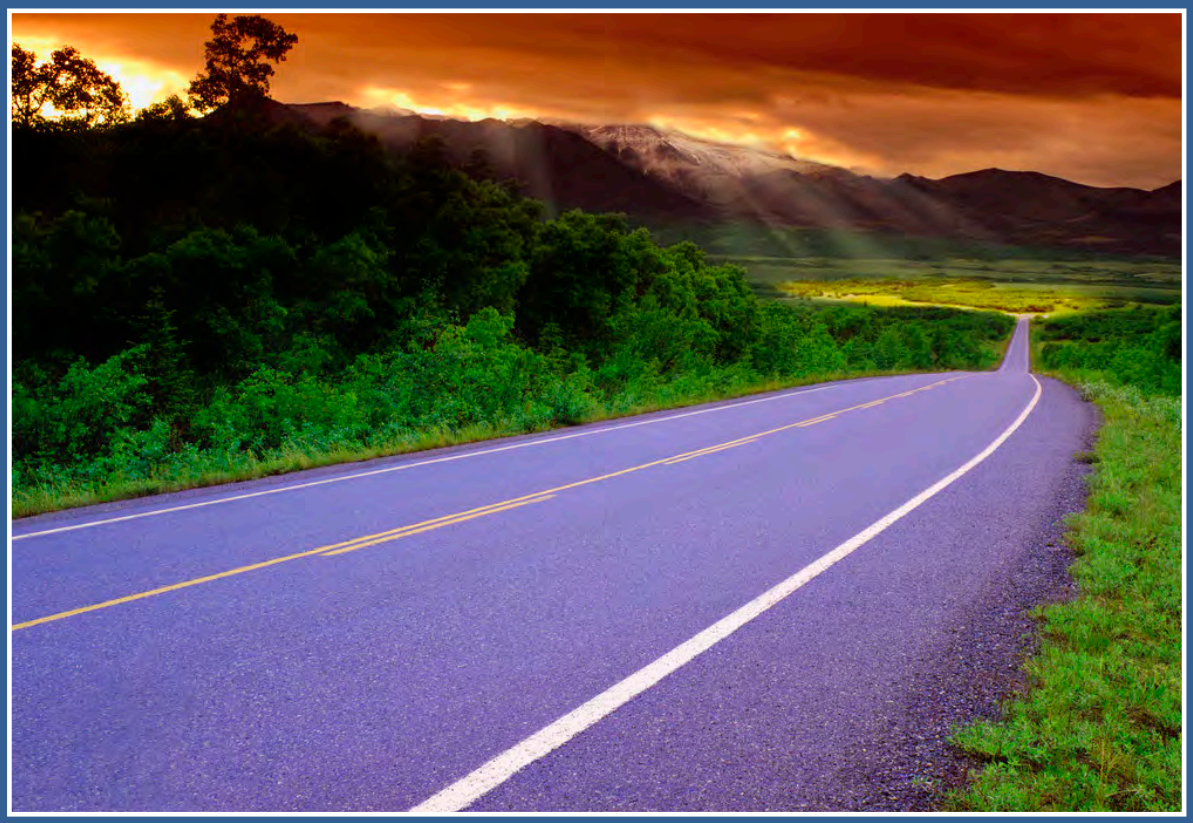


The Elder Justice Roadmap

A Stakeholder Initiative to Respond to an Emerging Health, Justice, Financial and Social Crisis

An initiative funded by the US Department of Justice with support from the Department of Health and Human Services. The recommendations, points of view and opinions in this document are solely those of the authors, subject matter experts and stakeholders and do not represent official positions or policies of either Department.

This initiative asked 750 stakeholders (see Appendix I) to complete, with as many ideas as they wished, the following statement: **"To understand, prevent, identify or respond to elder abuse, neglect, or exploitation, we need…"** Their responses provided the foundation for a dialogue involving various subject matter experts from across diverse disciplines, fields, professions, and settings (see Appendix B), and resulted in this report, which was drafted by:

- Marie-Therese Connolly, JD, *MacArthur Foundation Fellow; Senior Scholar, Woodrow Wilson International Center for Scholars*
- Bonnie Brandl, MSW, *Director, National Clearinghouse on Abuse in Later Life (NCALL), End Domestic Abuse Wisconsin*
- Risa Breckman, LCSW, *Weill Cornell Medical College, Division of Geriatrics and Palliative Medicine; Director, New York City Elder Abuse Center*

The recommendations, points of view, and opinions in this document are solely those of the authors, subject matter experts and stakeholders and do not represent official positions or policies of either the U.S. Department of Justice or the U.S. Department of Health and Human Services.

The Elder Justice Roadmap

The Elder Justice Roadmap

A strategic planning resource *by the field for the field,* spanning four domains:

THE ELDER JUSTICE ROADMAP

Responding to an Emerging Health, Justice, Financial, & Social Crisis

EXECUTIVE SUMMARY

Elder abuse – including physical, sexual, and psychological abuse, as well as neglect, abandonment, and financial exploitation – affects about five million Americans each year, causing untold illness, injury and suffering for victims and those who care about and for them. Although we do not have a great deal of data quantifying the costs of elder abuse to victims, their families, and society at large, early estimates suggest that such abuse costs many billions of dollars each year – a startling statistic, particularly since just one in 24 cases is reported to authorities. Given the aging population and the widespread human, social, and economic impact of elder abuse, a broad range of stakeholders and experts were consulted on how to enhance both public and private responses to elder abuse.

Among the many priorities identified in this Roadmap, ***five*** stand out:

The **Top Five Priorities** critical to understanding and reducing elder abuse and to promoting health, independence, and justice for older adults, are:

1. **Awareness:** **Increase public awareness of elder abuse, a multi-faceted problem that requires a holistic, well-coordinated response in services, education, policy, and research.**
2. **Brain health:** **Conduct research and enhance focus on cognitive (in)capacity and mental health – critical factors both for victims and perpetrators.**
3. **Caregiving:** **Provide better support and training for the tens of millions of paid and unpaid caregivers who play a critical role in preventing elder abuse.**
4. **Economics:** **Quantify the costs of elder abuse, which is often entwined with financial incentives and comes with huge fiscal costs to victims, families and society.**
5. **Resources:** **Strategically invest more resources in services, education, research, and expanding knowledge to reduce elder abuse.**

The Elder Justice Roadmap Process

Developing a Roadmap to set strategic priorities to advance elder justice involved collecting information from numerous sources. The data were collected, with guidance from subject matter experts from around the country, in several phases including:

- Using a concept mapping process to solicit the perspectives of 750 stakeholders who were asked to identify the most critical priorities for the field;
- Convening facilitated discussions with experts on six particularly important topics: (1) diminished capacity/mental health, (2) caregiving, (3) diversity, (4) prevention, (5) screening, and (6) victim services;
- Conducting leadership interviews with high-level public officials, thought leaders, and heads of influential entities regarding how best to gain traction, engage vital partners, and set and implement an agenda to promote elder justice; and
- Compiling a bibliography and list of resources including articles, books, DVDs, curricula and toolkits relevant to the issues and priorities identified in the project.

This process resulted in the identification of the **Top Five Priorities** noted above, and specific recommendations identified by Roadmap contributors, who sorted them into three categories:

- **First Wave Action Items** – Priorities to address first, chosen by subject matter experts based on criteria outlined on page 9.
- **High Priorities by Domain** – A wider range of priorities sorted by the Roadmap's four domains: *Direct Services, Education, Policy,* and *Research*, for users interested in a more in-depth list of options, and the reasons those priorities were deemed important.
- **Universal Themes that Cut across Domains** – Vital issues that arose repeatedly.

A Dynamic Document

This Roadmap is intended primarily to be a strategic planning resource *by the field, for the field* to advance our collective efforts to prevent and combat elder abuse. It is a dynamic document that can be adapted and used by grassroots and community groups, multidisciplinary teams, and local, state, and national governmental and non-governmental entities, all of which have critical and complementary roles to play in tackling and implementing the recommendations identified in this document.

While the views and information contained in this document do not reflect or represent the official positions or policies of the federal government, they have already helped to inform certain federal efforts. For example, the Roadmap helped to inform the structure of and subjects addressed at the inaugural meeting of the Elder Justice Coordinating Council[1] in October 2012, and to help target certain federal data collection, research, and training initiatives and projects.

There is much to do to address elder abuse. This Roadmap is just the beginning.

A. The Problem

Elder abuse *"includes physical, sexual or psychological abuse, as well as neglect, abandonment, and financial exploitation of an older person by another person or entity, that occurs in any setting (e.g., home, community, or facility), either in a relationship where there is an expectation of trust and/or when an older person is targeted based on age or disability."* (See note on definition, Appendix A.)

In other words, any older adult, in any family, may experience elder abuse. Sometimes individuals bear responsibility for the abuse. Sometimes broken or ineffective systems and entities bear responsibility. Much more research is needed, but existing data indicate that:

- One out of every ten people ages 60 and older who live at home suffers abuse, neglect, or exploitation.[2]
- In several small studies, about half of people with dementia suffered from abuse or neglect by their caregivers.[3]
- Cognitive impairment reduces financial capacity, increasing risk of financial exploitation.[4]
- High rates of neglect, poor care or preventable adverse events persist in nursing homes and other long-term care settings where more than two million people (most of them elderly) live.[5]
- About two-thirds of elder abuse victims are women.[6]
- African American,[7] Latino,[8] poor, and isolated older adults are disproportionately victimized.[9]
- For every 1 case of elder abuse that comes to light, another 23 remain hidden.[10]

"Facts matter. So do stories. We need to do a better job of getting out the word that these issues affect everyone."

