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:

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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

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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


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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

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

"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.

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"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

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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.


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"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

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"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


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- **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

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.


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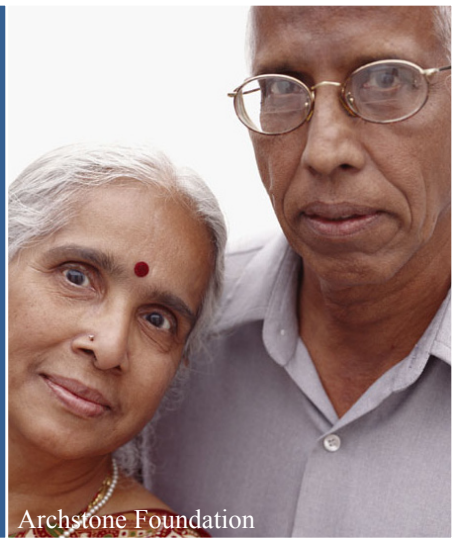
"Some messages about elder abuse are offensive. We need to craft messages for caregivers that make them feel respected and help them to recognize, acknowledge, and prevent elder abuse, and learn what supports are available."

– 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.
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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.
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The Elder Justice Roadmap Appendices

APPENDICES

APPENDIX A. Definition of Elder Abuse

After studying many options, the following definition of *elder abuse* was used for this project:

Elder abuse is –

- *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.*

The reasons for using this definition/description fall into several categories:

Age: We used the term "older person" rather than designating a specific age because we did not want to limit stakeholders' responses. By not specifying a precise age, participants could respond regardless of the age used in the laws or protocols governing their state, tribe, agency, or program.

Younger vulnerable adults: Some definitions of *elder abuse* include abuse not only of older people but also of younger vulnerable adults ages 18 to 60 (or 18 to 65, depending on the jurisdiction). It is conceptually confusing and factually inaccurate to say that that the abuse of younger adults, such as a person age 18, constitutes *elder* abuse. Although similar and overlapping issues often relate to both older adults and younger people (usually described in laws as "vulnerable" or "adults with disabilities") who are victimized, there may also be significant differences. For the purposes of this project, we believed it was important not to conflate those populations or assume that the needs, wishes, priorities, and considerations relating to older and younger victimized people were the same.

That said, critical players in the elder abuse field – such as some Adult Protective Services, long term care ombudsman programs, and health providers, as well as the Administration for Community Living – have missions, jurisdictions, clients, and patients that include *all* adults, regardless of age. We recognize the overlap in the issues facing older and younger populations, that there often is good reason to provide seamless services across ages, and that those who serve both populations should not be forced to choose between them, for example, by conditioning resources on age.

Types of abuse: In developing the definition of elder abuse for this project, we used broad terms that describe the types of abuse older people experience (e.g., physical, sexual, or psychological abuse, financial exploitation, neglect). Though abandonment is a form of neglect, we also included it because some states refer to it separately in their elder abuse laws.

Self-neglect: Though some definitions of elder abuse include *self-neglect* we did not because conceptually, one person being mistreated by another is fundamentally a different type of phenomenon than a person neglecting him or herself. Conflating abuse, neglect, or exploitation that one actor inflicts on another with situations involving a sole actor is confusing and counter-intuitive to many stakeholders. That said, self-neglect (like mental illness and cognitive impairment) often is associated with elder abuse (including as a potential risk factor or consequence) and thus is a critical factor to consider in any

discussion about the problem. In addition, some agencies that respond to allegations of elder abuse also provide services to individuals who neglect themselves.

***Relationship of trust*:** Some definitions of elder abuse have required that the perpetrator be someone in a "relationship of trust" with the victim. This excludes older people victimized wholly or in part because of their actual or perceived age or disability where the victimization did not occur in *a relationship of trust*. The definition in this project included older people targeted based on their age or disability even where no relationship of trust exists. We used this broader definition in part to not exclude a range of stakeholders whose role is not conditioned on a *relationship of trust*, for example those responding to financial exploitation and consumer protection issues. Additional discussion is needed to address how responders can or should determine whether a relationship of trust exists or targeting has occurred.

Setting: When elder abuse occurs, victims suffer regardless of setting of the mistreatment, identity of perpetrator, or the professionals and entities with jurisdiction or responsibility to respond. Inadequate response or coordination among responders, or during transitions from one setting to another, can exacerbate vulnerability to and duration of elder abuse. In addition, given the emphasis on providing care, services, and assistance in a person-centered manner, it is increasingly important to have definitions of abuse, neglect, and exploitation that apply across settings (home, community, and facilities). Thus, for this project, we did not limit the definition of elder abuse to any one setting.

