department of Elder Affairs because they contended that APS doesn't do anything. Only three APS cases were referred to the police.

Lori Stiegel — A Multisite Assessment of Court-Focused Elder Abuse Initiatives

Goal: To provide judges, court administrators, policy makers and funders with evidence-based knowledge about the structure, process and outcomes of these initiatives so that they can make informed decisions about whether and how to spend limited resources, to enhance courts' approaches and activities to protect elder abuse victims, and to hold perpetrators accountable.

Study Design: Two-year project (begun October 2007) with five sites, using data sources (informant surveys, stakeholder surveys, randomly selected case file reviews and observation of court proceedings, if possible) to make a quantitative and qualitative assessment of court-focused elder abuse initiatives.

Observations: Is there a conflict of interest for courts that are acting as both decision makers and service providers? Areas to be considered include:

- Redundancy - are courts duplicating efforts?
- Training - do key people have training in elder abuse?
- Court leadership and support, and is there compliance with the mission?
- Institutionalizing projects so that if people leave, the project moves on.
- Time of case processing - is it too slow?
- Interaction with other community services.
- Costs.
- Is there any follow-up with victims?

Conclusions: None yet.

Carmel Dyer — Factors That Impact the Determination by Medical Examiners of Elder Mistreatment as a Cause of Death in Older Persons

Overview: Elders reported to APS have nearly triple the mortality rates of those never reported, but elder abuse is rarely identified as a cause of death. Why?

Results of Studies Conducted:

Summary and Conclusions of Phase I:

- Medical examiners (ME) infrequently determine elder mistreatment as a cause of death in older decedents. Chronic diseases and features of old age confound the picture. Medical records and other information, including scene investigation reports, are often inadequate.

Summary and Conclusions of Phase II:

- MEs are not versed in the standard of care for older persons. It seems more appropriate for geriatricians to review the records and to render opinions about the standard of care, as well as the presence or absence of elder mistreatment. There is little information concerning the effects of collaboration between MEs and geriatricians.

Summary and Conclusions of Phase III:

- Scene investigation is not geared to the detection of forensic markers and risk factors. Training of investigators in elder mistreatment may be helpful. Consider the use of standardized investigation forms that prompt the investigators to look for signs of elder mistreatment.

Phase IV: To compare variables regarding scene investigation, medical records, toxicology, and daily workloads in the case of persons ages 65 years or older whose cause of death was elder mistreatment with those from cases of deaths whose cause was not elder mistreatment. A pilot study indicated that APS cases were sharply different in terms of finding elder mistreatment. The questions are: Could APS predict some deaths if they had data available? Could MEs make elder mistreatment diagnoses at autopsy?

- New study design asked how to determine lethality factors. How can we be sure that the death was due to elder mistreatment? Begin by looking at causes of death once referred to APS, i.e., if you come in from APS, what are the risk factors?

Summary and Conclusions of Phase IV:

- Documented dementia or skin findings were more likely to trigger an autopsy and more likely to have been an APS case. Other issues include ME access to APS records and performing autopsies in targeted cases.

A goal is to develop lethality risk factors. This is an important issue and any suggestions would be welcome.

Discussant, Kathleen Quinn

Ms. Quinn noted how much everyone has learned at this conference and how honored she was to be a part of it. She thanked NIJ, NIA, the Archstone Foundation and Ms. Connolly for providing the leadership for this meeting.

Ms. Quinn reviewed the research projects. She praised Dr. Newman's research for developing a tool to help prevent elder abuse based on the voices of the victims themselves. This experience will shape our outreach. Dr. Jackson's research into financial exploitation is of critical importance to give us insight into a form of abuse that was not initially recognized. Experience would lead us to believe that financial exploitation is a motivating factor behind neglect, and it is important to find out. Again, this is based on the victims' voices. Ms. Slipka's study will identify risk factors and clarify things that work in protecting victims, as well as give insight into the effect of reporting. Dr. Klein's

