



## University of Southern California Judith D. Tamkin International Symposium on Elder Abuse

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We thank Judith D. Tamkin for her generous gift to establish this and future elder abuse symposia. Her deep personal commitment to the field is helping reshape our understanding of, and ultimately save innumerable older adults from, abuse and neglect.

This white paper was made possible by a gift from the Elder Justice Foundation. We are grateful for this support. With input from Symposium presenters and directors, this paper was produced by Maria Siciliano, MPA, MSG, Gerontology in Action.

### LETTER FROM THE SYMPOSIUM DIRECTORS

On September 15-16, 2016, researchers, practitioners, and students from around the globe assembled in Los Angeles, California to focus on closing the gaps in elder abuse research at the inaugural University of Southern California (USC) Judith D. Tamkin International Symposium on Elder Abuse. The mission of the Tamkin Symposium is to create safe and healthy environments for elders in the United States and abroad by bringing together thought leaders, activists, caregivers, researchers, lawmakers, and other stakeholders to share findings and strategize solutions.

At this exciting event, presenters offered new ways of thinking about the topic of elder abuse, from how we conceptualize it to how we study it to how we communicate research findings. This was a dynamic event in which presenters as well as audience members actively participated and collaborated to share ideas and findings.

Pioneering practitioner and researcher Georgia Anetzberger, PhD, ACSW was honored for her significant contributions to the field. Through an invited competition among graduate students, three people were selected to be Tamkin scholars and participated in the Symposium: University of Colorado medical student Elizabeth Bloemen, MPH; University of Minho (Portugal) School of Psychology doctoral student João Fundinho, MS; and University of Texas School of Public Health doctoral candidate Katelyn Jetelina, MPH. We also would like to acknowledge the work of Lauren Rosell and Ana Poblet-Kouttjie for their contributions to this successful inaugural Symposium.

This white paper encapsulates the events of these two days and provides key points upon which we can and must act.

We are excited to share the findings of the inaugural Tamkin Symposium in the following pages.

Sincerely,

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## **Executive Summary**

The inaugural USC Judith D. Tamkin International Symposium on Elder Abuse was held September 15-16, 2016 in Los Angeles, California. Our mission is to create safe and healthy environments for elders in the United States and abroad by bringing together practitioners, researchers, thought leaders, caregivers, lawmakers, and other stakeholders to share findings and strategize solutions.

The following themes emerged from the Symposium:

- New ways and approaches to conduct elder abuse research must be considered. There is much to learn from other fields that have performed high quality research on topics that are equally challenging.
- Now is the time to study interventions on prevention, detection, and treatment.
- It is not feasible to conduct randomized controlled trials for many proposed interventions. Therefore, it is necessary to consider and utilize a variety of methods and approaches to advance our knowledge.
- There is a need to nurture a new generation of researchers; this will require mentors and funding.
- It is important to cultivate partnerships by (a) linking academia to community-based agencies and practitioners and (b) hearing the voice of older adults.

Section I of this paper provides a history of the elder abuse field as told by Marie-Therese Connolly. Section II describes strategies for overcoming barriers to research. Specific topics addressed include: the challenges and benefits of community partnerships; reaching vulnerable and hidden populations; working with Institutional Review Boards (IRBs); and definitional issues.

Innovative research approaches is the topic of section III. Several techniques are discussed, including use of technology, neuroimaging, and novel research methods. These approaches offer ideas and stimulate new thinking about methods used in other fields that may be applied to elder abuse research.

In section IV, representatives from three federal agencies and two private foundations discuss the promise, perils, and pitfalls of funding elder abuse research. Section V focuses on how to communicate findings to the public, drawing on research conducted by the FrameWorks Institute. It is an important wake-up call that challenges us to rethink effective communication strategies.

# I. Gaps and Opportunities in Elder Abuse Research: Who Needs What? – Marie-Therese Connolly, JD, Woodrow Wilson International Center for Scholars

#### PRESENTER'S BACKGROUND

Marie-Therese (MT) Connolly is a Global Fellow at the Woodrow Wilson International Center for Scholars and a 2011 MacArthur Foundation fellow. In 2016, she was awarded a residency at Yaddo and a fellowship at the Carey Institute for Global Good to complete a book of nonfiction about elder abuse (to be published by W.W. Norton). Ms. Connolly conceived of and was the original architect of the Elder Justice Act (EJA), the first comprehensive federal law to address elder abuse, enacted with the Affordable Care Act in 2010.

Previously, while working at the U.S. Department of Justice (DOJ), Ms. Connolly founded the Elder Justice Initiative and, with the National Institute of Justice (NIJ), helped to launch and co-fund DOJ's elder abuse research program She also organized numerous interagency groups and events, including the first ever roundtable discussion on the medical forensics of elder abuse. After leaving the DOJ, she worked on policy projects such as the federally- funded and DOJ-led Elder Justice Roadmap Project (EJRP).

In her presentation, Ms. Connolly provided an historical and conceptual framework for reviewing elder abuse research to illuminate knowledge gaps and focus on analytic challenges.

#### HISTORICAL PERSPECTIVE FROM A RELATED FIELD

In 1962, Colorado pediatrician Henry Kempe and colleagues published a groundbreaking article – *The Battered-Child Syndrome* – in the *Journal of the American Medical Association* (JAMA). The article described child abuse cases reported by district attorneys's offices and medical centers that resulted in hundreds of children dying or becoming permanently brain damaged. In the article, Kempe implored his colleagues (some of whom thought he was overly-dramatic) to consider child abuse when they saw children with unexplained injuries. That JAMA article resulted in child abuse entering the popular press and public consciousness, and Kempe was credited with "rediscovering" the problem.

As healers and scientists, the views of physicians like Kempe are given weight. To underscore this status, Ms. Connolly noted that at the same time as Kempe's work in Colorado, two other medical centers – in Los Angeles and Pittsburgh, respectively – were conducting similar efforts led by social workers. Those programs did not receive the same attention as Kempe's. Moreover, Kempe's multidisciplinary teams (MDTs), the first one formed in 1957, were integral to his research but received little credit (Nelson, 1984). Over time, MDTs gained increasing recognition in the child abuse field and others. Today, elder abuse researchers recognize that MDTs and community entities are indispensible partners.

Also critical to advancing knowledge about child abuse was the creation of a sub-specialty of experts in that field, many of whom also conduct research as part of their work. Fellowship programs have provided cross-training for hundreds of physicians in pediatrics and forensic pathology, and many major medical centers employ such specialists.

When it comes to elder abuse, however, there are no physicians cross-trained in geriatrics and forensics, no programs to train them, and scant research or research funds, which are deficits that perpetuate gaps in knowledge to inform practice, policy, education, and the public.

<sup>1</sup> Portions of Marie-Therese Connolly's talk and this white paper are excerpted from her forthcoming book, to be published by W.W. Norton.

#### KNOWLEDGE GAPS

#### THE DEARTH OF INTERVENTION DATA

Adult Protective Services (APS) provides the most glaring example of insufficient intervention research. In the 1960s, Cleveland's Benjamin Rose Institute (BRI) on Aging conducted a study of elder protective services that remains the most rigorous such research ever done. The results shocked everyone: clients who received protective services had a higher mortality rate and higher rates of institutionalization than those who received traditional services. Despite studies "that showed these protective services units to be very costly and of questionable effect," said Rosalie Wolf, a pioneer in elder abuse research, "advocates for the system went right ahead with their work in the Congress" (Wolf, 2001). In 1975, Congress amended the Social Security Act to encourage protective services units in all states.

Questions about the impact of APS raised by the BRI research remain unanswered. Researchers who reviewed APS studies from 1998 to 2014 found not a single study evaluating APS efficacy (Ernst et al., 2014). This is part of a broader problem: the dearth of *any* intervention research in the elder abuse field. Researchers do not know if one intervention model works better than any other for intended beneficiaries and often do not even have consistent definitions of what constitutes "success" to measure.

#### THE DEARTH OF DATA TO INFORM POLICY-MAKING

The dearth of evidence about the efficacy of elder abuse interventions means that policy-makers launch programs and legislators pass laws, without evidence to inform their efforts. Mandatory reporting laws provide an example: Kempe successfully advocated for mandatory child abuse reporting laws; by the end of the 1960s, every state had enacted such a law. Fifty years later, however, there is little evidence that mandatory reporting reduces child abuse. Nevertheless, using child abuse laws as a model, lawmakers have passed laws mandating elder abuse reporting in 49 states, with equally little supporting evidence.

#### A NEW WAY TO VIEW ELDER ABUSE RESEARCH: GAPS & OPPORTUNITIES

Ms. Connolly created a chart to analyze what types of research are relevant to what types of "consumers." The chart helps reveal the biggest gaps in knowledge and the potential impact of those gaps. She divided elder abuse research into five categories listed along the **vertical axis**: Dimension, Risk, Identification, Intervention, and Prevention (DRIIP). And she divided research "consumers" into four categories listed across the **horizontal axis**: Practitioners, Policy-makers, Educators, and the Public (PEPP):

	<b>P</b> ractitioners	<b>P</b> olicy-makers	Educators	<b>P</b> ublic
Dimension		3		
Risk	1		5	7
Identifica- tion			6	
Intervention	2			
Prevention		4		8

See pages 5-6 for explanation of the numbers in the boxes.

Ms. Connolly provided general descriptions of each **research type** as follows:

A) Dimensions – This category includes broad general information pertaining to elder abuse, such as its prevalence, harms and costs, and factors relevant to navigating ethical aspects of the problem. (Much elder abuse research to date has focused on this category, but gaps remain. Most large prevalence studies have excluded people with dementia. Also, there are few data about the prevalence of abuse and neglect in nursing homes or other long-term care settings.)

- B) *Risk* There is some research about risk: dementia, mental illness, isolation, and poor social supports are among proven risk factors for elder abuse.
- C) *Identification* Screening criteria fall into this category. The U.S. Preventative Services Task Force, however, did *not* recommend that health professionals screen for elder abuse because there was not enough data to show that screening actually helps people. Recognizing suspicious "forensic markers" (such as bruising and fractures) is one way to identify elder abuse but such evidence is scant. (It includes Laura Mosqueda, MD's research on accidental vs. inflicted bruises and Tony Rosen, MD's ongoing work with radiologists to distinguish between accidental and inflicted fractures. Dr. Rosen is also reviewing medical records in court cases to analyze the types of physical injuries known to have been caused by abuse.)
- D) *Intervention* This category includes research into APS, victim services, financial services, aging network services, law enforcement, health care, and prosecution responses to elder abuse. Little is known about which interventions work in responding to elder abuse or even how the field should define "success."
- E) *Prevention* This category might include public service announcements, social supports, home visits, and a public health approach. To date, there is virtually no evidence about what measures successfully prevent elder abuse.