– leadership interview

Archstone Foundation

B. The Human and Economic Toll

Elder abuse triggers downward spirals for many victims, eroding their health, financial stability, and well-being. It also causes untold suffering for millions of people of all ages. That suffering, in turn, needlessly depletes scarce resources of individuals, families, businesses, charities, and public programs (like Medicare and Medicaid). Research is beginning to illuminate the huge cost of elder abuse:

- Elder abuse triples the risk of premature death and causes unnecessary illness, injury, and suffering.[11]
- Victims of elder abuse are four times more likely to be admitted to a nursing home[12] and three times more likely to be admitted to a hospital.[13]
- Understaffing at nursing homes leads to a 22% increase in unnecessary hospitalizations.[14]
- Most adverse events in nursing homes – due largely to inadequate treatment, care and understaffing – lead to preventable harm and $2.8 billion per year in Medicare hospital costs alone (excluding additional – and substantial – Medicaid costs caused by the same events.)[15]
- Financial exploitation causes large economic losses for businesses, families, elders, and government programs, and increases reliance on federal health care programs such as Medicaid. Research indicates that those with cognitive incapacities suffer 100% greater economic losses than those without such incapacities.[16]
- One study of older women found that verbal abuse only leads to greater declines in mental health than physical abuse only.[17]
- Elder abuse causes victims to be more dependent on caregivers. As a result of providing care, caregivers experience declines in their own physical and mental health and their financial security suffers.[18]

The cumulative toll of elder abuse has not yet been quantified but is estimated to afflict more than 5 million people and cost many billions of dollars a year. Emerging evidence indicates that prevention could save lives and prevent illness, injury and suffering, while also yielding major cost savings.[19]

"It's important to include cost-benefit analyses. People ask: *'If we do this, can we save costs?'* So those cost-benefit data are valuable."

– leadership interview


Archstone Foundation

C. Challenges in Responding

In communities across the country, diverse multidisciplinary groups of people trying to address elder abuse in their professional and personal lives are working together to find ways to prevent and respond to the problem. States are grappling with enacting appropriate laws and creating programs, roles for responders, and sanctions for abusers. These efforts are largely uncoordinated, lack sufficient resources, and are uninformed by existing data and program models.

Elder abuse is not an easy problem to address: It can manifest itself in many ways – an older parent isolated and neglected by an adult child or caregiver; domestic violence by a partner (long-term or new), adult child or caregiver; sexual assault by a stranger, caregiver or family member; abuse or neglect by a partner with advancing dementia; financial exploitation by a stranger, trusted family member or professional; or systemic neglect by a long-term care provider that hires too few staff members, provides insufficient training to its staff, and expends too few resources on resident care.

As a result, elder abuse requires responses that take an array of factors into consideration: Norms can vary by racial, ethnic, and religious identity (such as relating to caregiving and money) that can shape the context of elder abuse. Shame, fear, love, loyalty, pride, and a desire to remain independent often influence the decisions of older people at risk. Cognitive incapacity and isolation are accompanied by high rates of elder abuse, and also can influence the decision-making of older adults and their ability to access and participate in services. And Adult Protective Services ("APS") workers report that mental health and substance abuse issues often are present among perpetrators, victims, or both. Thus, effective prevention, investigation and intervention require cultural competency and sensitivity to a broad array of issues. In addition, one of the greatest challenges in addressing elder abuse is navigating the right balance among autonomy, safety, and privacy goals.

In short, elder abuse does not fit a single profile. It is a complex cluster of distinct but related phenomena involving health, legal, social service, financial, public safety, aging, disability, protective services, and victim services, aging services, policy, research, education, and human rights issues. It therefore requires a coordinated multidisciplinary, multi-agency, and multi-system response. Yet, as noted by the General Accountability Office in 2011,[20] services, education, policy, and research are fragmented and under-resourced. These challenges have been magnified by the lack of a coordinated strategic agenda. This Roadmap is intended to address that gap.

"There's great concern about elder abuse. But without resources it's really hard to be anything but frustrated about it."

– leadership Interview


Madeline Kasper

D. Elder Abuse is a Problem with Solutions

This Roadmap seeks to forge a path to solutions with an informed, coordinated, public, and private effort at the local, state, and national levels. This Roadmap offers opportunities for engagement by numerous constituencies – the public, state and local officials, professionals who routinely address elder abuse, allied professionals in related fields, policy makers, educators, researchers, caregivers, others who work to reduce elder abuse, and older adults themselves. It is time not only to identify the problems, but also to expand our knowledge about successful strategies and implement common sense, cost-effective solutions to stem this rising epidemic of elder abuse.

Communities have different needs and resources when it comes to addressing elder abuse. The priorities identified in this Roadmap provide ample opportunity for organizations, practitioners, and other interested individuals and entities to participate in tackling aspects of the problem that are most relevant to them. No single entity can address elder abuse by itself. Everyone can make a difference.

The vast suffering, cost and dislocation caused by elder abuse demand a commensurate investment of resources. Such an investment could yield substantial gains.

"The definition of successful advocacy on these kinds of issues is 'gentle pressure applied relentlessly.' You just never stop. And eventually, you move things forward."

– leadership interview


Sally Aristei Photography

PRIORITIES, ACTION ITEMS, AND UNIVERSAL THEMES

To begin forging a path toward solutions, the Roadmap identifies the elder justice field's most urgent needs as well as threshold barriers and challenges that must be overcome to address them. To accomplish this, stakeholders first suggested solutions that, through the concept mapping process, were used to generate a list of 121 recommendations. (See Appendix D for the full list.) They then were asked to sort the ideas, which fell into four conceptual domains: **Direct services**, **Education**, **Policy**, and **Research**.

A. The Top Five Priorities

Next, they ranked and rated priorities resulting in identification of ***five major priorities*** that pertain to virtually all efforts to understand and reduce elder abuse:

1. **Awareness:** Increase public awareness of elder abuse, a multi-faceted problem that requires a holistic, well-coordinated response in services, education, policy, and research.
2. **Brain health:** Conduct research and enhance focus on cognitive (in)capacity and mental health – critical factors both for victims and perpetrators.
3. **Caregiving:** Provide better support and training for the tens of millions of paid and unpaid caregivers who play a critical role in preventing elder abuse.
4. **Economics:** Quantify the costs of elder abuse, which is often entwined with financial incentives and comes with huge fiscal costs to victims, families, and society.
5. **Resources:** Strategically invest more resources in services, education, research, and expanding knowledge to reduce elder abuse

"The greatest ethical dilemmas often are not in choosing between good and evil but in choosing among goods."

– leadership interview


conejoaureo

"If you don't know where you're going, you're never going to get there."

– leadership interview

The priorities also were sorted into three categories that provide Roadmap users with additional detail, background, and choices as they decide which priorities to pursue. One size does not fit all: Practitioners, educators, policy-makers, researchers, and multidisciplinary groups should select, plan, and implement the priorities that best fit their needs, skills, and resources:

B. **First-Wave Action Items** are foundational priorities that subject matter experts identified as having a realistic chance of completion or implementation based on the criteria set forth on page 9.

C. **High Priorities by Domain** supplement the "first wave action items," which may not include items appropriate for all Roadmap users. Each listed priority includes background information and is grouped into one of four color-coded domains: **Direct services, Education, Policy,** or **Research.**

D. **Universal Themes that Cut Across Phases and Domains** arose repeatedly in all phases of the project as critical to inform efforts to reduce elder abuse.

Archstone Foundation

"FOCUS: If you try to do everything you'll end up accomplishing nothing."

– leadership interview

B. First Wave Action Items

In 2014, diverse subject matter experts, joined by federal partners, convened to identify *first wave action items* from the broader array of priorities. In identifying the first wave action items, the group considered the following variables:

1. **Importance:** Was the priority of high importance?
2. **Actionable:** Could the priority be accomplished?
3. **Foundational:** Did it need to be completed before other work could occur?
4. **Momentum:** Could implementing the priority build momentum and lead to other work?
5. **Champions:** Was there an individual or entity that could champion it?
6. **Concrete:** Was the priority concrete and specific?
7. **Impact:** Would it provide meaningful help to victims or reduce risk to older adults?

"The definition of a priority is what you do first. It's not all you're going to do. But you have to start somewhere."

– leadership interview

Archstone Foundation

Direct Services Action Items

- Designate more prosecutors and prosecution units dedicated to pursuing elder abuse. (9)*
- Include older people's input in all aspects of elder justice efforts. (24)
- Develop more multidisciplinary teams throughout the country that have adequate support for facilitators and operations. (35)[21]
- Ensure protection from and response to abuse, neglect and exploitation of individuals receiving long-term supports and services, regardless of setting. (53, 54 and 119)
- Ensure that existing domestic violence, sexual assault, and other victim assistance programs better meet the needs of older victims by allocating resources, collecting data, developing, and evaluating programs, and incorporating elder abuse issues into training and technical assistance. (96)
- Develop prevention, intervention, and surveillance methods tailored to protect cognitively impaired older people in all settings. (110)

* Each idea generated in the concept mapping process was assigned a number (see Appendix D). These numbers appear in parentheses beside the action item to which that idea corresponds. Some action items merge two or more ideas into a single statement.