work in Rhode Island gives us numbers that could influence criminal victim surveys. It substantiates what we see in the field with the adult son, and the criminal background issue was very interesting. It is also important to note that APS is different across states, and we should be cautious about generalizations. Ms. Steigel's work is so important in terms of educating the judges, and it will help show what really works and what is considered ethical and legal. Dr. Dyer's work is critical, for what is more important than finding out how many people are murdered by abuse and neglect? In summary, we have miles to go, but it is encouraging to see the excitement and interest and get the sense that we are starting to catch up. It is wonderful to hear the victims' voices through this research and to see the emphasis, first and foremost, on victim safety. We need to consider how to use these data to increase awareness and influence other systems like law enforcement and health care to join this awareness and shape their responses accordingly. We need to address the endless logistical problems and delays — and we can learn from each other some ways to ease this barrier. Finally, and very significantly, we need to consider how to attract other private foundations beyond Archstone to join this effort.

Question/Answer/Comment Period

Dr. Anetzberger asked how to increase private funding and wondered about calling a special session to address the issue. **Ms. Laura Giles** from the Archstone Foundation stressed the need for continued networking, noting that Archstone was paired with other foundations at recent meetings, which provided valuable opportunities to spread the message. She added that Archstone is on the agenda at an upcoming conference and will be able to bring this issue to the attention of other foundations and funders. **Ms. Brenda Uekert** noted that the Pew Foundation is going to address elder issues and have an end-of-life agenda, as well. **Dr. Hawes** suggested that a problem with funding for elder abuse is that it is not a "feel good" topic, and no one wants to fund such an ugly issue, including CMS. An approach is needed that attracts funders, and research should be packaged to show that not only is there a problem, there is a solution. If it is not possible to persuade federal agencies of this need, we should be prepared to go to Congress. **Ms. Quinn** pointed out that domestic violence isn't pretty, and yet it gets funded. **Dr. Hawes** noted that the difference is that domestic violence victims speak out. **Dr. Maggie Baker** recounted a difficulty in getting funding for a study to review medical records in the long-term care setting, then realized that the title of study was not resonating with funders who wanted to see more a health promotion theme. This problem could be addressed by changing the title because the study was always geared to promoting safety in the facility. The research must be framed in a way that will receive the best reception. **Dr. Anetzberger** opined that it is systems failures, whether they are real or perceived, that attract funding. **Dr. Newman** stressed the importance of meeting with agencies to ask what the results of the research mean to them in terms of their policies and procedures, and what research we need to do next.

Dr. Mosqueda asked Dr. Jackson about APS barriers to follow-up once a case is closed, noting that her researchers have not been allowed to do follow-up. She wondered if this was a matter of state law or policy and asked for guidance on how to handle this. **Dr. Jackson** replied that she particularly wanted to work with closed cases in her research and that APS allowed her to work on these cases and do it with verbal consent, so it has not been a problem. But, she stressed, this is not considered reopening a closed case. **Dr. Dyer** suggested that Dr. Mosqueda obtain consent from the client before the case is closed. **Ms. Connolly** suggested that perhaps NAPSA might prepare some guidance on this issue. **Dr. Newman** observed that as researchers gain more experience working with IRBs and APS, they might view the barriers as opportunities to spread the word and communicate the message of research to a broader audience so that ultimately these barriers will break down.

Dr. Stahl, referencing the earlier research of Dr. Mark Lachs, asked Dr. Dyer whether she had any estimate of the incidence of deaths due to elder abuse. **Dr. Dyer** replied that Dr. Lachs used death certificate data from ME records in his research. However, she said, death certificates are notoriously inaccurate, and no one is going to write "died of elder abuse" as the cause of death. Based on chart reviews she said her best guesstimate is 11-22 percent. **Dr. Hawes** suggested that a worthwhile project would be to study the ME's decision to sign off on so many deaths as natural. An elderly person who is scalded to death in a bathtub has not died of natural causes. **Ms. Connolly** asked Dr. Patricia McFeeley about the handling of elder deaths. **Dr. McFeeley** explained that there is a triage between the coroner and the ME, and often someone with no medical knowledge is handling the investigation. She said that basically death certificates are useless even when signed by the ME. **Dr. Solomon Liao** noted that not only do physicians fill out death certificates incorrectly, but also many deaths are not even attended by physicians, who get secondhand information about the death from the nurse. He suggested that more training is needed for these nurses.