Ms. Connolly described the following categories of **consumers** of elder abuse research:

- A) *Practitioners* anyone serving older people or responding to possible or confirmed elder abuse, such as law enforcement, APS, bank tellers, health workers, caregivers, prosecutors or victim, aging, and social and financial services providers.
- B) *Policy-makers* individuals at national, state, and community levels who write laws, make policy, promulgate protocols and guidance, or fund programs.
- C) *Educators* trainers and educators who create curricula and train people in both discipline-specific and multidisciplinary settings.
- D) *Public* older people, family, friends, caregivers, anyone planning to grow old, the interested public, and those designated as "victims" and "perpetrators."

As illustrated by the chart, different "consumers" have interests in different types of data. Looking at research this way helps to illuminate who is affected by knowledge gaps and provides a framework for setting priorities going forward.

#### For example:

*Practitioners* want to know what risk factors to look out for **(#1)** and whether the intervention they provide or recommend works **(#2).** They are less likely to be interested in the overall cost of elder abuse.

*Policymakers*, on the other hand, must consider the cost of elder abuse and programs to address it **(#3)** and whether prevention measures they consider are proven to work **(#4)** as they try to decide which programs to fund or laws to pass.

*Educators* train audiences about what risk factors to look out for **(#5)**, and what signs (such as bruises, pressure sores, etc.) **(#6)** indicate that an older person is being abused or neglected.

Members of the *public* want to know what factors (like isolation, or caregivers with mental health or substance abuse problems) create risk for older persons (#7), and, most crucially, steps they can take in their own lives and families to prevent elder abuse. (#8)

#### STRUCTURAL IMPEDIMENTS TO RESEARCH AND A CALL TO ACTION

1) *Inadequate research funding*: Elder abuse research is rarely a priority of funders. That funding gap helps to explain the knowledge gap.

In the executive branch, funding for elder abuse research has accounted for just a tiny fraction of federal research budgets (GAO, 2011). In 2005, DOJ's National Institute on Justice and Elder Justice Initiative began funding what remains the only on-going federal elder abuse research program.

Congress has not appropriated money for elder abuse research comparable to research on child abuse, violence against women, or Alzheimer's disease. The 31<sup>2</sup> Alzheimer's Disease Research Centers (ADRCs) provide a good model for elder abuse research centers in that they integrate research, provide community outreach and education, and coordinate and harmonize data and efforts across centers.

Despite enacting the Elder Justice Act (EJA) in 2010, Congress appropriated no funds to implement the law until 2015. (It appropriated \$4 million in 2015 and \$8 million in 2016, a pittance compared to funding to address comparable issues.) Few of those EJA funds have gone to research. Moreover, EJA provisions intended to help researchers (such as a mandate that the U.S. Department of Health and Human Services issue guidance to help researchers navigate human subjects and ethical issues) have not been carried out.

Few private funders have designated elder abuse research as a priority either. In 2016, however, the newly created Elder Justice Foundation did so, funding research and seeding projects designed to narrow elder abuse knowledge gaps.

- 2) Failure to assess programs: Given the dearth of intervention data, the field should insist that existing programs be assessed and that all new ones include methodologically-rigorous evaluation components.
- 3) Accepting a problematic paradigm: Those in the field have become stuck in a rut of measuring mostly process data, e.g., numbers of reports and investigations. It is much harder to measure if victims/clients/patients/older persons are better off because of an intervention. Researchers should make the effort to measure what matters to the people the interventions are intended to help.
- 4) Americans should make their voices heard: For individual, social, and economic reasons, we can and should insist on having better knowledge to inform programs, professionals, education, policy, and the public's responses to elder abuse. By building coalitions, joining efforts with those with common cause, and speaking out, Americans can demand evidence to show the most effective ways to respond to and reduce elder abuse. This is within reach.

<sup>2</sup> As of December 16, 2016.

## II. Addressing Barriers: Moderator - Karl Pillemer, PhD, Cornell University

Overview: Karl Pillemer, PhD, Cornell University

#### PRESENTER'S BACKGROUND

Sociologist Karl Pillemer, Ph.D. is the Hazel E. Reed Professor of Human Development at Cornell University and Professor of Gerontology in Medicine at the Weill Cornell Medical College. Dr. Pillemer has a career-long program of research, intervention, and policy analysis on the mistreatment of older persons. He conducted the first large-scale epidemiological survey of elder abuse and neglect, which established the benchmark prevalence rate for elder mistreatment.

Dr. Pillemer has studied elder abuse in long-term care settings, including the most extensive survey of mistreatment of residents in nursing homes by staff. He has developed programs based on this research to reduce nursing home mistreatment. Additionally, over the past two decades, Dr. Pillemer has conducted a program of research and intervention to improve staff training in nursing homes and other long-term care environments, and to help reduce conflict and abuse in those settings.

Dr. Pillemer served as moderator for this session.

#### PRESENTATION SUMMARY

Research is more than an academic exercise: people's lives depend on advancing knowledge in elder abuse. Woman and child abuse research have progressed more quickly; elder abuse research needs to catch up.

Researchers seek to develop evidence-based solutions for a public health crisis. Even though the field is more focused, it still lacks a coherent vision for the highest priorities of research.

To date, the following progress has been made:

- 1) Today, a greater consensus exists as to what elder abuse is. The National Research Council has developed a comprehensive definition of elder mistreatment, which makes it analogous to other forms of family violence. This definition excludes abuse by strangers and also self-abuse.
- 2) More than three dozen large-scale population studies in the U.S. and internationally provide a substantial body of evidence in the field. Additional studies are not necessary because there is sufficient robustness in current ones. Moreover, their clinical relevance is hard to gauge.
- 3) These population-based studies have identified risk factors. The elder abuse field, however, is lacking in several key areas:
  - Only one prospective study to date has been conducted, by Mark Lachs, MD, in the 1990s.
  - No evidence-based treatment or prevention strategies exist.
  - Researchers have not discovered evidence-based interventions for elder mistreatment. Those few interventions that have been rigorously evaluated using controlled designs have revealed negative consequences for victims.

Providing better research is the key to sound practice and policy. Researchers must build on these advances: finding the problem, uncovering its extent, and identifying risk factors. Then, they must turn to translational research to create interventions that shed light on elder mistreatment.

#### **KEY POINTS**

- 1) Researchers must devote their attention and resources to develop and rigorously test prevention programs, treatments, and interventions; randomized controlled trials are needed (RCTs).
- 2) Researchers must put their most energetic efforts towards discovering evidence-based interventions for elder abuse.
- 3) Access to patients/clients for research is difficult, but can be eased by collaborating with community agencies.
- 4) Institutional Review Board (IRB) and Health Insurance Portability and Accountability Act (HIPAA) issues need to be examined and mitigated. A legal and ethical strategy needs to be developed, especially since some subjects are over-protected.
- 5) Funding is a barrier, and the field should be submitting more proposals to the National Institute on Aging (NIA), pushing the federal government to fund more studies.
- 6) Elder abuse lacks gerontological researcher interest and engagement. Furthermore, no research training programs exist, unlike in domestic violence, child abuse, and partner violence. Researchers need to think how established researchers (e.g., in nursing, criminology, emergency medicine, family sociology, injury prevention, clinical psychology) can be attracted to find this area interesting.

# Community Partnerships: Why, When & How – Bonnie Olsen, PhD & Kathleen Wilber, PhD, University of Southern California

#### PRESENTER'S BACKGROUND

Clinical psychologist Bonnie Olsen, PhD has extensive experience as a geropsychologist, having worked in academic medicine for over 17 years. She provides mental health and cognitive assessment and short-term treatment in a collaborative model with several primary care physicians and serves as a leader in the University of Southern California's (USC) inter-professional Geriatric Assessment Clinic. As vice chair of Academic Affairs in the Department of Family Medicine at the Keck School of Medicine of the University of Southern California, Dr. Olsen is also involved in a number of research grants that focus on elder abuse education and prevention. In 2009, she was awarded the Gold Humanism Honor Society's Gold Star Award for Humanism in delivery of health care and has remained dedicated to community service throughout her career.

#### PRESENTATION SUMMARY

Dr. Olsen's research focuses on individuals suffering from dementia and/or cognitive impairment. She has found numerous barriers to accessing these individuals for participation in elder abuse research. Creating community partnerships, however, has helped lessen these barriers.

Dr. Olsen discussed lessons learned from three of her studies. The first one was called the Abuse Intervention Model (AIM) study, and the researchers sought to recruit dyads from primary care clinics, eldercare agencies, and Adult Protective Services (APS) consisting of the patient and a family caregiver. While APS was engaged in the study, clinics and agencies were not eager to participate because of the study title, Abuse Intervention Model Study. That title had the "ick" factor. It took over two years to recruit 76 dyads, which required multiple visits to each recruitment site. Lesson: Be careful how you title your study.

At one primary care clinic, Dr. Olsen and her team sought to recruit participants from six geriatricians. When working directly with these physicians proved unsuccessful because of the demands on the physicians's time, the team made six changes to its recruitment strategy in six months to figure out how best to recruit subjects. In the final plan, a researcher met with a clinic nurse to identify potential participants from the list of that day's patients. The nurse then asked the geriatrician for approval for the researcher to contact potential subjects. informing them that the physician had recommended him/her to the study.

Another project consisted of developing education material for caregivers of individuals with dementia to warn them about the risks of elder abuse. Researchers encountered difficulty accessing caregivers. Working with a community agency that oversees a network of caregiver support groups, they began with English-speaking caregivers, followed by Spanish-speaking ones. The researchers found only one support group facilitator in East Los Angeles, a Spanish-speaking section of the city, and wondered why recruitment was so difficult. Soon they determined that an "underground" network of support groups existed. The researchers quickly learned that before any recruitment could occur, it was necessary to earn the trust of the facilitators. The researchers spent time with the facilitators learning about the needs of the caregivers and sharing the benevolent purpose of the study. Ultimately, their trust – and participation – developed. Lack of trust can be a barrier when partners do not fully understand the purpose of the study or see it as mutually beneficial.

Dr. Olsen's elder abuse teleheath project studied the viability of conducting capacity assessments in the field remotely. The Los Angeles County Elder Abuse Forensic Center and APS were the community partners. Researchers worked for a year to develop a protocol whereby a clinician in an office could conduct the assessment remotely. Then, the researchers learned that APS workers could not participate because of limits to the scope of their work. The study proceeded by having one clinician in the field and one in a remote office.

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#### PRESENTER'S BACKGROUND

Gerontologist Kathleen Wilber, PhD and her research team at the University of Southern California Leonard Davis School of Gerontology focus on improving health outcomes and quality of life for vulnerable elders, including those with chronic illness, disability, cognitive impairment, and/or economic insecurity. Her group's current projects seek to improve the design and delivery of services and include: 1) evaluating the effectiveness and cost effectiveness of the Elder Abuse Forensic Center model, a multidisciplinary team that links health and social services with the justice system, 2) examining economic security indicators among diverse groups of older adults, 3) developing a universal assessment for the State of California's home and community-based programs, and 4) developing a better understanding of the challenges family caregivers face and the available evidence-based programs and service models that effectively enhance support and improve outcomes. Dr. Wilber is co-director and faculty liaison for the Los Angeles Caregiver Resource Center and co-director of the National Center on Elder Abuse.