Archstone Foundation

"You need to overcome people's reluctance to talk about this stuff. They don't want to believe it has anything to do with them. They think, 'I don't know anyone who would do that…'"

– leadership Interview

2 Education Action Items

"Training is not just talking at people. There are techniques and technology out there for adult education. You need to invest in being good adult educators. That's part of capacity building. But most people don't know how to do this."

– leadership interview

Education Action Items

- Educate all types of caregivers about elder abuse. (42)
- Create and implement a national elder abuse education and training strategic plan. (23, 33, 45, 82, 104, 106, 107, and 120).

"We desperately need to develop ways to train individuals on the front lines about cognitive impairment and decision-making capacity and how to assess these. Practitioners are poorly informed and they need to catch up to where science has taken us in the last 10-20 years. The average caseworker will tell you – they use out-dated questionnaires and screening tools. That needs to stop."

– facilitated discussion

Policy Action Items

- Improve law, policies, training, oversight, and data collection related to substituted decision-making, including abuse of powers of attorney, guardianship, and conservatorship. (31, 79)
- Build a strong movement to advance elder justice, informed by key teachings from other social movements. (103)
- Develop national APS definitions and standards, including topics such as feasible caseloads, collaborations, training requirements, and data collection. (116)

"We can say that elder abuse is really important but it doesn't mean the resources come. And funding decisions often are far more influenced by external players than by internal agency players."

– leadership interview

Archstone Foundation

"To get something done, you don't have to convince everyone. Just the right people."

– leadership interview

4 Research Action Items


Roger Tully

"Could you create a prediction model? When a person reaches age X, they get some assessment and education about the likelihood they'll fall victim to abuse, neglect, or exploitation because of the following factors: age, cognitive status, financial security or lack thereof, and family and social support. If 3 of 4 factors are present, their probability of being mistreated by age, say 80, is XYZ. So, what factors are 'treatable?' What can we do to prevent them proactively from going down that road?"

– leadership interview

Research Action Items

- Conduct research, including program evaluation, to determine the effectiveness of interventions that are used to address elder abuse. (62)
- Measure the economic cost of elder abuse and neglect (e.g., facility placements, hospitalizations, trips to the emergency room, lost assets and wages, etc.) in order to identify areas of cost savings gained by addressing the problem. (74)

"If you could link the cost of elder abuse to Medicare and Medicaid, that could be very powerful."

– leadership interview

C. High Priorities By Domain

This project involved honing a large number of priorities to a smaller implementable number – and ultimately the *Top Five Priorities* and the *First Wave Action Items* described in the previous pages. In an intermediate step in the project, the 121 ideas offered by stakeholders (listed in Appendix D) also were sorted by domain and winnowed into **High Priorities in each Domain – Direct services, Education, Policy, and Research**. Though still numerous, those *High Priorities by Domain* are included in this section (pages 14 – 25) because, (1) they were identified as critical by the experts who guided the Roadmap project and/or participated in the facilitated discussions and leadership interviews, and (2) this longer list may provide additional options for users of the Roadmap who do not find priorities suiting their needs among the *Top Five Priorities* (on page 1, 7) or among the *First Wave Action Items* (on pages 9 – 13).

Practitioners, educators, policy-makers, and researchers are encouraged to select and pursue priorities that best fit their needs, skills and resources. They also are encouraged to partner with allies with related interests in doing so.

Katherine Fogden, Smithsonian Institution

"Given that this is a difficult and touchy issue, you have to have compelling messages for why the issue is important, but also what you can do about it, nationally and locally, in ways that will make people's lives better."

– leadership interview

"What is competence? Is there variable competence? And who gets to make decisions? If my mom wants to give her money to some quack preacher and she's competent to do so and it's her money, fine. They're complicated questions, but I don't think we've done a good job of laying them out for people."

– leadership interview

Direct Services Priorities

The *Direct Services* region of the Roadmap focuses on front-line practitioners and the services and responses they provide, including: (1) caregivers; (2) first responders and investigators such as adult protective services workers, emergency medical technicians ("EMTs"), law enforcement and state licensing and oversight agencies; (3) professionals who might identify abuse and make referrals to an investigative or services agency such as health and mental health providers, case managers and discharge or care coordinators; (4) aging services network personnel, senior centers, meals on wheels, social service providers, guardians, powers of attorney and others; (5) victim advocates who focus on trauma services, safety planning, shelter and advocacy such as domestic violence and/or sexual assault; (6) legal system responders such as prosecutors, elder law and public interest attorneys and court personnel; (7) ombudsmen who advocate for persons in long-term care residential facilities by resolving complaints about and promoting resident health, safety, well-being and rights; (8) financial services industry entities, such as banks and brokers; and (9) members of the faith community.

Some potential responders, like APS, respond to elder abuse daily. Yet most cases are not reported to the entities designated to address elder abuse. For every one case that comes to light, another 23 remain hidden.[22] Individuals who do not specialize and are not trained in elder abuse issues (e.g., police officers, bank tellers, letter carriers, or clergy) may be the only ones in a position to notice that abuse may be occurring. Whatever their role, they are *potential allies* whose involvement is critical to an informed approach to prevention, detection, reporting, and response. The following priorities apply to all potential responders who interact with older people and who may be in a position to prevent, report or respond to suspected elder abuse:

- **Caregiving workforce:** Develop ways to better enlarge the caregiving workforce – paid and unpaid – to promote and support good care in home, community, and facility settings. Ensure adequate pay, benefits, and working conditions for paid caregivers. And, for all caregivers, assure quality training on caregiving and elder abuse.
- **Care/case management:** Increase the availability of community care coordinators and case managers trained to recognize risk factors, respond to elder abuse, and aid clients in prevention and risk reduction.

- **Cultural capacity:** Ensure that practitioners know how to identify and respond to the unique attributes of elder abuse as they relate to factors such as age, incapacity, disability, ethnicity, family structure, language, gender, national origin, race, religion, sexual orientation, and socioeconomic status.
- **Funding:** Increase resources for practitioners who work to prevent elder abuse and respond to the needs of victims.
- **Gap analysis:** Identify and address gaps in services across networks to improve prevention of elder abuse, neglect, and exploitation – including aging, consumer, disability, legal, financial, health, hotline, housing, mental health, social, trauma, or victim services.
- **Geriatric experts:** Develop more health professionals with expertise in aging and elder abuse by providing additional training to existing professionals and recruiting students into the field. Such professionals also should learn about local multidisciplinary teams that address legal, social service, or financial issues, and, where appropriate, participate in such teams. Training for some also should include cross-training in geriatrics and forensic pathology. These experts need to know how to detect suspicious signs and report elder abuse cases (when appropriate) so that they can assist older adults to prevent, ameliorate, or end elder abuse.
- **Justice system and legal responses to elder abuse:**
  - Create law enforcement and prosecution units that specialize in elder abuse, and enhance involvement of Medicaid Fraud Control Units and State Attorney General Offices in elder justice cases, such as those involving abuse and neglect in long-term care.
  - Educate court personnel about the needs of elder abuse victims so that they can knowledgably handle elder abuse cases and accommodate older people's needs.
  - Educate civil attorneys about the needs of elder abuse victims and their critical role in identifying and responding to these cases.
- **Multidisciplinary responses:** Develop and support multidisciplinary responses to elder abuse. Encourage participants involved in multidisciplinary teams to collect data about their practice and to describe their successes and challenges in ways that can inform others engaged in similar efforts.
- **Partnerships with related fields:** Develop collaborations between the elder justice field and other allied fields involved with older adults, including aging, caregiving, civil, legal, domestic violence and sexual assault, mental health, substance abuse, and trauma.