Entities as perpetrators: Elder abuse can be perpetrated by entities such as long-term care institutions, fraudulent financial organizations, corporations, and others. Abuse in these cases may be deliberate (e.g., scams targeting older clients or long-term care entities that knowingly siphon off funds intended for resident care), or it may occur as a result of an entity failing to affirmatively act to protect the safety of older adults and their assets.

***Definition versus description*:** Individuals, entities, and documents use different *definitions* of elder abuse depending on discipline and context. For example, a *definition* of elder abuse for purposes of a criminal law might include the concept of knowledge or intent. Our aim in this project was to employ a definition that *described* the core conduct included in elder abuse so that it could be used in various contexts and by people in many applicable disciplines, understanding that additional specification might be necessary in some applications.

***

In developing the definition used in this project, we considered and built on many of the varied existing definitions, including: those found in laws (such as the federal Elder Justice Act, Older Americans Act, and Violence Against Women Act, various states' laws, and others), and those developed by various entities such as the National Academy of Sciences, the Administration on Aging (through the National Center on Elder Abuse), the Centers for Disease Control and Prevention (not publicly released or in use), and the New York City Elder Abuse Center (a definition rigorously vetted by a broad range of stakeholders and that, subjected to the crucible of daily application by myriad systems for three years, has held up well).

APPENDIX B. Contributors to the Elder Justice Roadmap

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Names listed on pages 36-52

The 750 Stakeholders

750 stakeholders were asked to identify ways to improve how we address elder abuse. Their views are the foundation of this Roadmap. The ideas they contributed were synthesized into the 121 statements listed in Appendix D that were further honed in subsequent phases of the project. Those stakeholders also sorted and rated the ideas as described in Appendices C, E and F. Because the stakeholders were promised confidentiality, their names are not listed in this document although demographic information about them can be found in Appendix I.

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APPENDIX C. Concept Mapping Process and Methodology

The *Elder Justice Roadmap Project* involved a multi-step process, including convening and working with the subject matter experts who provided guidance throughout the project; seeking views from hundreds of stakeholders to develop the concept map; exploring six key topics in greater depth with groups of experts; seeking strategic guidance from thought-leaders in the elder justice and related fields; identifying relevant resources to inform and supplement the project; seeking guidance from experts to identify "first wave" priorities and develop action plans to implement them; identify additional high priorities by each of the four domains; identify universal themes that cut across the domains; and drafting preliminary and final documents summarizing the process, findings, and recommendations elicited in this project.

The Department of Justice and Department of Human Services provided funding for this project. Concept Systems, Inc. received the contract to create the concept map and worked closely with three subject matter experts, Bonnie Brandl, Risa Breckman, and Marie-Therese Connolly, and federal officials to guide the substantive aspects of the project and engage as broad a range of perspectives, stakeholders, and experts as feasible in developing the priorities described in this document.

Concept Mapping Process and Methodology

Concept mapping[1] is a mixed methods structured conceptualization approach that integrates familiar qualitative group processes (brainstorming, categorizing ideas, and assigning value ratings) with multivariate statistical analyses to help a group describe its ideas on any topic of interest and represent these ideas visually through a series of related maps. Concept mapping requires participants to brainstorm a set of statements relevant to the topic of interest, individually sort these statements into piles of similar content or themes, and rate each statement on one or more dimensions. Following these participatory activities, a sequence of multivariate statistical analyses is used to generate a series of maps that reveal a topology of thought resulting from the analysis of the participant data. Participants can then use these maps as a basis for further discussion and a framework for conclusions and action planning. The entire process is driven by the stakeholders themselves, ranging from initial brainstorming, to the eventual identification and naming of clusters, to interpretation and analysis of these maps.

The following steps were taken to gather the necessary input and data to produce the concept map:

- **Establish the Focus Prompt:** To facilitate the collection of meaningful input, members of the Project Team developed a focus prompt to which stakeholders responded: *"To understand, prevent, identify, or respond to elder abuse, neglect, or exploitation we need…"*

[1] The methodology is described in detail in Kane and Trochim: Concept Mapping for Planning and Evaluation. 2007: Sage Publications, Thousand Oaks, CA. Concept mapping is a qualitative and quantitative process designed to engage key stakeholders in conversations to create consensus-based conceptual frameworks and to identify priorities. The use of concept mapping in this project is not intended to be scientific research, but rather a process to gather data from a large number of stakeholders to assist in building cohesion and developing strategy.