#### PRESENTATION SUMMARY

Dr. Wilber continued the presentation with a discussion of successes and failures with community partnerships and lessons learned. She asked the question: How do researchers best disseminate their knowledge and learn what questions are most important, going forward, using this to generate new knowledge? Identifying and putting this knowledge into effect is the mission of community-researcher partnerships.

What is success? Who decides it, and what are the trade-offs? How do researchers know what constitutes a good outcome? To answer this, Dr. Wilber and colleagues conducted focus groups, asking diverse groups of older adults to give their thoughts on elder abuse. Listening to older adults gave them insights into why interventions often are unsuccessful. Some older adults concluded that what the suspected abuser offered was potentially the best option to avoid isolation and institutionalization. Another important motivation for staying in the shadows is that victims do not want to see family members and others they care about go to jail. Dr. Wilber and colleagues received additional insight in areas such as sweetheart scams: "I know she'll leave me but the relationship is the only thing that brings me joy." Researchers and practitioners need to ask themselves what they can offer victims that is more powerful and compelling than their relationship with the suspected abuser.

Dr. Wilber offered several examples of work done with professionals on the frontlines of addressing elder abuse. In one example, developers from the USC Leonard Davis School of Gerontology sought advice from the Los Angeles County Elder Abuse Forensic Center regarding *A Guide for Elder Abuse Response* (GEAR) app. Instead of checking a box that says a senior is 65+, the police at the Center recommended putting in an age calculator instead. This makes it easier to quickly calculate ages for law enforcement who may be addressing multiple issues at the scene. The GEAR app describes the various types of elder abuse and identifies services and resources available in the surrounding community.

In another example, Dr. Wilber's team interviewed six district attorneys (DAs) to determine how participating in Elder Abuse Forensic Center meetings affects their work. Researchers learned that the DAs gain understanding of the variety of roles and perspectives of other team members. This insight helps them communicate more effectively with these professionals on Forensic Center and other cases they address. They also take information learned in the meetings back to colleagues in their offices in what was termed the ripple effect.

In a third example, Dr. Wilber described a role that was designed to fill a gap in the Elder Abuse Forensic Center team. The multidisciplinary team takes referrals on complex cases that benefit from its expertise, which includes several core groups: APS, law enforcement, health, prosecutors (district attorney), and others. The team has the capacity to investigate cases and offer support through home visits and follow-up investigations, reporting new information back to the team. Research indicates that the model increases prosecution and conservatorship, called guardianship in some states. Sometimes, however, sufficient resources are not available to provide support to the victim over time, so a Forensic Center Service Advocate (FCSA) was introduced. The FCSA is being piloted at the Los Angeles County Elder Abuse Forensic Center. Supporting those in high need, the FCSA's focus is person-centered, seeking to learn from victims how they experience abuse and asking them what they think would help. Dr. Wilber and colleagues are conducting an evaluation of the effectiveness of this pilot.

In conclusion, Dr. Wilber noted that community-research partnerships are essential for putting knowledge into practice and keeping researchers focused on the right questions. These partnerships require understanding each other's incentives, constraints, and motivations, recognizing that things will go wrong, monitoring closely, and making contingency plans.

#### **KEY POINTS**

- 1) Researchers can find community partners at recruitment and intervention sites and data retrieval locations. They include Adult Protective Services (APS), ombudsman's offices, elder law practitioners, financial institutions, community health clinics, Alzheimer's Association, skilled nursing facilities, and social service agencies, among others.
- 2) Partnerships with practitioners will help researchers develop relevant questions, insuring an understanding of perspectives and issues. Many professionals work on solutions to elder abuse, but they may not be aware of other individuals and groups working in the field and sometimes even working on the same case. Bringing people together to share approaches and goals will lead to more effective action, as in the case of the Los Angeles County Elder Abuse Forensic Center, where experts from a variety of disciplines meet weekly to discuss cases.
- 3) To create successful partnerships, researchers need to show their commitment to community organizations by identifying key personnel at sites, engaging them early in the planning process, and providing them with information about the reason and purpose behind the research to foster passion in them for the work. In short, researchers must gain agency buy-in. Importantly, researchers must focus on goals and interests that align with those of the community partner, because partner and researcher goals are not the same.
- 4) Keeping personnel engaged throughout the process will likely lead to a successful partnership. Facilitating a culture of collaboration includes asking for partner input and advice; understanding the organization's limitations and workflow; and identifying motivators for their engagement. Importantly, researchers need to insure that they do not impede the work of the community partner.
- 5) Be humble as researchers and go to community partners to learn more about their realities, issues, and questions. Researchers must recognize their work is not the top priority of their partners. They must determine how their recruitment request/techniques blend in with the workflow of those from whom they are recruiting. Researchers always make agencies's work harder, and they must, therefore, go in humbly and hear their reality and learn from it.
- 6) Accessing hard-to-reach populations is worthwhile. In spite of the difficulties, do not abandon the effort, but put in the time necessary to figure out the mechanism that works.

# Accessing Elders Who Live in Nursing Homes: Wenche Malmedal, PhD, Norwegian University of Science and Technology

#### PRESENTER'S BACKGROUND

Wenche Malmedal, PhD is associate professor at the Norwegian University of Science and Technology (NTNU), Trondheim, Norway, Faculty of Medicine and Health, Department of Public Health and Nursing. She is a specialist in psychiatric nursing and holds a doctorate in health science. Dr. Malmedal has focused on elder abuse since the 1990s; the title of her doctoral thesis is *Inadequate Care*, *Abuse and Neglect in Norwegian Nursing Homes*.

Dr. Malmedal has been a member of several national advisory boards and a frequent invited speaker nationally and internationally about the elder abuse topic for health authorities, NGO's, and others. She is also a consultant to the Norwegian Pensioners Association and Norwegian Center for Violence and Traumatic Stress

studies (NKVTS). Dr. Malmedal has been a guest lecturer at the University of California San Francisco School of Nursing; Jiao Tong University, Shanghai, China; and Health College, Cuprija, Serbia.

#### PRESENTATION SUMMARY

The health care system of Norway is organized at both national and local levels. Approximately 14% of individuals age 80 and older live in institutions, which are largely owned and run by municipalities. More than 80% of nursing home residents suffer from dementia, and that same percentage has extensive care needs. While institutional care is of a high standard, there is also abuse and neglect. Dr. Malmedal's research provided significant knowledge of such abuse as she is the only researcher trained in nursing home abuse in Norway.

Dr. Malmedal and colleagues conducted a cross-sectional survey of nursing staff from 16 nursing homes, receiving a high response rate of 79%. The survey looked at staff behavior that could be considered emotionally abusive, neglectful, physically abusive, or financially exploitative (stealing money or valuables). Eighty-seven percent of the nursing staff reported that they had committed at least one act of inadequate care, abuse, or neglect. All types of acts were reported by respondents except the theft of money or valuables. Abuse that had occurred more frequently than once a month was also recorded.

The study excluded questions regarding sexual abuse because this type of abuse was not reported and such questions provoked the staff (they refused to answer the questionnaire), so they were removed from the survey. To learn more about sexual abuse in nursing homes, Dr. Malmedal conducted a study on this type of abuse, which is said to be the most hidden form of elder abuse. The study sought to increase knowledge of sexual abuse and raise awareness of this serious problem experienced by nursing home residents.

Seven experienced staff nurses participated in focus group interviews, which began with a true story about sexual abuse. The topic provoked strong reactions from them, ranging from anger and sadness to nausea. Sexual abuse remains a taboo subject among health professionals.

In a survey on the same topic, nearly one-third of the 64 respondents reported knowledge of the occurrence of sexual abuse and nearly a quarter were not certain whether the incidents they had observed were sexual abuse or not. The largest group of abusers were co-residents. Importantly, more than half of respondents answered that they did not know what to do if a nursing home resident experienced sexual abuse.

As a result of this data, Dr. Malmedal was able to put this topic on the media's agenda in Norway. She noted that many countries lack awareness of all types of elder abuse, and if you do not believe it happens, you will not see it. Recognition of the problem is the first step towards finding its solution.

Nurses had a hard time believing that sexual abuse could happen, and she believes this topic needs to be put in the curriculum. Also, in Norway, the laws are unclear about reporting, including to whom to report abuse.

Dr. Malmedal is starting to analyze 2,500 answers on an elder abuse survey from people aged 65+ in the community. Because she is the only person with a PhD in nursing home abuse research in Norway (she has one other colleague, who has a PhD in community dwelling older persons abuse research), Dr. Malmedal needs to rely on colleagues in other countries to forward her research.

#### **KEY POINTS**

- 1) Recognition of the problem is part of the solution: with her research, Dr. Malmedal was able to put elder abuse onto the national agenda in Norway.
- 2) You have to believe it to see it! If people do not believe elder abuse exists, especially sexual abuse, they will miss the problem. This is a matter of reframing.
- 3) Legislation and continued knowledge development are the next steps in Norway and in other countries for dealing with elder abuse.

## Working with the IRB: Kristin Craun, MPH, University of Southern California

#### PRESENTER'S BACKGROUND

Kristin Craun, MPH, is director of the University Park Institutional Review Board (IRB) at the University of Southern California (USC) and a specialist on vulnerable populations in social and behavioral studies. Ms. Craun is a faculty member of Public Responsibility in Medicine and Research (PRIM&R) and the Association for Accreditation of Human Research Protection Programs (AAHRPP); a site reviewer for AAHRPP; and recipient of its 2016 Distinguished Site Visitor Award.

#### PRESENTATION SUMMARY

United States regulations have been silent on older research participants, who need additional protections as members of a vulnerable population. Researchers can provide such protection by offering comprehensive training and education to their study personnel about both the research itself and the study population. Specifically, all involved must understand study protocol, including responsible research conduct and the environment and neighborhoods where research is conducted.

Another form of protection involves informed consent: IRBs have the ability to waive elements of consent when research risk is minimal. Innovative and creative methods exist that both assess capacity and provide a means to obtain consent. At a local hospital, for example, comic books were used as a visual aid. In studies involving non-competent elders, IRBs require justification for their inclusion. Capacity to consent must be determined by legally authorized representatives, and re-evaluation is recommended throughout the study.

Mandated reporting of elder abuse is required by health care, medical, and non-medical practitioners. If not a clinician, a researcher is <u>not</u> considered a mandated reporter. In addition, researchers should include in the informed consent a description of all types of information the research team will report to authorities. Sometimes, ramifications of reporting may be worse for the victim and the family, and researchers need to keep this in mind.