Education Priorities

Without raising public awareness, millions of older people and the people who care about and for them will be unaware of ways to prevent elder abuse in their lives and how to identify or address it if it does occur. Without training and education, first responders and service providers in numerous fields – many of whom are natural allies for the elder abuse field – will lack the skills they need to prevent, identify, report, or address elder abuse. Education and training are needed within individual professions, agencies, disciplines, *and* in multidisciplinary settings that bring together diverse responders. In addition, where research has identified critical knowledge, it should be disseminated to the field. The same is true of programs, policies, and procedures that have demonstrated effectiveness in combating elder abuse. For all of these reasons, participants in this project identified a number of priorities relating to education, training, and raising awareness, including:

- **Awareness about cultural competence:** Work with grassroots organizations and leaders from underrepresented and underserved populations to ensure that public awareness and consciousness raising efforts are tailored to their realities of elder abuse and the media outlets that reach them, and that they contain messages specific to their perceptions and needs.
- **Culture change:** Assure that long-term care providers at all levels are trained in progressive and innovative models of person-centered long-term care. Ensure that those models are responsive to consumer preferences and respectful of caregivers.
- **National training plan:** Create and implement a national elder abuse education and training strategic plan by identifying existing curricula and training materials, evaluating those materials, creating new quality materials to fill existing gaps, pilot testing and evaluating those materials, and disseminating the materials to the field. Ensure that older adults and persons from diverse communities are involved in the development and delivery of materials. Ensure that, where appropriate, curricula and programs are culturally competent.
- **Populations and disciplines that need training and education:** Train people in a position to prevent, recognize, and respond to elder abuse – whether it is a core aspect of their lives or work or whether they are natural allies. Those who require training include the following:
  - **Aging services network personnel and volunteers.**

- **Caregivers** (both informal and formal) to build resiliency and protective factors using model programs, such as home visits used in the child abuse field.
- **Care managers** (including in managed care and long-term supports and services systems).
- **Health care workers** such as doctors, nurses, nursing assistants, dentists, and rehabilitation staff that work with patients short-term, acute, or emergency department settings, as well as in long-term care facilities.
- **Faith leaders.**
- **Financial services industry personnel.**
- **Forensic experts** to aide in the detection, analysis, investigation, and prosecution of elder abuse cases.
- **Individuals working with persons with disabilities.**
- **Individuals working in the elder abuse field** at the local, state, and national levels (discipline-specific and multidisciplinary).
- **Individuals who come into contact with older people** (such as postal workers, home delivered meals staff, and volunteers, etc.) on how to recognize, respond to and refer suspected elder abuse.
- **Justice and legal system personnel** including civil and elder law attorneys, law enforcement, prosecutors, investigators, coroners, and medical examiners.
- **Mental health service providers**, including employee assistance programs.
- **Substance abuse program providers**.
- **Victim services providers.**

- **Public awareness:** Work with experts in communication and media to create a strategy to raise consciousness and public awareness about elder abuse. Decide on the goals for such a campaign, including who to target and what messages will most effectively reach them, and impart the desired information.
- **Spokespersons:** Expand the cadre of skilled spokespersons who can articulately and accurately communicate compelling messages about elder abuse and raise awareness and consciousness at local, state, and national levels. (See also "Public awareness".)
- **Trainers/educators:** Expand the cadre of individuals in all sectors who can provide quality training and technical assistance relating to elder abuse at the local, state, and national levels. We need more trainers to provide both discipline-specific and multidisciplinary training and technical assistance.

"As a preventive measure, people can become better prepared. We do a lot to prepare people to become parents of children but little to prepare children to care for parents in their old age." – *leadership interview*

Policy Priorities

Participants in this project identified a variety of potential policy responses to elder abuse. They include: promulgation of laws, regulations, and guidance by government entities at all levels; implementation and enforcement of laws and policies; use of the bully pulpit for leadership purposes; initiatives that support, evaluate and develop new policy or lead efforts to prevent or address elder abuse; outreach to and development of a political constituency, including potential partners and champions; and the development of infrastructure and entities (a government office or nonprofit organization, for example) with capacity to lead, push, keep track of, and analyze policy change. Specific policy-related priorities identified by informants include:

- **Adult Protective Services:** Develop national APS definitions, collaborations, training requirements, data collection mechanism, training, technical assistance, and standards, including for realistic caseloads. In addition, create a national office for APS.
- **Evaluation:** Assess existing programs, laws, and trainings to ensure efficacy and inclusivity when identifying policy priorities and what programs, laws, and trainings to replicate.
- **Funding and implementation of laws:** Fully fund and implement elder justice provisions in existing federal laws, such as the Elder Justice Act, the Older Americans Act, the Violence Against Women Act, and the Social Services Block Grant.
- **Impediments to expanding knowledge and responding:** Institutional Review Boards ("IRBs"), Health Insurance Portability and Accountability Act ("HIPAA"), and other privacy laws, including financial privacy laws, are intended to protect people but often undermine research and efforts to prevent and address elder abuse. HHS should promulgate guidance (as required by the Elder Justice Act) to assist IRBs, researchers, and multidisciplinary teams in navigating consent and other human subjects protection issues in elder abuse research. Federal agencies should provide guidance about how all relevant entities and individuals, including practitioners, multidisciplinary teams, and researchers, can navigate privacy concerns when it comes to elder abuse.

"There's a growing body of evidence that reflects the relationship between violence, fear, health and mental health."

– *leadership interview*

- **Infrastructure:** Develop infrastructure to promote consistency, coordination, efficiency, and focus in policy-development, practice, research, and training at the federal, state, and local levels, for example:
    - **Federal Offices:**
        - Federal Office(s) of Elder Justice, comparable to federal offices at DOJ and HHS that address child abuse and domestic violence.
    - **Resource centers:** As exist in other fields, the elder justice field needs well-funded resource centers including:
        - One strong general resource center addressing many overarching issues (for example by enhancing resources to the National Center on Elder Abuse with resources comparable to those allocated to centers that address child abuse and domestic violence/violence against women).
        - Specialized resource centers such as for Adult Protective Services, Long-term care Ombudsman program, older victim services, legal services, and guardianship.
- **Long-term Care:** Strengthen monitoring of long-term services and supports (e.g., survey and certification systems), and examine policies to better prevent, detect, and redress abuse and neglect in home, community-based, and institutional long-term care settings, whether perpetrated by family members, staff, other residents, or others.

"You have to have a communication strategy that actually communicates with people, not just repeat your message over and over again, which is what some people think communication is, as opposed to really finding out what people are absorbing from the message you're sending."

– leadership interview


Archstone Foundation

- **Medicare and Medicaid reimbursement policy:** Examine how Medicare and Medicaid policy could be modified to prevent and mitigate elder abuse, for example by reimbursing for actions designed to screen for, detect, intervene in, and prevent elder abuse.

- **Multidisciplinary efforts:** Cultivate and fund multidisciplinary efforts in elder abuse matters. Address impediments to coordination including confidentiality, privacy and other laws, regulations and protocols. Evaluate the efficacy of varying multidisciplinary models.
- **Political constituency:** Develop coordinated, well-funded advocacy entities and multidisciplinary networks to inform policy, increase resources, and raise awareness at the national, state, and local levels. These efforts should include cultivation of allies, political leaders, the private sector, and charitable foundations. In addition, these efforts should involve promoting public awareness that elder abuse is an issue for people of all ages.
- **Related fields:** The elder justice field should engage in and partner with a variety of overlapping fields (with their individual and organizational leaders alike) whose constituencies are affected by elder abuse. These partnerships should work toward greater integration of efforts, cross training, and joint initiatives targeting awareness, prevention, detection, intervention, and referrals. The related fields, issues, networks, and areas of interest identified by stakeholders as important for greater coordination with the elder justice field include the following:
  - **Aging services network**
  - **Caregiving**
  - **Cognitive capacity**
  - **Disability rights**
  - **Domestic violence**
  - **Elder rights**
  - **Financial services**
  - **Justice system**
  - **Law enforcement**
  - **Legal services**
  - **Mental health**
  - **Public health**
  - **Protective services**
  - **Research**
  - **Sexual assault**
  - **Victim services**
- **Transitions:** Identify and develop policy to respond to transitions that might heighten the risk of elder abuse, such as when an older adult goes from a rehabilitation facility or hospital to a home with inadequate care or when an inappropriate caregiver moves in with an older person.

"There needs to be empowerment for the network. Nothing can be done in isolation; no one agency can provide all services. If a victim falls through the cracks, they receive services too late.

So there needs to be leadership in the federal, state, and local networks to oversee how services are organized, funded, and supported."

– facilitated discussion


Archstone Foundation

4 Research Priorities

Research Priorities

Experts generally agree that the knowledge base relating to elder abuse lags decades behind that of child abuse and domestic violence. The consequences of this deficit are not merely academic. It means that those on the front lines often are without the tools or resources to detect elder abuse or the most appropriate ways to respond to it. It also means that we know little about what language is effective in talking about the problem (with older people or the public) or what preventative measures are effective. In addition, older people and victims of elder abuse have not been asked in any systematic way what *they* consider to be successful outcomes of interventions. Their answers could and should inform all efforts.

The experts who worked with the Elder Justice Roadmap Project point out that elder abuse will not stop while we wait for (often time-consuming) research to inform practice. Thus, in the interim, practitioners should proceed based on practice-based evidence of what is effective. But the need for more research is urgent and it is an area that calls out for a coordinated, systematic approach that includes policy-makers, researchers and funders. In addition, translating challenges faced by practitioners into research questions and translating the findings of researchers into usable forms for practitioners is critical. Researchers and practitioners need to work together in all phases of research, including identifying research questions, interpreting results, and disseminating information.

Research-related priorities identified in this project include the following:

- **Elder justice researchers:** Cultivate and mentor a cadre of elder justice researchers. The dearth of academic researchers studying elder abuse issues impedes knowledge development in the field. As a result, there are few data to inform and guide practitioners, policy-makers, and trainers. Such researchers also play important roles as thought leaders in the field.
- **Definitions:** Develop comprehensive, consistent definitions of elder abuse to be used in various contexts such as research, law, critical care, and services.
- **Standards and methods: Evaluate and validate the standards and data collection methods currently employed by the field.** Standards and data collection methods used by various entities (such as surveyors, adult protective services, long-term ombudsman, and others) are variable. Researchers should assist in developing the parameters and methods used to build an evidence base designed to collect accurate data and show the impact of effective practices.