Ms. Stiegel suggested two projects:

1. Assess the effect of fatality review teams on ME reports.
2. Do a fatality assessment in terms of what we can learn.

Dr. Mulford said that Dr. Klein's study had influenced her thinking about theory development, particularly in light of the predatory offspring findings. **Dr. Klein** noted that Rhode Island is one of the states that mandates treatment for domestic violence and suggested that the state is diverting cases into the wrong resource. **Dr. Jackson** also expressed interest in Dr. Klein's findings about psychopathological behavior of family members, saying that model may fit for financial abuse cases.

VISION Report

Ms. Connolly reviewed the preliminary comments from participants from the VISION survey, noting that not all the information was tabulated:

Short-Term Research Priorities

Incidence and Prevalence (21)

- Document incidence and prevalence (17).
- Conceptualize comprehensive national prevalence and incidence study (3).
- Use existing data sources to collect data.

Interventions (13)

There was a lot of interest in intervention. One issue is that we want to know more but realize that people are still being hurt, so we must try to bridge that gap between finding the best interventions and intervening.

- Criminal justice response research (5).
- Intervention theory development and testing/evaluation (5).
- Effectiveness of EA (elder abuse) interventions.
- Effectiveness of trainings.

- Effectiveness of Forensic Centers and other MDTs (multidisciplinary teams) and IDTs (interdisciplinary teams).

Risk Factors and Detection (11)

- Risk factors to identify characteristics of abusers (6).
- Screening tools (4).
- Improve detection reporting of abuse and neglect.

Laws and Justice System Approach (6)

- Create model laws and systems.
- Criminal justice response research (5).

Consequences

- Follow up on individuals who have been abused.

Theory/Model Development (4)

- Understand the role of childhood trauma.
- Conceptual differences in how EA manifests itself (3).

Definitions (4) (define by discipline)

Characteristics

- Cultural characteristics in how EA manifests itself (2).
- Victim and perpetrator characteristics.

Examining Elder Deaths—Interest in How to Mine the Data that We Have

- Elder deaths in LTC.
- Suspect elder deaths, especially from neglect.
- What are markers that make death suspicious?

Process—Practitioners and Researchers Need to Maintain Communication

- Health effects of elder abuse, neglect, exploitation.
- Hospice end-of-life care.
- More on resident-on-resident abuse.
- Psychological abuse in nursing homes.
- Cost of elder abuse.

Long-Term Research Priorities

- Intervention research (20).
- Determining effectiveness of our ("best") practices (9).
- Effectiveness of intervention and prevention (especially APS) (5).
- Emphasis on effective victim-safety response intervention (3).

- Data to inform development and evaluation of intervention.
- Survey ombudspersons and guardianship about effectiveness of their programs.
- Identify risk and protective factors (8) (longitudinal).
- National incidence and prevalence study (8).
- Assess long-term impact on victims (4).

Models/Theory/Causes (4)

- Model/theory testing.
- Causes of elder abuse.
- Screening tool for practitioners.
- Make measurement useful to practitioners and researchers in field.
- Longitudinal documentation of EA throughout justice agencies.

Greatest Challenges

- Funding (9).
- Ageism/mindset (7).
- Capacity - ethics questions (6).
- Agency cooperation/participation (5).
- IRB (5).
- Developing definitions (5).
- Mandated reporting issues (3).
- Research to practice (3).
- Confidentiality (3).
- Finding subjects (3).
- Lack of research guidelines (2).
    - Bring in more researchers (2).
- Multidisciplinary collaboration (2).
- Fears of providers (2).
- Not reinventing the field.
- Acceptance of universities.
- Informed consent.
- Large studies with a large n.
- Conceptual clarity/models.
- Good research.

What Help Do We Need From Federal Agencies and Others?

- Facilitate/promote.
    - Discussion about ethics, methods and IRBs.
    - Multiple agency funding.
    - State justice institute might be co-funder.
- Establishment of research priorities (field or government).
    - Bring together agencies (NIA, NIJ, AARP and others) for more planning.
    - Work on best practices.
    - Communication with public/media outreach.
    - Multisite projects.
    - Learning from other fields.
- Dissemination.
    - Disseminate research findings as they become available.