#### **KEY POINTS**

1) Under federal law, researchers may obtain a <u>Certificate of Confidentiality (CoC)</u>, issued by the National Institutes of Health (NIH). CoCs allow researchers to refuse to disclose names or other identifying characteristics of research subjects in response to legal demands if the research is greater than minimal risk and data disclosure would adversely impact participants. Researchers do not need NIH funding to obtain a CoC. Data maintained outside the U.S. is not protected under a CoC.

- 2) USC participates in a nationwide <u>Flexibility Coalition</u>, which consists of a group of university and hospital IRBs that have joined together to handle federal requirements in a more flexible way for studies that have no greater than minimal risk and do not receive federal funding. Most IRBs adhere to federal guidelines even for non-federal grants.
- 3) IRBs can provide valuable support to researchers and, in fact, seek partnerships with them. They can, for example, allow investigators to write in more general terms to alleviate the need for minor modifications.
- 4) Effective May 25, 2017, the NIH will require single IRB review for multi-site research.
- 5) Researchers would benefit from establishing a relationship with their IRBs; if an IRB does not have expertise in a researcher's area of study, volunteer! IRBs seek to facilitate research, not constrain it. Regarding informed consent, IRBs can minimize barriers for researchers. There can be room for flexibility.

## Definitional Issues: The Good, the Bad and the Ugly – Jeffrey Hall, PhD, MSPH, Centers for Disease Control and Prevention

#### PRESENTER'S BACKGROUND

Medical sociologist Dr. Jeffrey Hall serves as Deputy Associate Director for Science in the Centers for Disease Control and Prevention (CDC)'s Office of Minority Health and Health Equity (OMHHE). He assists with the provision of leadership and consultation across a broad range of science, research, evaluation, and practice issues to promote the elimination of health disparities and the achievement of health equity. He also conducts research to develop or enhance local, state, and national systems or capacities for measuring and monitoring progress towards health equity. Previously, Dr. Hall was a lead behavioral scientist in the Surveillance Branch of the Division of Violence Prevention of CDC's National Center for Injury Prevention and Control.

#### PRESENTATION SUMMARY

Dr. Hall led the CDC initiative to develop definitions of elder abuse for use in collecting data on elder abuse within a public health surveillance framework.<sup>3</sup> Definitions shape our frames for seeing, thinking about, and interpreting behaviors that are abusive, neglectful, and exploitative and thus must be created with care. They also determine how we view groups of persons in need of services and how we develop, implement, and evaluate strategies for action. In summary, definitions reflect a social construction process that undergirds the work researchers and practitioners do in elder abuse.

The CDC invested significant time and resources into developing definitions and gaining their approval, engaging multiple stakeholders across disciplines. Uniform definitions were created for: elder abuse, physical abuse, sexual abuse, emotional/psychological abuse, neglect, financial abuse/exploitation, and involved parties. For the CDC, the creation of uniform definitions is the first step in a larger process, addressing causes of gaps in

Public health surveillance is the ongoing, systematic collection, analysis, and interpretation of health data, essential to the planning, implementation, and evaluation of public health practice, closely integrated with the dissemination of these data to those who need to know and linked to prevention and control. Reference: Thacker SB, Berkelman RL. History of public health surveillance. In: Public Health Surveillance, Halperin W, Baker EL (Eds.): New York; Van Norstrand Reinhold, 1992.

what we know about elder abuse. The validity of the developed definitions must be further examined to indicate their acceptability, appropriateness, and resonance with key groups impacted by changes in definitions.

Key questions to be explored could include:

- 1) Is the scope of the definitions appropriate and optimal?
- 2) Are substantive elements inadvertently excluded or insufficiently described?
- 3) Are there stakeholder perspectives that are not reflected?
- 4) Are the intended and possible uses of the definitions clear?
- 5) Will the definitions better position the field for greater effectiveness in preventing or stopping older adults' exposure to elder abuse?

#### **KEY POINTS**

Feasibility studies are needed to determine the true relevance and utility of the definitions, engaging stakeholders in the process. Feasibility studies are required to:

- 1) Cultivate diverse partnerships needed to achieve lasting implementation of the definitions across various organizations;
- 2) Identify sociocultural and environmental factors that may impede or facilitate definition adoption;
- 3) Clarify what types of support is needed to enhance standard implementation;
- 4) Determine legal, governance-related, political, ethical, and operational consequences of implementing the proposed definitions; and
- 5) Establish strategies and resources required to integrate the proposed definitions within specific settings of practice, service, or research.

The proposed elder abuse definitions should be operationalized in different sectors with different end-users and in light of research, practice, and policy agendas. This must entail grappling with scalability considerations that should have been identified in feasibility assessments; dividing this large project into discrete manageable tasks; and agreeing upon activities to receive priority. Scalability assessments are needed to ensure that the new definitions are efficacious on a small scale and to establish that their use can be effectively expanded under real world conditions. Insights from seminal works such as the National Center on Elder Abuse's Elder Justice Roadmap and the proceedings of (a) the National Institutes of Health (NIH) workshop on multiple approaches to understanding and preventing elder abuse and of (b) the National Academies of Science, Engineering, and Medicine's elder abuse and its prevention workshop could inform priority-setting activities. Lastly, strategies for operationalizing the definitions could be explored in collaborative fora such as the federal Elder Justice Interagency Working Group and meetings of elder abuse experts such as the Tamkin Symposium.

The CDC believes that evaluation, piloting, and eventual use of the proposed uniform definitions may make it possible to monitor and compare local, state, and national trends and patterns in the occurrence and impacts of elder abuse.

## III. Innovative Research Approaches: Moderator – Carrie Mulford, PhD, National Institute of Justice (NIJ)

Overview: Carrie Mulford, PhD, National Institute of Justice (NIJ)

#### PRESENTER'S BACKGROUND

National Institute of Justice (NIJ) social science analyst Carrie Mulford, PhD has conducted research on juvenile justice, teen dating violence, child abuse, elder mistreatment, enforcement of victims rights laws, hate crime, and situational crime prevention. Since joining the NIJ, Dr. Mulford has managed its elder abuse research portfolio and represented the agency on the Elder Justice Working Group.

Dr. Mulford served as moderator for the innovative research approaches session of the conference and focused her own presentation on evaluation, which the NIJ has strongly emphasized in the past year.

### **PRESENTATION SUMMARY**

Over the past 10 years, NIJ has funded over 30 projects focused on elder abuse mistreatment evaluation research, three of which evaluated elder abuse forensic centers. NIJ, however, has funded no projects studying preventive intervention evaluations.

Dr. Mulford cited the lack of elder mistreatment programs compared to those for violent crimes and child abuse, as indicated in the CrimeSolutions.gov program registry. The authors of the 2016 Cochrane Review, which looked at interventions for preventing elder abuse, concluded that evidence to assess the effects of elder abuse interventions is inadequate.

While randomized controlled trials (RCTs) are preferable when ethically feasible, rigorous alternatives exist. Two options include propensity score matching (PSM) and regression discontinuity. The former uses a quasi-experimental design that estimates the difference in outcomes between program participants and non-participants that can be attributed to the program. PSM was successfully used in an NIJ-funded evaluation of the Los Angeles County Elder Abuse Forensic Center (Navarro, Gassoumis, & Wilber, 2013).

The second rigorous alternative to RCTs, regression discontinuity, uses a pre-test/post-test design where participants are assigned to a program or comparison group based on a pre-program cut-off score, such as risk for abuse. Regression discontinuity requires that there be a continuous quantitative pre-program measure to create a cut-off point. It does not allow for judgment to override the cut-off classification. Intervention is delivered only to those most in need as determined by the cut-off score. Cut-off scores can be determined by availability of resources or on substantive grounds. If there is a treatment effect, there will be a discontinuity in the regression line at the cut-off.

#### **KEY POINTS**

1) Evaluation research in elder abuse needs clearly identified theory and logic model, driven by strong evidence about risk and protective factors. Researchers must agree upon an understanding of desired outcomes for intervention programming across a wide range of domains, use creative research methods, and adopt relevant models from related fields.

- 2) Strong advocacy that pushes for programming and evaluation is important.
- 3) The FY 2016 NIJ elder abuse prevention demonstration project solicitation seeks to fund two rigorous multiyear demonstration projects that prevent abuse, neglect, and financial exploitation of older adults who reside in the community and are at risk for elder abuse. NIJ will offer the awards in the form of cooperative agreements, each with an 18-month planning phase, with funding to occur in three phases. The NIJ expects grantees to work together. [Update: Since the conference, the NIJ has funded two projects.]

## Goal Attainment Scaling: David Burnes, PhD, University of Toronto

#### PRESENTER'S BACKGROUND

David Burnes, PhD is an assistant professor at the University of Toronto and affiliate scientist at Baycrest Health Sciences. Dr. Burnes's program of research focuses on understanding and preventing elder mistreatment in both community and long-term care settings, including the development of basic knowledge, prevention/response interventions, and outcome measurement.

Current projects focus on identifying the prevalence and risk factors of elder abuse/neglect in the community; exploring the nature of resident-to-resident aggression in long-term care settings; developing a conceptual practice model for community-based elder mistreatment intervention programs; adapting/implementing goal attainment scaling intervention/measurement procedures into elder protective/supportive services; and developing innovative ways to measure elder abuse outcomes that integrate construct heterogeneity across cases.<sup>4</sup>

#### PRESENTATION SUMMARY

In collaboration with Mark Lachs, MD, Dr. Burnes adapted goal attainment scaling (GAS) to elder abuse research to address the question, "How do we measure the effectiveness of elder abuse interventions when the nature of the problem and the definition of success is different across cases in community-based elder mistreatment response programs?" Dr. Burnes is working with secondary prevention programs to minimize revictimization.

In the field of elder mistreatment, the biggest knowledge gap is in understanding effective interventions. Barriers include the lack of tools that allow researchers to compare different interventions rigorously and systematically and those that measure client change over the course of the intervention. Tools are also needed that measure older adult clients's self-determined notion of problem resolution. Without a measure of success, researchers cannot systematically compare the effectiveness of different Adult Protective Service (APS) intervention models or move towards an evidenced-based system.

In some fields, the outcome of an intervention is defined uniformly across cases, using a standardized scale. This, however, is not the case with elder mistreatment, in which heterogeneous outcomes exist. A common scenario, for example, is that of a victim seeking a self-defined version of resolution that continues to carries some risk level, e.g., preserving a harmful family relationship.

In other words, enabling the measurement of elder abuse outcomes (e.g., what success means to an older adult going through intervention) that vary in meaning/definition across clients.

Used since the late 1960s in a variety of fields, goal attainment scaling (GAS) provides a client-centered measure of change over the course of an intervention, with each case assessed on an individualized set of goals that reflect the client's objectives and construction of success. GAS fits into APS practice during the intervention phase. A collaborative process between practitioner and client, the two parties identify mutually agreed-upon goals, tasks, and expectations.