- **National research agenda:** Develop a focused research agenda to get the most information from limited funding. Priorities to consider include:

  Cognitive Impairments

  - Develop better instruments and methods to assess whether potential victims have cognitive impairments.
  - Determine effective surveillance, intervention, and prevention strategies for victims with cognitive impairments in all settings – at home, in community-based care, and in institutional settings.
  - Identify ways to measure the prevalence of elder abuse among people with dementia and other cognitive impairments.

"It's hard to make the case for resources without some good surveillance data. And, that's been a huge handicap."

– leadership interview

Cost and Consequences

- Identify the costs and consequences of elder financial exploitation, such as the impact on health, financial well-being and risk for other types of elder abuse.
- Calculate the economic cost of other forms of elder abuse and neglect (e.g., facility placements, hospitalizations, trips to the emergency room, lost assets and wages, increased reliance on Medicaid and other public programs, etc.) to assist in identifying areas of costs savings from addressing the problem.
- Develop validated methods and tools to collect data from various systems that have data relevant to elder abuse, including APS, criminal justice, financial services, guardianship, health care, law enforcement, ombudsman, Social Security (representative payees), survey, and others.

Intervention and Prevention

- Determine what messages are effective in reaching critical audiences.
- Determine what causes elder abuse, determine what theoretical models explain it, and develop and evaluate interventions to test the theoretical models.
- Create partnerships between researchers, first responders, and other service providers who have experience working with older victims.
- Recruit researchers with expertise in studying prevention to the elder justice field.
- Evaluate the efficacy of programs designed to address elder abuse, such as adult protective services and long-term care ombudsman programs, and identify which models and practices are most effective.

- Determine how victims, potential victims, and their caring family and friends define successful interventions.
- Evaluate the availability of emergency/transitional housing and other victim service options for older victims. Evaluate existing services to determine which models best meet older victims' needs and preferences.
- Create and test intervention strategies that are designed to enhance strengths and ameliorate risks for elder abuse.
- Evaluate the effectiveness of laws and legal interventions in preventing and stopping elder abuse.
- Test and evaluate the efficacy of various types of multidisciplinary responses to elder abuse to determine critical components and which models are most effective in which circumstances.

Law, Policy, and Protocol Evaluation

- Systemically evaluate existing laws and how (if at all) they are implemented.
- Draft model laws and policy to fill gaps in elder abuse prevention and response.
- Evaluate safety audits used in the domestic violence field to determine if a similar process might be useful in elder abuse interventions.
- Create demonstration projects that test criminal justice and civil legal interventions targeting abusers or individuals deemed high risk for abusing, neglecting, or financially exploiting older people.

Risk Factors and Forensic Markers

- Identify forensic markers to assist in the detection of elder abuse.
- Study neglect of older people, including risk factors (e.g., social isolation, loneliness,"unbefriended elders," and poverty), and the assessment of and intervention in such situations.
- Conduct a long-term (longitudinal) study examining the characteristics of victims and/or perpetrators (such as substance abuse, mental illness) and contextual factors (such as poverty, isolation, dependence or disability, family violence) in elder abuse cases.
- Determine the rates of elder abuse by type of abuse, neglect, or exploitation and by type of perpetrators (including characteristics of long-term care providers).

- **National research centers:** Create national research centers of excellence to coordinate and accelerate research, based on models from numerous other fields.
- **Research Translation:** Develop effective strategies to translate and disseminate information learned through research projects to the field, and translate questions faced by practitioners to researchers for study.
- **Successful outcomes:** Develop definitions for "success." An ongoing impediment to effective interventions is that the elder justice field lacks a definition of what constitutes successful outcomes. There is no benchmark against which to measure the success of various efforts. A critical research priority is to define what constitutes successful outcomes in elder abuse interventions and prevention efforts.

"Before we do research or data analysis, we've already thought through how it's going to be used. We think through a larger communications, government affairs, field operations and dissemination strategy ahead of time to determine whether all the effort is going to be worth it to reach our objectives."

– leadership interview

D. Universal Themes that Cut Across Phases and Domains

The following themes and topics arose in all phases of the project and do not fit neatly into any one of the four domains: direct services, education, policy and research. Participants indicated that it is critical to be cognizant of these issues in all efforts to address and prevent elder abuse:
Ageism: *Confront ageism through education, training, and public outreach.* By marginalizing older adults, our youth-oriented culture often ignores or fails to identify instances of elder abuse. Addressing ageism must be part of awareness and prevention strategies.

- **Ageism**
- **Awareness**
- **Brain health and functioning (of older people at risk)**
- **Brain health and functioning (of potential perpetrators)**
- **Caregiving (family; unpaid)**
- **Caregiving (paid; all settings)**
- **Coordination and multidisciplinary approaches**
- **Data collection and evaluation**
- **Diversity and inclusion**
- **Economic motives and consequences**
- **Knowledge development**
- **Long-term care**
- **Older peoples' voices**
- **Prevention**
- **Resources**
- **Screening**
- **Victim services**

Awareness: *Create a compelling narrative for the field.* We need to create narratives that articulate the depth and breadth of the problem, engage community members and professionals to respond effectively, clarify language used in connection with elder abuse, and provide accurate and useful information about how best to respond when elder abuse happens and how to prevent it in the first place.

Brain Health and Functioning of Potential Victims: *Expand knowledge and improve integration of cognitive capacity and mental health issues as they relate to elder abuse.* Many elder abuse victims have organic conditions, such as Alzheimer's and other forms of dementia, brain injuries or developmental disabilities that lead to diminished or limited cognitive capacity. Older people with diminished capacity are more susceptible to abuse, neglect, and financial exploitation. Some older victims may experience mental health issues, such as depression and post-traumatic stress disorder – especially those who have experienced ongoing, long-term trauma related to the elder abuse. We need additional research to understand how to evaluate cognitive capacity and mental health issues within the context of elder abuse and how to protect and provide a range of effective services to those with cognitive impairments and/or mental health issues.

Brain Health and Functioning of Potential Perpetrators: *Expand knowledge to inform policy and practice about the role of mental illness, substance abuse, intellectual disability, diminished capacity, and abuse history in potential perpetrators.* Preliminary research indicates that intervention with potential perpetrators may be more effective than intervention with victims in preventing elder abuse.[23] Those on the front lines also have observed that many elder abuse perpetrators have mental illness, diminished capacity, or substance abuse problems. An additional complicating factor arises when, for example, an adult child who was previously abused by a parent becomes that parent's caregiver. (A similar scenario also arises with abused partners becoming caregivers.)

Caregiving – by family and other informal caregivers: *Consider and address the critical nexus between elder justice and informal caregiving.* Stakeholders from family caregiving and elder justice fields rarely have focused on the common goals of their work, the difficult issue that some caregivers may be responsible for abuse, neglect, or exploitation, or how to raise awareness about and prevent such mistreatment. Few family caregivers receive the training or support they need.

Caregiving – by paid caregivers in any setting: *Consider and address the critical nexus between elder justice and a paid caregiving workforce.* Paid caregivers often receive insufficient training and support, raising the risk of poor care. In addition, although more people are receiving home and community-based care, such settings often lack protections and oversight, an important focus as increasing numbers of people become consumers of such care. To meet the demand of an aging population, there must be an expansion of the workforce with caregivers who are adequately trained, supervised, overseen, and paid, and who, among other things, know how to prevent, identify, report, and respond to elder abuse.

Coordination and Multidisciplinary Approaches: *Encourage coordination and the development of multidisciplinary approaches.* Understanding and addressing elder abuse will require enhanced coordination among players with diverse expertise and formation of multidisciplinary teams and approaches in direct services, education, policy, and research. Such multidisciplinary approaches should also be evaluated to identify the most effective among them.


Archstone Foundation

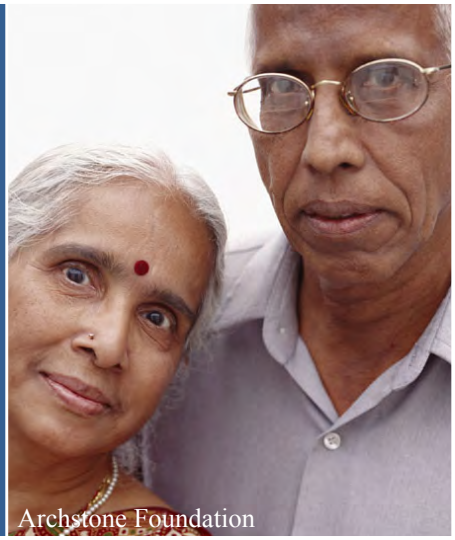
"Some messages about elder abuse are offensive. We need to craft messages for caregivers that make them feel respected and help them to recognize, acknowledge, and prevent elder abuse, and learn what supports are available."

– facilitated discussion

Data Collection and Evaluation: *Collect uniform national elder abuse data to inform efforts to prevent and respond to the problem.* It is difficult to mount an effective response to a problem about which we know so little. The child abuse and domestic violence fields have collected data for decades that have revealed the nature and dimensions of those problems and informed and shaped more effective responses. However, federal law only began requiring the collection of elder abuse data in 2005. In 2013, both HHS and DOJ were engaged in complementary projects to begin collecting data on elder abuse reported to APS. Those projects are an important first step towards achieving a better understanding of elder abuse. But APS data are only a subset of all data relevant to elder abuse. (They do not include health, law enforcement, financial, or medical examiner data, for example.) And collecting pilot data is a first step to nationwide data collection. Comprehensive data collection is critical to inform efforts to detect, respond to, and prevent elder abuse, to shape policy, and to allocate resources where they're most needed.