- Implement.
- Next steps.
- Legislation.
- Help pass the EJA (Elder Justice Act).
- Access.
    - Help with access to facilities.
- Funding (6)
    - Encourage other agencies and funders to participate and help with research.
    - More RFPs (requests for proposals) with more money.
    - Streamline awards.
    - Increase funding levels.
    - Fund research that builds.

Critical Research Priorities

- Funding, funding, funding.
- Bring in private foundations.
- More private-public funding.
- Fund a center for comprehensive assessment.
- Evaluation - especially key interventions (e.g., APS).
- Awareness.
    - Increase awareness, MADD (Mothers Against Drunk Driving) model.
    - Public outrage that EA not acceptable.
- Coordination.
    - Among medical and social services, criminal justice.
    - Among all entities.
- Assessment/screening of outcome.

Ideas in a Box

- Use OSCAR or MDS to look at differences over time with states with different levels of criminal background checks.
- Impact of deinstitutionalizations on APS.
- Relationship between APS and nursing home/long-term care placement.
- Examine/research guardianship and conservatorship.
- Examine hidden cases of EA in courts.
- Study efficacy of criminal background checks—do they improve safety or quality?
- Number of persons in nursing homes on Medicaid because of financial exploitation.
- (Reverse) mortgage, annuity, insurance fraud.
- Comprehensive study of abuse by adult sons.
- Develop screening tool for courts in guardianship monitoring to detect abuse.
- Meta-analysis in IRB issues and in research, barriers to research on elder abuse.
- How does the language we use impact the outcome in these cases?
- Elder abuse in dementia patients?
- Develop "lethality risk factors" (Carmel Dyer).

Stay tuned..!

Conversation with Potential Funders and Closing Remarks

A. Laura Giles, Archstone Foundation

Ms. Giles began with the Archstone Foundation's mission statement: "The Archstone Foundation contributes to preparing society for the growing needs of an aging population." She noted that the Archstone Foundation began focusing exclusively on seniors in 1995. The Foundation has an endowment of $130 million and pays out about $5 million per year. In 2003, the Foundation, aiming to make a greater impact, refined its focus to three areas: fall prevention, end-of-life issues, and making grants that were responsive to emerging needs.

Ms. Giles described the Elder Abuse & Neglect Initiative: Phase I: 2006-2007,

Phase II: 2008-2010. The project categories include:

- Education and Training
- Financial Protection Projects
- Forensic Centers/Center of Excellence
- Legal Services
- Multidisciplinary Team Development
- Ombudsman Services
- Systems Analysis
- Convening and Technical Assistance
- Evaluation

The Phase I accomplishments include 997 meetings to develop services infrastructure; 145 trainings for mandated reporters; 111 media events (including television segments, radio broadcasts, press releases, DVDs, newspaper articles); recruitment of 410 volunteers, primarily experts in financial abuse or litigation (not including additional hours of pro bono legal resources); 3,099 brief assessments or screenings of elder abuse victims; 520 assessment meetings to review and create action plans based on the results of the brief assessments; 482 formal medical, psychological and social work assessments of victims of elder abuse; assisting the district attorney in filing more than 40 cases of elder abuse; and preserving more than $15 million in assets of vulnerable seniors.

Contact Information:

Archstone Foundation
401 E. Ocean Blvd. #1000
Long Beach, CA 90802
(562) 590-8655
www.archstone.org Exit Notice

B. Gavin Kennedy, Assistant Secretary for Planning and Evaluation, HHS

Mr. Kennedy noted that his office's charge is to inform the Secretary of Health and Human Services. He suggested that his office has done a lot that would be of interest to this group, and vice versa. One project under development is an informational report to Congress to determine the feasibility of establishing a national uniform database on elder abuse. This meeting has helped sharpen the focus on this project. Mr. Kennedy pointed out that his office is not a grant maker per se, but rather

contracts out work. Interested parties can bid under an umbrella contract that puts them on "retainer" to be available for five years.