Dr. Burnes is currently working with the State of Maine APS across multiple sites, adapting GAS to measure change in client re-victimization risk status over the course of the intervention process. His research group is piloting the feasibility of GAS in the APS context using application (app) software technology. The researchers are also examining GAS psychometric properties of reliability, validity, and responsiveness.

During Phase 1, Dr. Burnes and his group held multiple meetings with State of Maine APS case workers, supervisors, and managers. Together, they developed 19 goals and GAS goal scales for (1) those cognitively intact and (2) those lacking capacity, who were under private or public guardianship, but could still express their wishes. During Phase 2, which just began, caseworkers are implementing GAS prospectively with incoming clients using tablets.

#### **KEY POINTS**

- 1) It is both hard to conduct interventions and measure outcomes.
- 2) Goal attainment scaling (GAS) is a technique to measure client change during an elder abuse intervention and is based on the client's idea of success. The definition of success varies by client and the lens of those helping the client, e.g., social, work, law enforcement, et cetera.
- 3) Having APS workers and clients arrive at a set of goals is an intervention in itself. Dr. Burnes plans to conduct a randomized controlled trial (RCT) that studies people exposed to goal attainment scaling and those who are not, looking at outcomes.
- 4) The inter-rater reliability of GAS among APS practitioners has not yet been determined.

# Technology Solutions: Carolyn E.Z. Pickering, PhD, RN, The University of Texas Health Science Center at San Antonio School of Nursing

#### PRESENTER'S BACKGROUND

Assistant professor and geriatric-trained nurse Carolyn E.Z. Pickering, PhD, RN conducts research on elder abuse and neglect prevention, seeking to understand the dynamics and development of abuse, neglect, and high-risk caregiving in order to identify effective intervention strategies. Dr. Pickering is a member of the University of Texas Health Science Center San Antonio School of Nursing "Caring for the Caregiver Program," which aims to help support the local community's caregiving needs through research, service, and practice. She has also served as a long-term care ombudsman.

#### PRESENTATION SUMMARY

Dr. Pickering discussed the use of technology to deliver elder abuse interventions. She recently completed a secondary prevention project for the State of Michigan utilizing a virtual-reality simulation training program. The training program was provided to professionals (registered nurses and social workers) within Michigan's Medicaid Waiver program who provide services to older adults so that they may remain in their homes. The simulation training focused on use of the QualCare Scale, an assessment instrument used to evaluate the quality of caregiving provided by informal caregivers. In the simulations, trainees were supported to develop caregiving assessment skills and make clinical decisions based on their findings. Previous research has found that simulation training supports interpersonal communication skills, team performance, critical thinking skills, and clinical reasoning in complex care situations.

After the educational intervention was completed, nurses and social workers participated in an evaluation which indicated that they were able to make decisions regarding mandatory reporting obligations with 99% accuracy based on their QualCare assessment. Furthermore, most participants reported making changes in their daily practice as a result of participating in this simulation training. These changes included considering resource allocation within families and inquiring about ways in which the older adults's values were honored. Participants reported a high level of satisfaction with the intervention.

Currently, in a project funded by the Robert Wood Johnson Foundation Systems for Action Portfolio, Dr. Pickering is leading a team of community agencies in the implementation of a community complex care response team (CCCRT) in Battle Creek, Michigan that provides an array of multi-sector services, through coordinated case management, to older adults at risk of victimization as a primary prevention strategy. The goal of the CCCRT intervention is to decrease vulnerability of older adults by promoting and supporting independence and capacity for self-care, thereby reducing opportunities for abuse, neglect, and poor care. The CCCRT case coordination model relies on a custom-designed electronic case management system, developed with iterative input from the community partners, to allow for secure electronic sharing of sensitive data and communication related to service planning.

The researchers hope to identify implementation and translational issues of data sharing across health, human, and civil service sectors to ensure generalizability and successful dissemination. A randomized controlled trial will evaluate the impact of the CCCRT care model as a primary prevention strategy for incidences of elder abuse and neglect and emergency department utilization.

#### KEY POINTS

- 1) Using virtual reality (VR) to teach clinical skills related to elder abuse and neglect assessment and management is both effective and cost- and time-efficient. VR is reusable and modifiable to other types of training, such as those for APS and first responders.
- 2) Other exciting technologies are on the horizon, including mHealth, which is the practice of medicine and public health supported by mobile devices, and wearables, such as fitness trackers, wearable cameras, smart watches, heart rate monitors, and GPS tracking devices.

## Neuroimaging: Duke Han, PhD, University of Southern California

#### PRESENTER'S BACKGROUND

Clinical neuropsychologist Duke Han, PhD is an NIH Paul B. Beeson Career Development Award recipient and Director of Neuropsychology in the Department of Family Medicine at the Keck School of Medicine of the University of Southern California. Dr. Han studies factors that affect cognition and decision-making in aging, and he uses novel neuroimaging and statistical approaches to better understand these factors and inform prevention and intervention strategies. He maintains an active research collaboration with the Rush Alzheimer's Disease Center in Chicago.

Adults over the age of 65 hold \$18.1 trillion of the \$53.1 trillion in U.S. household net worth. Moreover, they lose more than \$3 billion annually to financial scams or fraud, with some estimates as high as \$36 billion. The problem of financial and healthcare fraud targeted at elderly persons is so significant that the FBI maintains a website dedicated to it.

If an older adult shows impaired financial decision-making or becomes a victim of a scam, the burden is experienced by both the older adult <u>and</u> family members, caregivers, or society. Poor financial decision-making (1) may be an early sign of Alzheimer's disease, however, not all adults making such decisions suffer from Alzheimer's disease or cognitive impairment and (2) is associated with increased risk of mortality, making it a public health concern.

#### PRESENTATION SUMMARY

Dr. Han uses neuroeconomics, the integration of the fields of economics and neuroscience, to understand how the brain works when making financial decisions. Neuroscience methods, which include brain imaging and computational neuroscience, can detect differences in brains of those individuals who are susceptible to financial exploitation from those who are not.

Using behavioral and economics data from Dr. Patricia Boyle's Decision Making Study at the Rush Alzheimer's Disease Center in Chicago, Dr. Han looked at neuroimaging in the brain. He noted age-associated neuropathologies that accumulate in certain brain regions in known patterns that might affect functioning over time. His first study looked at financial risk aversion in old age, using functional magnetic resonance imaging (fMRI), which revealed brain differences between older adults who were high risk averse from those who were low risk averse in financial decision-making.

Dr. Han conducted a study on temporal discounting, in which one delays the gratification of taking an immediate reward for a much larger reward in the future (e.g, choosing between \$5 now, or \$10 in an hour). He found that different parts of the brain were involved, depending on whether an individual was an immediate reward taker or one who delayed. Those who delayed had higher functional connectivity of the right parahippocampus, and this has not been seen in younger adults.

In another study, Dr. Han and his research team discovered that financial literacy may change the brain, making it stronger and creating greater structural connectivity of certain brain regions, thereby serving as a protective feature. With this knowledge, financial literacy courses could benefit older adults to help protect them from fraud and scams.

Dr. Han investigated the susceptibility of community-dwelling older adults to scams in another study using voxel-based morphometry (VBM) to look at structural densities in the brain. He saw a bright blue spot in the right hippocampus of those susceptible to scams, suggesting that lower grey matter density in this region is associated with increased susceptibility. Dr. Han noted that these are very early studies, with much variability, and they need to be replicated.

Dr. Han's next study, FINCHES: <u>Finance</u>, <u>Cognition</u>, and <u>Health in Elders Study</u>, has recently been funded by the Elder Justice Foundation, which will support its pilot phase. This longitudinal study will allow him to study potential causal mechanisms and consequences of fraud.

#### **KEY POINTS**

- 1) Financial fraud among older adults is neither well-studied nor well-understood.
- 2) Cognition may not fully explain poor financial decision-making among all older adults: one can have intact cognition, but poor decision-making ability and vice-versa.
- 3) To date, most study participants have been highly-educated because these are the ones who volunteer for research; those with lower literacy levels need to be included in future studies.
- 4) Age-associated financial vulnerability is an emerging public health issue. Providing older adults with financial literacy courses could help protect them from fraud and scams.
- 5) Neuroeconomics can help us understand poor decision-making in old age. Neuroimaging is a non-invasive tool that can be used to study brain characteristics associated with susceptibility to scams and financial fraud among older adults.
- 6) NIA-funded Alzheimer's disease research centers may provide a strong infrastructure to study these issues and fine-tune research approaches.
- 7) Causal mechanisms and consequences of fraud are unknown, but could be determined using a longitudinal design, which the FINCHES study will use.

Funders Panel: Moderator – Marie Bernard, MD, National Institute on Aging (NIA)

Overview: Marie A. Bernard, MD, National Institute on Aging (NIA)

#### PRESENTER'S BACKGROUND

As deputy director of the National Institute on Aging (NIA) at the National Institutes of Health (NIH), geriatrician Marie A. Bernard, MD serves as the principal advisor to the NIA director. NIA has been a leading funder of research related to elder abuse.

Within NIH, Dr. Bernard co-chairs the Inclusion Governance Committee of the Extramural Activities Working Group, and chairs the Women of Color Committee of the Women in Biomedical Careers Working Group. Dr. Bernard co-chairs two U.S. Department of Health and Human Services Healthy People 2020 objectives: 1) older adults and 2) dementias, including Alzheimer's disease.

Until October 2008, she was the endowed professor and founding chairman of the Donald W. Reynolds Department of Geriatric Medicine at the University of Oklahoma College of Medicine, and associate chief of staff for Geriatrics and Extended Care at the Oklahoma City Veterans Affairs Medical Center.

Dr. Bernard served as session moderator, during which she was one of two presenters discussing federal funding opportunities; two others focused on foundation funding. In her presentation, she discussed how researchers can receive agency funding. From fiscal year 2013 through 2015, the NIA awarded between \$5.2 to \$6.7 million in elder abuse grants.

#### PRESENTATION SUMMARY

In addition to supporting multiple research grants and training awards related to elder abuse, NIA's past initiatives include commissioning a 2002 National Academies of Sciences, Engineering, and Medicine report, *Elder Mistreatment*. In 2010, the NIA sponsored a meeting through the National Academies on research issues in elder mistreatment, abuse, and financial fraud. The NIA has also collaborated with the Administration for Community Living, supporting the analysis of the prevalence of elder abuse.

As an activity for the 2015 White House Conference on Aging, one of whose four themes was elder justice, the NIH hosted a workshop on understanding and preventing elder abuse, including abuse across the lifespan and novel interventions and prevention strategies. NIH brought experts in intimate partner violence and child abuse to the workshop. Conference break-out sessions outlined the need for: basic research; prevalence studies; intervention studies; reconsideration of successful outcomes (in the past the victim was taken out of the setting; it is more nuanced today); understanding the interplay of multiple forms of abuse (e.g., long-term abuse, polyvictimization); and improved research infrastructure, specifically, the need to work on the pipeline of future researchers.