"I don't think elder abuse is perceived as an issue by a lot of people. Even though there's clearly underreporting of child maltreatment, it's still perceived as an issue. People know that it happens and feel some sense of obligation to report it, at least some circumstances. People see elder abuse as a problem, nor understand the importance of reporting. So we don't even have mediocre data."

– leadership interview


Archstone Foundation

Diversity and Inclusion of Underrepresented and Underserved Populations: *Address and integrate the unique needs of older people related to race, ethnicity, gender, age, national origin, language, literacy, disability, religion, sexual orientation, socio-economic status, and family structures.* The experience and context of elder abuse may differ based on the identities – cultural, ethnic, gender, racial, religious, sexual orientation, etc. – of both victim and abuser – and awareness and respect for these diverse identities must be integrated into all aspects of elder abuse work. As the field grows, professionals and programs must ensure that their reach – in services, education, policy-making, data collection, and research – extends to and includes traditionally underrepresented and underserved populations.

Economic Motivations and Consequences: *Investigate the many economic causes and consequences of elder abuse.* Many elder abuse cases are financially motivated, and financial exploitation and other types of elder abuse often occur in the same case.[24] We are learning more about financial capacity, especially in mild cognitive impairment,[25] and how it makes older

people much more vulnerable to mistreatment. The financial services industry and public agencies addressing economic issues and consumer protection have interests in addressing financial exploitation, and these efforts should be coordinated. Additionally, while the high cost of elder abuse has not yet been calculated, it is estimated to be in the many billions of dollars for individuals, families, communities, states, the financial services industry, businesses, and government programs, such as Medicaid and Medicare.[26] All of these economic aspects of elder abuse merit attention.

Knowledge Development: *Conduct research to expand knowledge to inform responses to elder abuse.* We need more research, evaluation, and data collection to inform: (1) whether programs, laws and treatments work; (2) the signs of elder abuse; (3) how to assess risk; (4) the nature and dimensions of different aspects of the problem; (5) how functional impairments to vision, hearing, and mobility impact vulnerability and add to the risk being victimized; (6) how to define success; and (7) how to fashion interventions, laws, and messages that accomplish what they are intended to accomplish.

Long-term Care: *Strengthen quality long-term services and supports in homes, community-based, and institutional long-term care settings.* Quality of care can be improved by strengthening provider training; coordinating care; bolstering oversight through survey, certification, and state licensing agencies; implementing federal and state standards; and increasing support for consumers (through programs like long-term care ombudsmen). Additionally, stakeholders must examine how to shape and implement policies that better prevent, detect, and address all types of abuse, neglect, and exploitation of long-term care consumers.

Older People's Voices: *Incorporate the voices of older adults in shaping the response to elder abuse.* To the extent possible, older adults, especially those victimized, should be involved in and recruited for leadership positions in elder justice efforts and their voices should be included.

"Diversity and cultural issues cut across all aspects of elder abuse, including the definition of whether someone has been abused. But in deciding how best to respond, there's a fine line between 'respect everyone's culture,' and 'everyone has the right to live in safety without harm.' Dignity and respect are fundamental."

– facilitated discussion

Eric Montfort

Prevention: *Develop knowledge and initiatives regarding prevention of elder abuse.* The field would benefit from studying what has worked in other fields and working with prevention experts on issues such as child abuse, domestic violence, sexual assault, smoking, and traffic safety (e.g., seat belt use and drunk driving).

Resources: I*ncrease the allocation of resources to the field of elder abuse.* Every aspect of elder abuse research, policy, practice, and training is undermined by a dire and chronic dearth of resources. Existing federal laws should be fully funded and other public and private funders must allocate resources to this problem if we are to implement the policy, practice, research, and training priorities described in this document.

Yves Picq

"We know a whole range of risk factors for child maltreatment, from economic to social and environmental issues to childcare, to support services.... There are incredible opportunities for primary prevention in elder abuse. But you have to start thinking – what are the risk factors? What are the precursors? What can you do to influence individual behavior? What can you do to create a social environment that has a prevention quality to it? What kind of services can you create for elders that diffuse or reduce stress levels of caretakers? And, what can you do with health care providers to maximize cognitive ability for as long as possible?

All of those kinds of things are linked to preventing elder abuse...." The ability to support safety, to enhance nurturing, to teach nurturing skills, to promote connectedness, all of that kind of stuff mediates risk and creates protective factors."

– leadership interview

Screening: *Improve the practice of and tools used in screening for elder abuse.* To prevent ongoing abuse and ameliorate current suffering, we need to increase our ability to identify and detect elder abuse, both at the population level and also in one-on-one interactions between older people and direct service providers and first responders. This requires research to validate screening tools for different settings, training of professionals in how to use them and policy initiatives promoting screening when appropriate. Factors such as privacy, confidentiality, mandatory reporting, cognitive capacity, setting, training needs, and cultural variation should be taken into consideration in the development and use of screening tools. Improved screening will identify increased numbers of victims whose needs will only be met if additional resources are allocated. Identifying more victims but then not serving their needs poses complex ethical dilemmas that should be thoughtfully addressed but not serve as an impediment to improving screening practices.

Victim Services: *Evaluate existing victim services for best practices and pilot additional services to address the specific needs of older victims; integrate best practices into all services.* Core services designed to reach out to and address trauma, safety and the specific needs of older victims are integral. Existing, ongoing services should be evaluated and modified to reflect best practices in serving older victims. New pilots should be developed to identify ways to most effectively serve older victims. Policies are needed to ensure that victim services are provided to older adults. Training for service providers is needed to address the unique needs of older victims. Older adults also require certain services that are not designed specifically for elder abuse victims (e.g., transportation, home delivered meals, victim advocates in the court, prosecution, and law enforcement systems, etc.).


Gina Bower Photography

"Look for natural allies outside the field: financial institutions, criminal justice, long-term care, housing, the aging network, victim services. Often they know it's an issue but not how to get involved."

– leadership interview

NEXT STEPS AND CONCLUSION

The diverse subject matter experts who participated in this project found the meetings and calls to be so valuable that they decided to continue working together, as an initial matter on dissemination of this document and furthering implementation of the priorities identified in this project. To that end, they designated a provisional Elder Justice Roadmap Steering Committee. Other ongoing goals include: continuing and coordinating the implementation work; reaching out to policy-makers, funders and others to explore ways to further the priorities identified in this document; and fostering ongoing communication on these issues. Those who draw on this Roadmap to set and implement priorities are encouraged to report their experience and progress to the Elder Justice Roadmap Steering Committee by emailing elderjusticeroadmap@gmail.com.

"To the extent that things happen at different levels – federal, state, local, and so on, it seems to me that consciousness-raising is a top priority at this juncture because this issue is not on the radar of most people. But given that it's an aging society, there will be more of this. It's really worth doing but requires staff."

– leadership interview


Microsoft

Conclusion

The *Elder Justice Roadmap* is a groundbreaking partnership – among those who work primarily to address elder abuse and critical allies in related fields – to apply a wider lens to elder abuse in drafting this first national strategic plan for elder justice. This document reflects priorities that hundreds of practitioners identified as important and leading experts deemed critical and attainable. All participants in this project recognize that the priorities listed above are not the only important ones. All 121 ideas offered by stakeholders are listed in Appendix D for those wishing to use this document to inform their own priority-setting, action planning, and implementation efforts to reduce the blight of elder abuse through efforts at the local, state, and national levels.

Elder abuse is a problem with solutions – some complex and others simple and within reach. The vast suffering, cost, and dislocation caused by elder abuse demand a commensurate investment of resources and attention. This project steers a course toward a long-needed strategic approach to reducing elder abuse. There is a role for everyone. The time to act is now.