C. Carrie Mulford, National Institute of Justice, DOJ

Dr. Mulford noted that NIJ's interest in the area of elder abuse is evidenced by putting on this workshop and funding many of the studies that were presented over the past 2+ days, including practice-oriented research, and recommended that researchers fully consider practice and policy implications in their applications.

D. Meg Morrow, Office for Victims of Crime, DOJ

Ms. Morrow stated that some funding is available for training and demonstration projects that have a national scope and that one solicitation is open at this time. Elder abuse is an area of interest. Colleges, universities, nonprofits and public agencies are eligible and must have knowledge of the area and staff. Grants range from $50,000 to $500,000, with the majority totaling $100,000 to $150,000. Projects may be multiyear, must be national in scope, be relevant nationwide and add to practice in the field or best practices. For elder abuse, research should be collaborative. Areas that are not funded include prevention and ongoing research. The audience for the research is very wide and includes social workers, lawyers, virtually anyone.

E. Sid Stahl, National Institute on Aging, NIH, HHS

Dr. Stahl stated that nine R21s had been funded, and it is unlikely that there will be another specific solicitation for elder abuse. However, because 90 percent of NIH grants are unsolicited, feel free to apply anyway. The problem with unsolicited applications is that the applicant is competing against all other grants on all other topics. Dr. Stahl invited the participants to inform him if they were sending an application so that he could steer it to the proper study section. The NIA is interested in prevention, treatment, alternatives, autopsy issues and others. Dr. Stahl recommended going to the NINR (National Institute of Nursing Research) with applications for detection and care in nursing facilities. He noted that it is unlikely that NIA will fund a surveillance study, but he suggested that the NIA studies had provided the groundwork for such a study.

F. Naomi Karp, AARP

Ms. Karp stated that elder abuse is on the AARP radar screen under the umbrellas of access to health care and financial stability. The AARP has a good track record in this area, with a strong written policy on elder abuse and an incoming president supportive of the issue. Ms. Karp noted that the AARP Public Policy Institute (PPI) has an in-house research think tank and contracts out some research. She described work that was done at AARP that resulted in practices for monitoring guardianship and cited Ms. Stiegel's work surveying state power-of-attorney laws. A third project centers on criminal background checks in home care. The PPI funds small projects in the range of $50,000 to $100,000. There is a planning process, and Ms. Karp invited participants to contact her with their ideas.

G. Alex Crosby, Centers for Disease Control, HHS

Dr. Crosby stated that the CDC focus on elder abuse would essentially involve focusing on definitions through public health surveillance, and it might be possible to move from there toward

setting up monitoring systems. There might be the possibility of adding questions to existing CDC databases to help move the process along.

H. Stephanie Whittier, Administration on Aging, HHS

Ms. Whittier explained that the AOA takes the research conducted by others and applies it in the field. The AOA has discretionary money to fund the National Center on Elder Abuse to move forward in the areas of prevention, intervention, treatment and response. The Center has four components:

1. Multidisciplinary response to elder abuse - $300,000.
2. Training initiatives - training in the field for law enforcement, health care workers - $190,000.
3. Public awareness - will start with a survey of public awareness campaigns of all types and determine how to apply the theories and successes to our field - $200,000-294,000.
4. Emerging issues - two-year grant - $100,000 to $125,000 per year.

The AOA is interested in research that can be implemented into practice.

I. Andy Mao, Senior Counsel for Health Care Fraud and Elder Abuse, DOJ

Mr. Mao noted the importance of forensic research, which is so helpful to prosecutors. He urged the participants to coordinate the great work that is being done by thinking strategically and in a multidisciplinary fashion, and developing a strategy and an urgency to identify the systemic failures. There is a window of opportunity right now to convey the right message about the science and the potential advances and move the common agenda forward.

Closing Remarks

Ms. Connolly noted that the Office on Violence Against Women is funding self-assessment tools at $4 million to $5 million per year.

She hailed the amazing partnerships among those who work in elder abuse and found encouragement in the number of new researchers and people who have come forward to expand the field. She suggested that the frustrations in elder abuse are also an opportunity to define something cogent and important, and to collaborate to present the field smartly to the outside world. The challenge, she concluded, is to think how we are perceived, find a way to focus the energy, and build on what has already been accomplished.

Date Created: August 11, 2008