Following the 2011 passage of the National Alzheimer's Project Act (NAPA), NIA/NIH was allocated appropriations to assist with meeting the goals delineated in the strategic plan developed as response to NAPA. The plan calls for the prevention and treatment of Alzheimer's disease by 2025, as well as providing support for both formal and informal caregivers and training for healthcare professionals. NIA funding of Alzheimer's research has increased substantially, by an extra \$100 million in FY 2014; \$25 million in FY 2015; and \$350 million for FY 2016.

Between 2014-2016, the NIA released 22 funding opportunity announcements (FOAs) for Alzheimer's disease and related dementias. The FOAs cover a range of research areas, spanning basic, translational, and clinical research. There could be opportunities for elder abuse researchers among the FOAs, particularly related to caregiving.

#### **KEY POINTS**

1) In 2016, the NIA produced <u>Aging Well in the 21st Century: Strategic Directions for Research on Aging</u>. This document provides researchers with background on the NIA's research foci and guidelines.

- 2) The NIA will continue to hold workshops to receive input from the scientific community about the state of the science, including research needs.
- 3) The National Advisory Council on Aging (NACA) meets three times a year to consider applications for research and training and to recommend funding for promising applications. Both scientists and non-scientists make up the Council, where second level reviews of grants take place, and take into consideration concepts to include in future requests for application (RFAs) and program announcements (PARs).
- 4) The NIA produces a weekly blog for researchers (every other week in summer) about concepts brought up in Advisory Council meetings and other items and issues. Check out the blog at <a href="https://www.nia.nih.gov/research/blog">https://www.nia.nih.gov/research/blog</a>.
- 5) The NIH-sponsored workshop on elder abuse, held as a White House Conference on Aging activity, yielded insights that may be useful to researchers in the field. New opportunities exist with increased funding for Alzheimer's disease, ranging from research for a cure or prevention to caregiving issues.

## U.S. Department of Justice (DOJ) Funding: Andy Mao, JD, U.S. DOJ

#### PRESENTER'S BACKGROUND

Andy Mao, JD is the coordinator of the U.S. Department of Justice's Elder Justice Initiative and an assistant director in the Department's Civil Fraud Section. The Elder Justice Initiative supports and coordinates the Department's law enforcement and programmatic efforts to combat elder abuse, neglect, and financial exploitation. Mr. Mao joined the Department in 2000 after completing a federal clerkship in the District of New Jersey.

Mr. Mao stated that he was not at the Symposium in an official capacity, and his views did not necessarily reflect those of the Department of Justice (DOJ).

#### PRESENTATION SUMMARY

The Department of Justice (DOJ), through its National Institute of Justice and the Elder Justice Initiative, is one of the primary funders of elder abuse research, having funded over \$10 million since 2005. Projects focus on incidence, prevalence, evaluating interventions, and financial exploitation. Currently, two studies are evaluating potential screening tools in emergency departments/emergency medical services (EMS) settings. Funding priorities are influenced by research findings; meetings of the National Institute on Aging (NIA), the National Institute of Justice (NIJ), and the National Research Council; and the Elder Justice Roadmap.

The Elder Justice Initiative group is working to determine what elder abuse training exists for district attorneys and prosecutors and how to disseminate it. In order to capitalize on training already developed, the Initiative worked with the Department's National Institute on the Prosecution of Elder Abuse and subject matter experts to produce a video series for prosecutors on elder abuse prosecutions. Mr. Mao would like to put the core elements of that training into relevant DOJ websites and also create a place where prosecutors can share best practices. [Update: Since the Symposium, the videos have been placed on the <u>Elder Justice website</u> and on YouTube.] He is working with various organizations, including the National Center on Elder Abuse (NCEA) and others. He has also started conversations with several law schools about creating elder law programs.

Some barriers to prosecution involve first responders, e.g., emergency medical technicians (EMT), Adult Protective Services (APS), police, et cetera: if they do not know what they are looking for or what to ask, valuable information may be lost and the ability of prosecutors to bring prosecutions may be undermined. In addition to making sure that first responders can identify potential instances of elder abuse, proper documentation and preservation of evidence is also critical. The absence of a documentation protocol on how and what to document may lead to opportunity costs lost in terms of potential cases not brought to the attention of prosecutors, or cases not prosecuted because of the lack of evidence.

Mr. Mao discussed the role of juries in elder abuse prosecutions. Because juries are only supposed to consider the evidence before them, it is obviously critical to have good evidence presented both in terms of contemporaneous documentation<sup>5</sup> and expert testimony. Also, however, it is important to recognize that individual jurors come to the jury with their own (mis)conceptions about seniors (they are the swamp, to quote from Nat Kendall-Taylor's presentation) and their own personal experiences. As such, messaging and packaging matter a great deal, as Dr. Kendall-Taylor noted.

#### **KEY POINTS**

- 1) Research has real world application, and prosecutors and law enforcement are hungry for information. Researchers need to share their findings with these groups.
- 2) The need exists for more translational research, which means evidence of research a prosecutor can use.
- 3) A need for experts and a deeper bench of experts exists. The DOJ needs people willing to testify, experts such as researchers. It takes work to testify.
- 4) Scientific rigor matters. It will be subjected to rigorous scrutiny in the courts. Do not let up, researchers!
- 5) The DOJ is here for researchers: it wants to support, promote, and disseminate their findings. Please do not be afraid to come forward, and check out the DOJ website.
- 6) Other funding avenues for researchers exist, such as the Office of Victims of Crime, which puts out solicitations, and the DOJ's Elder Justice Initiative.
- 7) By late 2016, the DOJ will re-launch its <u>elderjustice.gov</u> website, which will contain a database of about 6,300 abstracts. Many ways are offered to search the literature, and Mr. Mao seeks input from researchers and practitioners. [Update: Since the Symposium, the <u>elderjustice.gov</u> website has been relaunched.]
- 8) A webinar research series is under discussion, which would focus on science-to-practice, translating for other constituents (e.g., law enforcement, EMTs, et cetera).

<sup>5</sup> Contemporaneous documentation refers to documentation generated at the time of the meeting/encounter. In the context of physicians/EMTs and other first line responders, it refers to documentation or evidence gathered during that first meeting.

## Foundation Funding: David R. Zimmerman, PhD, Elder Justice Foundation

#### PRESENTER'S BACKGROUND

David R. Zimmerman, PhD is professor (emeritus) of Industrial and Health Systems Engineering and the former director of the Center for Health Systems Research and Analysis (CHSRA), at the University of Wisconsin-Madison. Over the course of his academic career, Dr. Zimmerman supervised the work of many graduate and undergraduate students and taught courses on a variety of health systems and health information courses as well as courses on evaluation methodology and health performance measurement.

Dr. Zimmerman has more than 30 years of research experience in the measurement and evaluation of the quality of long term care and the development of long term care performance measures. He led the team that developed the original set of nursing home MDS (minimum data set) quality indicators. He has led many projects to develop quality measurement and assessment systems serving consumers, providers, and regulatory agencies. He is currently the principal investigator (PI) and academic partner of the Wisconsin Coalition for Collaborative Excellence in Assisted Living (WCCEAL), and he was the founder of that initiative.

Dr. Zimmerman has served on the Nursing Home Measures Steering Committee of the National Quality Forum. He has been a member of the board of directors of the American Medical Directors Association Foundation. He has been the recipient of multiple awards from government regulatory agencies and consumer advocate organizations. He has served on several national provider network boards and quality committees and has testified several times before Congressional committees on long-term care quality issues.

In 2015, Dr. Zimmerman and his daughter, Kate Hester, started a philanthropic foundation to prevent elder abuse and promote elder justice. Named the Elder Justice Foundation, the philanthropy funds projects to better understand and address elder abuse and in other ways promote elder justice.

#### PRESENTATION SUMMARY

One goal of the Elder Justice Foundation is to provide monies for seed work and pilot projects. In addition to research, the Foundation also plans to fund demonstrations of interventions that seem viable. A particular focus will involve studying planning and implementation of interventions, which Dr. Zimmerman dubbed, "intervention integrity." He has often witnessed the disconnect between planning and execution and believes process, or qualitative analysis, is critical.

Although he understands the importance of randomized controlled trials (RCTs), Dr. Zimmerman does not believe they have served the elderly, who are almost always excluded from such trials. Moreover, he has witnessed contamination of the intervention itself in RCTs. In one case, people knew what the superior intervention was, based on its initial effect, and undertook things to compensate for it, thereby compromising the rigors of the clinical trial. The Foundation looks favorably on other rigorous methods, such as propensity scoring and regression discontinuity.

Dr. Zimmerman recognizes the complexity of some elder abuse issues. Regarding financial exploitation, for example, a caregiver can end up financially abusing the older adult under his/her care. The Foundation is currently funding a study that relies on ombudsmen to report abuse, but an ombudsman may resist the role of mandatory reporter.

Other issues are not as complicated. For example, the tremendous increase in scam calls can be successfully handled, and law enforcement agrees. Police departments have crime stopper line for victims to call, but a more direct approach would help make reporting easier. Dr. Zimmerman seeks to expedite the transfer of the information from victim to law enforcement.

Dr. Zimmerman noted that the innovation fund section of the Elder Justice Act was removed from the Act, and he would like to resurrect some of the innovation fund ideas.

#### **KEY POINTS**

- 1) Newly created, the Elder Justice Foundation will provide seed monies for research and support demonstration projects.
- 2) The Elder Justice Foundation website Elder Justice Foundation.org will go online in March 2017, after which it will invite proposal submissions.

## Foundation Funding: Mary Ellen Kullman, MPH, CHES, Archstone Foundation

#### PRESENTER'S BACKGROUND

Mary Ellen Kullman, MPH, CHES is the executive vice president and chief operating officer of the Archstone Foundation, where since 1995 she has provided oversight of foundation operations and grant program, including initiative and request for proposal development, grant monitoring, technical assistance to grant recipients, and program evaluation. She has overseen more than 900 grants representing over \$90 million dollars in philanthropic investment by the Foundation. For five years prior to coming to the Archstone Foundation, Ms. Kullman was the manager of preventive health education for Southern California Edison, where she directed the health education and prevention programs for 55,000 employees, dependents, and retirees.

#### PRESENTATION SUMMARY

A private grantmaking foundation since 1986 with assets of \$110-\$112 million, the Archstone Foundation has funded over 1,000 grants in health and aging, totaling \$100 million. Since 1991, it has funded 133 grants in elder abuse and neglect research, for a total of \$16 million.

Primarily a California-focused foundation, the Archstone Foundation engages in national work if it can be shown to benefit California. It was involved in the creation of a statewide blue print and national conferences on elder abuse and neglect, bringing together practitioners in the field. Currently, the foundation focuses on family caregiving, late life depression, and aging in the community, but still funds elder abuse research on a selected basis. It recently funded a project of the Institute of Medicine (now National Academy of Science, Engineering, and Medicine) on family caregiving of older adults.