Endnotes

1. The Elder Justice Coordinating Council was created in the Elder Justice Act of 2010. The Council, which is chaired by the Secretary for Health and Human Services in consultation with the Attorney General and with the participation of other federal agencies, is responsible for coordinating activities related to elder abuse, neglect, and exploitation across the federal government.
2. Lifespan of Greater Rochester, Inc., Weill Cornell Medical Center of Cornell University, & New York City Department for the Aging. (2011). *Under the Radar: New York State Elder Abuse Prevalence Study. Self-reported prevalence and documented case surveys* [Final Report]. Retrieved March 24, 2014, from http://www.lifespan-roch.org/documents/UndertheRadar051211.pdf; Acierno, R., Hernandez, M. A., Amstadter, A. B., Resnick, H. S., Steve, K., Muzzy, W., & Kilpatrick, D. J. (2010). Prevalence and correlates of emotional, physical, sexual, and financial abuse and potential neglect in the United States: The National Elder Mistreatment Study. *American Journal of Public Health*, *100*(2), 292-297. The New York State prevalence study found rates of about 7.6% (p. 32), whereas the Acierno study found rates between 11 and 14%. (p. 294). Thus, this report uses "about one in ten."
3. Wiglesworth, A., Mosqueda, L., Mulnard, R., Liao, S., Gibbs, L., & Fitzgerald, W. (2010). Screening for abuse and neglect of people with dementia. *Journal of the American Geriatrics Society*, *58*(3), 493-500. This study, based on 159 dyads of people with dementia and their caregivers, concluded that 47.3% of people with dementia were abused or neglected. Researchers in this study did not screen for financial exploitation. Several international studies and one Florida study similarly have found high prevalence rates (34-62%) of abuse among people with dementia living in home and community settings. *See* Cooney, C., Howard, R., & Lawlor, B. (2006). Abuse of vulnerable people with dementia by their carers: Can we identify those most at risk? *International Journal of Geriatric Psychiatry*, *21*(6), 564-571. (52% overall, physical abuse 20%; psychological abuse 42.5%; neglect 4%; N=82); Cooper, C., Selwood, A., Blanchard, M., Walker, Z., Blizard, R., & Livingston, G. (2009). Abuse of people with dementia by family caregivers: Representative cross sectional survey. *British Medical Journal*, *338*, b155. (34% overall; physical abuse 4%; psychological abuse 33%; N=220); VandeWeerd, C., & Paveza, G. J. (2005). Verbal Mistreatment in Older Adults: A Look at Persons with Alzheimer's Disease and Their Caregivers in the State of Florida. *Journal of Elder Abuse & Neglect*, *17*(4), 11-30; (psychological abuse only 60.1%; N=254); Yan, E., & Kwok, T. (2010). Abuse of older Chinese with dementia by family caregivers: An inquiry into the role of caregiver burden. *International Journal of Geriatric Psychiatry*, *26*(5), 527-535, (n/a.; overall 62%; physical abuse 18%; psychological abuse 62%; N=122). Dong, X. Q., Chen, R., & Simon, M. A. (2014). Elder Abuse and Dementia: A Review of the Research and Health Policy. *Health Affairs*, *33*(4), 642-649. Samsi, K., Manthorpe, J., & Chandaria, K. (2014). Risks of financial abuse of older people with dementia: findings from a survey of UK voluntary sector dementia community services staff. *The Journal of Adult Protection*, *16*(3), (just published). Dong, X. Q., Simon, M. A., Rajan, K., & Evans, D. A. (2011). Association of Cognitive Function and Risk for Elder Abuse in a Community-Dwelling Population. *Dementia and Geriatric Cognitive Disorders*, *32*(3), 209-215. Selwood, A., & Cooper, C. (2009). Abuse of people with dementia. *Reviews in Clinical Gerontology*, *19*(1), 35-43.
4. Widera, E., Steenpass, V., Marson, D., & Sudore, R. (2011). Finances in the Older Patient with Cognitive Impairment. "He Didn't Want Me to Take Over." *Journal of the American Medical Association*, *305*(7), 698-706. (p. 700). (*See also,* Manthorpe, J., Samsi, K., & Rapaport, J. (2012). Responding to the financial abuse of people with dementia: a qualitative study of safeguarding experiences in England. *International Psychogeriatrics*, *24*(9), 1454-1464; Samsi, K., Manthorpe, J., & Chandaria, K. (2014). Risks of financial abuse of older people with dementia: findings from a survey of UK voluntary sector dementia community services staff. *The Journal of Adult Protection*, *16*(3), (just published).
5. **In nursing homes:** We note that the data relating to prevalence of abuse and neglect in long-term care settings are somewhat dated and require the attention of and updating by researchers. U.S. General Accounting Office. (1998). *California Nursing Homes: Care Problems Persist Despite Federal and State*

Oversight. (GAO/HEHS-98-202.) Washington, DC: Author; U.S. General Accounting Office. (1999). *Nursing Homes: Additional Steps Needed to Strengthen Enforcement of Quality Standards*. (GAO/HEHS-99-46). Washington, DC: Author; U.S. General Accounting Office. (1999). *Nursing Homes: Proposal to Enhance Investigation of Poorly Performing Homes Has Merit.* (GAO/HEHS-99-157.) Washington, DC: Author; U.S. General Accounting Office. (1999). *Nursing Homes: HCFA Initiatives to Improve Care Are Under Way but Will Require Continued Commitment*. (GAO/T-HEHS-99-155.) Washington, DC: Author; U.S. General Accounting Office. (1999). *Nursing Home Oversight: Industry Examples Do Not Demonstrate That Regulatory Actions Were Unreasonable*. (GAO/HEHS-99-154R.) Washington, DC: Author; U.S. General Accounting Office. (1999). *Nursing Care: Enhanced HCFA Oversight of State Programs Would Better Ensure Quality.* (GAO/HEHS-00-6.) Washington, DC: Author; U.S. General Accounting Office. (2002). *Nursing Homes: More Can Be Done to Protect Residents*. (GAO-02-312.) Washington, DC: Author. U.S. General Accounting Office. (2003). *Nursing Home Quality: Prevalence of Serious Problems, While Declining, Reinforces Importance of Enhanced Oversight*. (GAO-03-561.) Washington, DC: Author; U.S. Government Accountability Office. (2007). *Nursing Homes: Efforts to Strengthen Federal Enforcement Have Not Deterred Some Homes from Repeatedly Harming Residents*. (GAO-07-241). Washington, DC: Author; U.S. Government Accountability Office. (2008). *Nursing Homes: Federal Monitoring Surveys Demonstrate Continued Understatement of Serious Care Problems and CMS Oversight Weaknesses*. (GAO-08-517.) Washington, DC: Author; U.S. Government Accountability Office. (2010). *Poorly Performing Nursing Homes: Special Focus Facilities Are Often Improving, But CMS's Program Could Be Strengthened*. (GAO-10-197). Washington, DC: Author; U.S. Government Accountability Office. (2010). *Nursing Homes: Some Improvement Seen in Understatement of Serious Deficiencies, but Implications for the Longer-Term Trend Are Unclear*. (GAO-10-434R.) Washington, DC: Author; Pillemer, K., & Moore, D. (1989). Abuse of Patients in Nursing Homes: Findings from a Survey of Staff. *The Gerontologist*, *29*(3), 314-320; MacDonald, P. (2000). *Make a Difference: Abuse/neglect Pilot Project*. Danvers, MA: North Shore Elder Services; Atlanta Legal Aid Society. (2004). *The Silenced Voice Speaks Out: A Study of Abuse and Neglect of Nursing Home Residents*. Atlanta, GA: Author. Retrieved May 27, 2014, from http://www.atlantalegalaid.org/abuse.htm; Harrington, C., Carillo, H., Blank, B. W., & O'Brien, T. (2010). *Nursing Facilities, Staffing, Residents, and Facility Deficiencies, 2004-2009*. San Francisco: Department of Social and Behavioral Sciences, University of California. Retrieved May 27, 2014, from http://www.pascenter.org/documents/OSCAR_complete_2010.pdf. *See also,* additional reports authored by the U.S. General Accountability Office and the HHS Office of Inspector General relating to facilities. Office of Inspector General, Department of Health and Human Services. (1990). *Resident abuse in nursing homes: Understanding and preventing abuse*. (OEI-06-88-00360.) Washington, D.C.: Department of Health and Human Services; Office of Inspector General, Department of Health and Human Services. (2003). *State Ombudsman Data: Nursing Home Complaints*. (OEI-09-02-00160). Washington, D.C.: Department of Health and Human Services; Office of Inspector General, Department of Health and Human Services. (2013). *Medicare Nursing Home Resident Hospitalization Rates Merit Additional Monitoring*. (OEI-06-11-00040.) Washington, DC: Department of Health and Human Services; Office of Inspector General, Department of Health and Human Services. (2006). *Nursing Home Complaint Investigations*. (OEI-01-04-00340.) Washington, DC: Department of Health and Human Services; Office of Inspector General, Department of Health and Human Services. (1999). *Nursing Home Survey and Certification: Deficiency Trends*. (OEI-02-98-00331.) Washington, D.C.: Department of Health and Human Services; *Nursing Home Deficiency Trends and Survey and Certification Process Consistency*. (OEI-02-01-00600.) Washington, DC: Department of Health and Human Services; Office of Inspector General, Department of Health and Human Services. (2008). *Trends in Nursing Home Deficiencies and Complaints*. (OEI-02-08-00140.) Washington, D.C.: Department of Health and Human Services; Office of Inspector General, Department of Health and Human Services. (1999). *Quality of Care in Nursing Homes: An Overview*. (OEI-02-99-00060.) Washington, DC: Department of Health and Human Services; Office of Inspector General, Department of Health and Human Services. (1990). *Resident Abuse in Nursing Homes: Resolving Physical Abuse Complaints*. (OEI-06-88-00361.) Washington, DC: Department of Health and Human Services; Office of