#### **KEY POINTS**

1) While a foundation may not specifically fund elder abuse, it might fund an elder abuse project if the proposed grantee can show the relationship of the project to a related, funded area. Related areas include: elder justice, social justice, family caregiving, long-term care, vulnerable populations, and violence prevention, among others.

- 2) Resources for researchers include the <u>Foundation Center website</u> and library and the *Chronicle of Philanthropy*.
- 3) Foundation annual reports and websites contain valuable information. IRS Form 990s, which are posted on foundation websites two years after filed, provide an overview of the organization's activities and detailed financial information.
- 4) If the foundation permits it, researchers should talk with program staff at the preliminary stage, after they have developed a concept of the research they plan to conduct.
- 5) Foundations want to see a compelling case detailed in both human and economic costs, with a strong link between the intervention and desired outcomes. They also want grantees to show that the work will continue after the funding stops, that it is sustainable.
- 6) Grant seekers should write clearly, without the use of jargon, and ask specifically for the money they seek. Budgets should be realistic, acronyms spelled out, and writing, error free.
- 7) If deadlines become problematic, a grantee can ask for no-cost extensions. The funder wants the grantee to be successful.
- 8) Building a network of funders can help researchers. Getting to know funders, keeping them informed, being a thought partner, and having a clear idea of what is to be accomplished will help both the researcher and the foundation. While foundations offer greater flexibility and quicker turnaround time than other types of funders, grants are often of shorter duration and fewer dollars. If a foundation cannot provide funding, it can introduce researchers to other funders and include them in publications.
- 9) Researchers should put the foundation on distribution lists, invite its staff to events, engage them in strategic thinking, and otherwise involve them in the work in a positive, helpful way.

# Closing: Edwin Walker, JD, Acting Assistant Secretary for Aging and Acting Administrator, Administration for Community Living

### PRESENTER'S BACKGROUND

Acting Assistant Secretary for Aging and Acting Administrator of the Administration for Community Living (ACL) Edwin Walker, JD leads the Administration on Aging within ACL.

He guides and promotes the development of home and community-based long-term care programs, policies, and services designed to afford older people and their caregivers the ability to age with dignity and independence and to have a broad array of options available for an enhanced quality of life. This includes the promotion and implementation of evidence-based prevention interventions proven effective in avoiding or delaying the onset of chronic disease and illness.

Prior to federal service, Mr. Walker served as the director of the State of Missouri Division of Aging, responsible for administering a comprehensive set of human service programs for older persons and adults with disabilities.

The Administration for Community Living was created in 2012, bringing together the federal government's work on behalf of older adults and people with disabilities. From the beginning, ACL was based on a commitment to one fundamental principle: that people with disabilities and older adults should be able to live independently and participate fully in their communities. ACL works with states, tribes, community providers, researchers, universities, nonprofit organizations, businesses, and families to achieve that vision.

ACL's programs work collaboratively to enhance access to health care and long-term services and supports, while also promoting inclusive community living policies, such as livable communities and competitive integrated employment for people with disabilities.

#### PRESENTATION SUMMARY

Currently, elder abuse is handled state-by-state, with states responding using different approaches, statutes, and definitions, relying on protection and advocacy systems such as law enforcement, long-term care ombudsman programs, and Adult Protective Services (APS). Sometimes, differences exist within a single state.

APS is often the gateway for victims who need community, social, health, behavioral health, and legal services to maintain their independence where they reside. APS is enabled by and receives money from the federal Social Services Block Grant. APSs vary by state in terms of populations served, settings where served, types of services provided, relationship to other service providers in the justice system, and the timeliness of responses.

Moreover, within a given state, there is no way to ensure that APS will actually receive funding. The Government Accountability Office (GAO) has identified challenges with APSs, including collecting and maintaining statewide case-level data; growing caseloads; and chronic underfunding, which impairs the ability to assess client outcomes and effectiveness of services.

In 2014, the Office of Elder Justice and Adult Protective Services was created, which is designated as the official home of APS in the federal government. It seeks to expand elder abuse prevention and provide legal assistance and counseling programs. This office leads and supports the development and implementation of a comprehensive national infrastructure to prevent, detect, and respond to elder abuse, focused on the consumer.

Currently, in an effort to develop uniformity across states, the Office is facilitating voluntary APS guidelines. The process for developing guidelines is based on the best science available and includes an expert working group, stakeholder engagement, and an outreach strategy to refine and build consensus. Guidelines will highlight best practices for effective APS systems and will recommend that APS programs participate in research related to APS practice. Guidelines will be published by early 2017.

The GAO cited absence of data as a significant barrier to improving APS programs. As a start, ACL is developing a national adult maltreatment reporting system, the first of its kind, initially using data developed by APS. It will provide comprehensive, consistent, and accurate national-level data by collecting quantitative and qualitative data on practices and policies of APS and outcomes of their investigations. Annual data collection begins in January 2017 and will be voluntary. Policymakers, APS programs, and researchers will be able to use the data to improve programs.

#### **KEY POINTS**

- 1) Since 2012, the <u>Elder Justice Coordinating Council</u>, established by the Elder Justice Act, coordinates activities across the federal government related to elder maltreatment. Input to the Council has been received from stakeholders, citizens, practitioners, and industry members.
- 2) Established in 1988 and added to the Older Americans Act in 1992, the National Center on Elder Abuse (NCEA) is a national resource center to prevent elder mistreatment. It disseminates information to professionals and the public; provides technical assistance and training to states and community-based organizations; collaborates on research; offers education; answers inquiries; provides information about promising practices and interventions; operates a listserv; and helps professionals. A new research database is coming soon to the NCEA website. NCEA's goal is to become a national repository of elder abuse knowledge and resources.
- 3) Elder justice innovation grants will be awarded soon. Their purpose is two-fold: (1) to support development and advancement of solutions to new and emerging elder justice issues and (2) to support foundational work to create credible benchmarks for elder abuse prevention, control, and program development and evaluation. The grants focus on self-neglect, abuse in guardianship, elder abuse forensic centers, and elder abuse among Native Americans.
- 4) In 2015, the ACL initiated a grant program to address gaps and challenges in state APS systems. The program provides funding to improve APS systems statewide, including innovations, improvements, practices, services, data collection, and reporting. The goal is to improve experiences, health, wellbeing, and outcomes of APS clients. This is the first federally-funded program to target APS.
- 5) Researchers and those in the field must educate both the public and policymakers that no federal or national system to address elder abuse exists. The Older Americans Act and Elder Justice Act reauthorizations provide opportunities to raise the issue with new\_policymakers and legislators in Congress and to build upon the efforts initiated by ACL and the Council.
- 6) Persistent advocacy is critical: the Elder Justice Act, for example, took 8-10 years of dedicated advocacy to get it passed.

## Making Research Relevant: Reframing Elder Abuse – Nat Kendall-Taylor, PhD, FrameWorks Institute

#### PRESENTER'S BACKGROUND

Psychological anthropologist Nat Kendall-Taylor, PhD is chief executive officer (CEO) of the FrameWorks Institute, which was a 2015 winner of the MacArthur Award for Creative and Effective Institutions. As CEO, Dr. Kendall-Taylor employs social science theory and methods from anthropology to improve the ability of researchers, advocates, and practitioners to promote social change. This involves applying cognitive and cultural

theory to understand how people interpret information and make meaning of their social worlds and how frames can be used to create new ways of engaging with social and scientific issues.

Dr. Kendall-Taylor leads a multi-disciplinary team of social scientists in studying public understanding of and ways to reframe such pressing issues as criminal justice reform, immigration, elder abuse, taxation, early childhood development, addiction, environmental health, education, poverty, public health, and climate change. He presents findings and recommendations from this work in workshops, formal presentations, working papers, and peer-reviewed journal articles. His previous research has focused on child and family health and understanding the social and cultural factors that create health disparities and affect decision-making.

#### PRESENTATION SUMMARY

The frames through which people view the world affect how they respond to information and impact their understanding of issues. Ineffective framing can have devastating effects on the resolution of public policy problems. As an example, Dr. Kendall-Taylor described a study in Alberta, Canada, funded by the Alberta Family Wellness Initiative. The study examined why evidence-based addiction policies were receiving little public support. FrameWorks researchers found that the value "empathy," which was used in the majority of expert and advocacy materials about addiction in the province to garner public support, was actually negatively affecting support for target policies and programs. Research showed that the values of interdependence and ingenuity, on the other hand, increased public support for evidence-based addiction policies.

Dr. Kendall-Taylor made the point that while social science research is commonly used to find programs that work or examine causal mechanisms in order to build better policies, these same methods are rarely used to find effective ways of communicating these findings. Instead, communicators tend to rely on a set of seemingly logical, but ultimately ineffective communication practices. These ineffective practices include:

- 1) Providing more...and more data. While layering data on top of data might work to convince researchers, it does not move public thinking. Facts, by themselves, do not make for an effective framing strategy. Instead, to be effective, they need to be framed.
- 2) Disseminating sheets that present a series of myths and then facts designed to debunk them. Attempting to "myth-bust" in this way is common practice across fields, but research has shown that people misremember myths as true and attribute false information to the source of the communication.
- 3) Emphasizing urgency. Without a sense of solution, piling on statistics and examples that paint a picture of crisis is not an effective communications practice. Urgency without efficacy reduces engagement and depresses support.

Often, experts say one thing, and the public hears something different. To prove this point, Dr. Kendall-Taylor showed a video made as part of a FrameWorks elder abuse study. In the video, individuals were asked what they thought about elder abuse, what it is, and how to address it. The video revealed that people combine their understandings of "elder" with "abuse" and omit neglect and sexual abuse. They are also paternalistic about elder abuse and view older adults as undergoing physical and mental deterioration as the normal course of aging, which "naturally" leads to abuse.

Viewing elder abuse simultaneously as everyone's problem and no one's problem, the individuals interviewed saw no solutions, except surveillance (in the form of body cameras). Many cited modern life as the problem: caregivers are pushed to the limit, the culture devalues older people, and nursing homes are an unfortunate necessity of a rapidly dissolving extended family structure. Perhaps most importantly, members of the public

have considerable difficulty thinking systemically about elder abuse and overwhelmingly see it as an individual-level issue. Click <u>here</u> to read study findings.

#### **KEY POINTS**

- 1) Policy-makers, researchers, and advocates can utilize scientific research methods to better understand culture and craft more effective communications. Culture complicates communications—it is a complex stew of existing understanding, powerful assumptions, and widely held patterns of understanding. To become a communications expert, one must become a culture expert.
- 2) Those communicating about elder abuse face three challenges: (1) help people think at the systems level, (2) generate understanding of how proposed solutions can reduce and prevent elder abuse, and (3) increase the sense of efficacy, thereby overcoming fatalism and futility about the potential of meaningfully addressing elder abuse.
- 3) The field needs to think about how to mobilize frames and disseminate a new story about aging and elder abuse, one that puts the problem in the appropriate context and informs the public of the values and principles at stake. This is a path to culture change and Dr. Kendall-Taylor's challenge to elder abuse researchers and experts.
- 4) In mid-2017, a tool box of communication strategies will be available to the field at the <u>National</u> <u>Center on Elder Abuse</u> and the <u>USC Center on Elder Mistreatment</u> websites.

## **Appendices**

#### A. Break-out Sessions

During the afternoon of the first day of the Symposium, audience participants joined one of four small group discussions focused on overcoming research barriers in elder abuse, each covering a different topic. The goal of these discussions was to compare ideas on how to solve elder abuse research challenges with a multidisciplinary group of professionals. This section provides a summary of ideas and solutions generated by each group, which were facilitated by elder abuse experts.

## Group 1: Engaging Older Adults

The overarching question discussed by the group: How do we engage older adults in research on elder abuse?

- Incentivize involvement in research. Make it a social setting, not a lab (which can be frightening). This will help older adults relax and engage, combat isolation, and interact with peers.
- Interview insiders, someone who is sensitive to their culture.
- Engage with larger organizations, such as AARP.
- Make research sexier by bringing in celebrities to cover topics.
- Go to places where seniors go/congregate, such as senior centers, religious organizations, assisted living facilities, club.
- Bring families in to discuss prospectively.
- Ask open-ended questions when doing interviews. Example: If there were one thing you could change in your life, what would that be?
- Show empathy and make a personal connection during research. Shame is often involved and mentioned by victim and feelings of guilt researchers need to be aware of this. Also, people are resistant to seeing themselves as victims; they prefer to see themselves as advocates: I'm learning about/participating in elder abuse research to help someone else. First, must research how victims view themselves.
- What other research questions should we be asking? The process of relationship/dynamic how does it work between victim and abuser? How/what sustains it? Cancer analogy folks thought in the beginning that there was only one cure for cancer; today we know better. Elder abuse is multi-faceted.
- Community-based participatory research (CBPR) how do you get around the dilemma if you, as a researcher, are asked for something you can't do/provide? One answer: If you can find areas of alignment of goals/overlap for agency and researcher, this helps. Another answer: One researcher conducts a consensus workshop with researchers and practitioners; the latter group will have different goals and will ask the former group for help.

### Group 2: Outcomes

The overarching question discussed by the group: What outcomes should we assess and measure in intervention and prevention trials?

#### Overarching themes:

- Movement along stages of change rather than absolutely positive outcome, progress
- Should outcomes vary by type of abuse?
- Who reports the outcome? What if people can't report themselves?
- How to measure outcomes for cognitively impaired?
- Determine outcomes by context: nursing home vs. community
- Need multi-dimensional outcomes. Even if victimization stops, other outcomes may be worse. Need to make sure that we don't do more harm.

#### Treatment:

- Meeting client goals does intervention achieve his/her goals? Does the client feel his/her goals are met?
- Cost-effectiveness/savings of programs. Needed for sustainability
- Lab values
- Justice outcomes
- Victim impact, prosecution, sentencing, referral to DA's office, restitution, case pleadings
- Institutional placement
- Hospital placement
- Emergency department use
- Mortality
- Preservation of autonomy (as appropriate)
- Decreasing dependence on the abuser, removing the abuser
- Reduction in frequency and intensity, rather than elimination of the abuse
- Successful treatment for abuser or getting abuser into treatment
- Strong concern that circumstances under which abuse can be ended also have negative consequences for victims, like nursing home placement. These need to be measured.

#### Service Providers/Adult Protective Services (APS)

- More reporting
- Greater knowledge
- Awareness of what to do

### Community-wide interventions:

- Increase in reporting
- More referrals to services
- Need surveillance system to understand if public awareness campaigns work

### Group 3: Trenches to Tower to Trenches

The overarching question discussed by the group: How do we ensure that the questions researchers are addressing are important to workers in the field?

- 1) How do we insure that research outcomes are disseminated widely?
- Research needs to be translated. Translation by discipline would be helpful. Could do email research blasts/listserv with info about what peace officers, social workers need on elder abuse.
- Have a dissemination strategy beyond academic publications. Be aware of how to communicate across disciplines. Not everyone, for example, cares about research methodology, but would like to know instead what researchers did, what they found, and how that impacts practice.
- Importance of academic research: be responsible with message, be honest and representative of findings, do not oversell.
- 2) How do we improve collaborations between researchers and workers in the trenches?
  - Go into trenches (agencies, community partners) and ask what is needed. Hold a forum with both groups (researchers and community partners). Figure out mutually beneficial solutions.
  - Responsibility to the community to form a collaboration. Require it in funding announcements incentivize those bonds between trench and tower.
  - May need to build long-term partnerships.
  - Co-facilitate monthly meetings for researchers and practitioners.
  - One researcher writes honoraria into grants since partners are otherwise not compensated for helping researchers.
  - Another noted that her group engaged with the agency (APS) on a daily basis, sharing why the outcomes were important and how it would be useful to that agency. She kept them engaged. In exchange, the APS gave good ways to conceptualize cases. Personal level of engagement made the difference.
  - Another engaged in building trust with her study population, which garnered her a high response rate to her surveys. She built this trust by going to the institutions in which she was conducting her study and meeting with all the staff about the research and study. If there is trust, participants can and will answer freely.
  - Several conference participants stressed the importance of seeking input from community partners early in the study design process. An agency participant suggested including agencies in the process rather than presenting them with a design.
  - A researcher said that he asks his faculty members to volunteer where they want to collaborate for 6-12 months before submitting a research request. After that time, the research question almost always changes.
  - Another participant stated that a lot of agencies, such as hers, need training, so she suggested offering them training, with nice lunches, away from the office.

## Group 4: Research in Financial Abuse: Moving Toward Solutions

The overarching question discussed by the group: What are the key elements that studies on financial exploitation need to include and address?

#### Barriers:

- Screening: should clinicians screen their patients for financial abuse (FA)? And what kind of questions to ask?
- Perpetrators: there is no national database of FA perpetrators some think there is a need for a federal registry, and this is a controversial topic.
- Many FA cases never get prosecuted. Is there a mechanism for victims to provide information voluntarily so lawmakers and legislators could see this information and understand the scope of the problem?
- Much fear of reporting victims are ashamed or in denial makes it hard to collect data. Can shame be reduced and co-dependency, also? How can we take away the fear?
- Big barrier is convincing people that they can be victims. Higher financial literacy is a predictor of susceptibility to/victim of investment fraud. Overlap between FA of older adults and financial fraud of all people; cognitive impairment plays a role, also. Victim plays a key role in his/her own victimization in fraud; person is willingly consenting to disclose personal information to perpetrator.

#### Research solutions:

- Research gap: We look at only one side of the dyad: victims. Need to look at perpetrators and context of victimization. What kind of solutions could be implemented? How do we stop recidivism? How do we get perpetrators not to be dependent on the older adult for financial security and well-being?
- Struggling to understand intersection of cognitive impairment (CI) and financial exploitation. You do not need to have CI to become a victim of FA and fraud. At what point are people at risk of exploitation, what makes them vulnerable? What's the environmental context? One researcher has found it is a life event: in fraud, it could be widowhood or other trauma (e.g., being moved into an institution).
- Not much research on the effectiveness of interventions. Is a full clinical trial needed? Mental health consequences (suicidal thoughts) need to be looked at, also.

#### Other solutions:

- We need to engage the financial services industry: banks, credit unions. They are the conduit/link between victim and perpetrator. How can we get them (banks) to share their data? How can we get them to engage their clients in a discussion of FA? Whom should the bank contact if something happens? Publication can benefit scam artists and unethical family members.
- Data mining barriers financial institutions do not give out client information. Not a lot done with these data sources. We should pursue how/why they (banks, etc.) might be interested in partnering with researchers.

## B. Tamkin Symposium Agenda

## USC Judith D. Tamkin International Symposium on Elder Abuse

Closing the Research Gaps: Moving the Field Forward

September 15-16, 2016

Los Angeles, California

This inaugural Symposium calls for researchers, academics, physicians, nurses, psychologists, and other health care professionals to attend in an endeavor to close the research gaps and move the field of elder abuse forward.

#### **AGENDA**

Day 1: Thursday, September 15, 2016

7:45 - 8:30 a.m.	Registration		
8:30 - 9:00 a.m.	Opening / Welcome - Laura Mosqueda, MD		
	Addressing Barriers (Moderator: Karl Pillemer, PhD)		
9:00 a.m. –	Overview – Karl Pillemer, PhD		
12:30 p.m.	Community Partnerships: Why, When & How – Bonnie Olsen, PhD and Kathleen Wilber, PhD		
Break from 10:30 a.m. to 10:45 a.m.	Accessing Elders Who Live in Nursing Homes – Wenche Malmedal, PhD		
	Working with the IRB – Kristin Craun, MPH		
	Definitional Issues: The Good, the Bad and the Ugly – Jeffrey Hall, PhD, MSPH		
12:45 - 1:45 p.m.	Networking Lunch		
	Breakout Sessions/Discussion Groups		
2:00 - 2:45 p.m.	Small Group Discussions		
3:00 - 4:00 p.m.	Large Group Discussion		
4:00 - 4:20 p.m.	<b>Gaps and Opportunities in Elder Abuse Research: Who Needs What?</b> - Marie-Therese Connolly, JD		
4:20 - 5:00 p.m.	Making Research Relevant: Reframing Elder Abuse - Nat Kendall-Taylor, PhD		

## Day 2: Friday, September 16, 2016

8:00 -8:15 a.m.	Welcome - Laura Mosqueda, MD		
	Innovative Research Approaches (Moderator: Carrie Mulford, PhD)		
8:15 - 11:15 a.m.	Overview – Carrie Mulford, PhD		
Break from 10:15 a.m. to 10:30 a.m.	Goal Attainment Scaling – David Burnes, PhD		
	Technology Solutions - Carolyn E.Z. Pickering, PhD, RN		
	Neuroimaging – Duke Han, PhD		
11:30 a.m. – 12:30 p.m.	Lunch (Honoring Georgia Anetzberger, PhD)		
	Funders Panel (Moderator: Marie A. Bernard, MD)		
	Overview – Marie A. Bernard, MD, National Institute on Aging		
12:30 – 2:30 p.m.	David R. Zimmerman, PhD, Elder Justice Foundation		
Break from 1:15 p.m. to 1:30 p.m	Mary Ellen Kullman, MPH, Archstone Foundation		
	Andy Mao, JD, U.S. Department of Justice		
	Closing		
2:30 - 3:00 p.m.	Edwin Walker, JD		