Inspector General, Department of Health and Human Services. (1998). *Safeguarding Long-Term Care Residents*. (A-12-97-00003.) Washington, DC: Department of Health and Human Services; Office of Inspector General, Department of Health and Human Services. (1999). *Long Term Care Ombudsman Program: Complaints Trends*. (OEI-02-98-00350.) Washington, DC, Department of Health and Human Services, Office of Inspector General, Department of Health and Human Services. (2014). Adverse Events in Skilled Nursing Facilities: National Incidence Among Medicare Beneficiaries. (OEI-06-11-00370.) Washington, DC: Department of Health and Human Services. HHS Office of Inspector General (OIG) has cited almost 3,000 reports addressing mostly facility issues; this endnote can not capture them all. *See* OIG website at http://oig.hhs.gov/. This note does not include reports about hospices, psychotropic drugs, specific settlements by DOJ or HHS or OIG's Corporate Integrity Agreements. **In non-nursing home facilities:** Hawes, C. & Kimball, A. M. (2010). *Detecting, Addressing, and Preventing Elder Abuse in Residential Care Facilities: Report to the National Institute of Justice*. Retrieved May 27, 2014, from www.ncjrs.gov/pdffiles1/nij/grants/229299.pdf; Philips, L., & Guo, G. (2011). Mistreatment in Assisted Living Facilities: Complaints, Substantiations, and Risk Factors. *The Gerontologist*, *51*(3), 343-353; Castle, N. (2013). *An Examination of Resident Abuse in Assisted Living Facilities*. Final Report to the National Institute of Justice. Retrieved May 27, 2014, from https://www.ncjrs.gov/pdffiles1/nij/grants/241611.pdf; Castle, N. G. & Beach, S. (2013). Elder Abuse in Assisted Living. *Journal of Applied Gerontology*, *32*(2), 248-267, concluding, "We could not objectively verify the cases of abuse described in the survey, still, they give a first indication that staff abuse may occur in AL. This may be significant given the large number of ALs in the United States and may influence the health, quality of life, and safety of many residents"; Castle, N. G., Ferguson-Rome, J., & Teresi, J. A. (2013). Elder abuse in residential long-term care: An update to the 2003 National Research Council Report. *Journal of Applied Gerontology*, (just published).

6. Lifespan of Greater Rochester, Inc., Weill Cornell Medical Center of Cornell University, & New York City Department for the Aging. (2011). *Under the radar: New York State Elder Abuse Prevalence Study. Self-reported prevalence and documented case surveys* [Final Report]. Retrieved March 24, 2014, from http://www.lifespan-roch.org/documents/UndertheRadar051211.pdf. (p. 5, 42).
7. Beach, S. R., Schulz, R., Castle, N. G., & Rosen, J. (2010). Financial exploitation and psychological mistreatment among older adults: Differences between African Americans and non-African Americans in a population-based survey. *The Gerontologist*, *50*(6), 744-757; Smith, D. B., Feng, Z, Fennell, M. L., Zinn, J. S., & Mor, V. (2007). Separate and Unequal: Racial Segregation In Quality Across U. S. Nursing Homes. *Health Affairs*, *26*(5), 1448-1458; *see also* Zuckerman, I. H., Ryder, P. T., Simoni-Wastila, L., Shaffer, T., Sato, M., Zhao, L., & Stuart, B. (2008). Racial and Ethnic Disparities in the Treatment of Dementia Among Medicare Beneficiaries. *Journals of Gerontology, Series B, Psychological Sciences and Social Sciences*, *63*(5), S328-S333.
8. DeLiema, M., Gassoumis, Z. D., Homeier, D. C., & Wilber, K. H. (2012). Determining prevalence and correlates of elder abuse using promotores: low-income immigrant Latinos report high rates of abuse and neglect. *Journal of the American Geriatric Society*, *60*(7), 1333-1339.
9. Lachs, M., Williams, C., O'Brien, S., Hurst, L., & Horwitz, R. (1997). Risk Factors for Reported Elder Abuse and Neglect: A Nine-Year Observational Cohort Study. *The Gerontologist*, *37*(4), 469-474; Johannesen, M. & LoGuidice, D. (2013). Elder abuse: A Systematic Review of Risk Factors in Community-Dwelling Elders. *Age & Ageing*, *42*(3), 292-298.
10. Lifespan of Greater Rochester, Inc., Weill Cornell Medical Center of Cornell University, & New York City Department for the Aging. (2011). *Under the radar: New York State Elder Abuse Prevalence Study. Self-reported prevalence and documented case surveys* [Final Report]. Retrieved March 24, 2014, from http://www.lifespan-roch.org/documents/UndertheRadar051211.pdf. (p. 52).
11. Lachs, M. S., Williams, C. S., O'Brien, S., Pillemer, K.A., & Charlson, M. E. (1998). The mortality of elder mistreatment. *Journal of the American Medical Association*, *280*(5), 428-432. (p. 431).
12. Lachs, M., Williams, C. S., O'Brien, S., & Pillemer, K. (2002). Adult Protective Service use and nursing home placement. *The Gerontologist*, *42*(6), 734-739. (pp. 736-737).

13. Dong, X. Q., & Simon, M. A. (2013). Elder abuse as a risk factor for hospitalization in older persons. *JAMA Internal Medicine*, *173*(10), 911-917.
14. Centers for Medicare and Medicaid Services. (2001). *Appropriateness of Minimum Nurse Staff Ratios in Nursing Homes, Phase II Final Report*. Baltimore, MD: Author.(pp. 1-7)
15. Office of Inspector General, Department of Health and Human Services. (2014). Adverse Events in Skilled Nursing Facilities: National Incidence Among Medicare Beneficiaries. (OEI-06-11-00370.) Washington, DC: Department of Health and Human Services.; *see also*, Office of Inspector General, Department of Health and Human Services. (2014). Medicaid Fraud Control Units Fiscal Year 2013 Annual Report. (OEI-06-13-00340). Washington, DC: Department of Health and Human Services.
16. Gunther, J. (2011). *The Utah cost of financial exploitation*. Salt Lake City, UT: Utah Division of Aging and Adult Services. Retrieved March 12, 2014, from www.dhs.utah.gov/pdf/utah-financial-exploitation-study.pdf. Gunther, J. (2012). *The 2010 Utah Cost of Financial Exploitation*. Salt Lake City, UT: Utah Division of Aging and Adult Services.
17. Fulmer, T., Rodgers, R. F., & Pelger, A. (2013). Verbal Mistreatment of the Elderly. *Journal of Elder Abuse & Neglect, 26*(4), 351-364; Mouton, C. P., Rodabough, R. J., Rovi, S. L. D., Robert, G., Brzyski, R. J., & Katerndahl, D. A. (2010). Psychosocial Effects of Physical and Mental Abuse in Post-Menopausal Women. *Annals of Family Medicine, 8*, 206-213.
18. Schulz, R., & Beach, S. (1999). Caregiving as a Risk Factor for Mortality: The Caregiver Health Affects Study. *JAMA*, *282*(23), 2215-2219 (reporting that participants who were providing care and experiencing caregiver strain had mortality risks that were 63% higher than noncaregiving controls); MetLife Mature Market Institute. (2011). *The MetLife Study of Caregiving: Costs to Work Caregivers: Double Jeopardy for Baby Boomers Caring For Their Parents*. Westport, CT: MetLife Mature Market Institute (estimating losses of $303,880 on average in lost income and benefits over a caregiver's lifetime including about $115,900 in wages, $137,980 in Social Security benefits, and conservatively $50,000 in pension benefits.
19. Vera Institute of Justice. (2011). *Guardianship Practice: A Six-Year Perspective*. Brooklyn, NY: Author. (p. 7). Retrieved May 27, 2014, from http://www.vera.org/sites/default/files/resources/downloads/Guardianship-Practice-a-Six-Year-Perspective.pdf. *Note:* This Vera project indicated that effective guardianship practices that aim to prevent unnecessary institutionalization and avoid costly crises can save Medicaid dollars. By contrast, abusive guardianships squander scarce court and family recourses and lead to expensive litigation and preventable acute care and crises. When it comes to elder abuse, guardianships can be either sword or shield – that is, when administered properly, they can help prolong independence and prevent elder abuse, but, wrongfully implemented can result in older people losing their assets or liberty.
20. U.S. Government Accountability Office. (2011). *Stronger Federal Leadership Could Enhance the Response to Elder Abuse*. GAO-11-208. Washington, DC: Author.
21. *See* Appendix D for list of statements.
22. Lifespan of Greater Rochester, Inc., Weill Cornell Medical Center of Cornell University, & New York City Department for the Aging. (2011). *Under the Rada*r: New York State Elder Abuse Prevalence Study. Self-reported prevalence and documented case surveys [Final Report]. Retrieved May 27, 2014, from http://www.lifespan-roch.org/documents/UndertheRadar051211.pdf.
23. Anetzberger, G. (2000). Caregiving: Primary Cause of Elder Abuse? *Generations*, *24(*11), 46-51.
24. Jackson, S. L., & Hafemeister, T. L. (2011). *Financial Abuse of Elderly People vs. Other Forms of Elder Abuse: Assessing Their Dynamics, Risk Factors, and Society's Response*. Final Report Presented to the National Institute of Justice. Retrieved May 27, 2014, from https://www.ncjrs.gov/pdffiles1/nij/grants/233613.pdf
25. Griffith, H. R., Belue, K., Sicola, A., Krzywanski, S., Zamrini, E., Harrell, L., & Marson, D. C. (2003). Impaired financial abilities in mild cognitive impairment: A direct assessment approach. *Neurology 60* (3), 449-457.
26. Connolly, M. T. (2012). High-Cost Blind Spot. *Public Policy and Aging Report*, *22*(1), 8; Gunther, J. (2011). *The Utah Cost of Financial Exploitation*. Salt Lake City, UT: Utah Division of Aging and Adult Services.