- **Participant Identification:** The project team and experts identified 750 individuals (stakeholders) to invite to participate, targeted for their knowledge of and involvement with various aspects of the elder justice field.
- **Idea Generation (Brainstorming):** Using the Concept System Global Max© software[2], participants generated over 686 ideas on a dedicated project website in response to the focus prompt.
- **Idea Synthesis:** The Project Team synthesized the ideas generated to a final set of 121 statements using the following criteria:
    - Honoring of the intent of the submission by attempting to include all relevant concepts in the final statement list;
    - Relevance to the stated focus question or within the scope of the question at hand;
    - Redundancy or duplication; and
    - Clarity of meaning.
- **Sorting and Rating:** The 750 stakeholders were invited to rate each of the final 121 statements along two dimensions: *Importance* (how relatively important each idea is to addressing elder abuse in the next five years, where 1=relatively unimportant and 5=extremely important) and *Feasibility* (how feasible it is to implement each idea within the next five years, where 1=not feasible and 5=extremely feasible)[3]. A subset of 250 of the 750 stakeholders who work particularly closely on issues related to elder abuse were also invited to sort the 121 ideas into groups or themes based on their perceived relatedness or similarity. Both the sorting and rating activities were also completed using a dedicated project website.
- **Participant Demographics:** Sorting and rating participants were asked to respond to a series of demographic questions upon completing the sorting and rating activities. These responses allowed the Project Team to ensure that the concept map reflected the input and perspectives of a wide range of professionals in the elder justice field. Descriptions of participant responses to the demographic questions can be found in Appendix I.

  Systems represented included:
    - Aging network (21%)
    - Faith-based (1%)
    - Financial services (1%)
    - Health care (8%)
    - Legal system (16%)
    - Mental health (2%)
    - Protective services (13%)
    - Social services (6%)
    - Victim services (12%)
    - Other (20%)

[2]Concept System Global Max© software is licensed through Concept Systems Incorporated, Ithaca, New York (http://www.conceptsystems.com).
[3] Many respondents indicated that in rating the statements on feasibility, the meaning of *feasibility* was unclear and their assessment of it variable or impossible.

Principal nature of participant work related to elder abuse included:

- Direct or frontline services (22%)
- Education/Training (29%)
- Policy (22%)
- Research (13%)
- Other (14%)

Primary geographic focus of participant work included:

- Local (30%)
- Statewide (25%)
- Nationwide (44%)
- Other (1%)

Concept Mapping Results

Overall, response rates were slightly lower than the average concept mapping project[4], with participation rates of 47% for the sorting task, 27% for the Importance rating and 20% for the Feasibility rating. (Respondents reported some confusion in rating by feasibility.) The absolute number of participants for each task, however, was considerably higher than the average number of participants in concept mapping needed to produce reliable results. These lower-than-average participation rates are mainly attributed to the larger-than-average stakeholder pool that was invited to participate in the sorting and rating activities.

Concept maps were produced to show the relationships among the 121 distinct ideas generated as part of the brainstorming process according to how stakeholders rated them.

[4] Rosas, S. R., & Kane, M. (2012). Quality and Rigor of the Concept Mapping Methodology: A Pooled Study Analysis. *Evaluation and Program Planning*, *35*(2), 236-245. The process did not allow identification of how many of the 750 persons invited to participate in brainstorming and rating actually received the email invitation. In some cases, the bulk email invitations went to junk mail and were not seen. In addition, it is not clear how many people who received the email actually responded. Due to privacy and confidentiality concerns, the brainstorming process only counts the number of responses, not the number of individuals who responded. Some individuals likely contributed multiple ideas, while others contributed none.

APPENDIX D. List of Stakeholders' Statements

The first phase of the project involved soliciting views from 750 stakeholders on ideas for addressing elder abuse by asking them to respond, as often as they wished, to the question:

"To understand, prevent, identify, or respond to elder abuse, neglect, or exploitation, we need…"

Their cumulative responses are synthesized and reflected in the following 121 statements. Each statement was assigned a random number to track it, (appearing in the left column below). Participants' ranking of the statements were used to create the concept map (see Appendices E and F). This chart lists the statements in numerical order. Their ranking by importance appears in the right column below. It is worth noting that on a rating scale from 0 to 5, with 5 being the most important, in fact, the difference in average rating between the statements deemed "least" to "most" important was narrow (from 2.86 – 4.54). Most participants assigned importance to most statements:

State-ment#	Statement *To understand, prevent, identify, or respond to elder abuse, neglect, or exploitation, we need…*	Average Importance Rating (1-5)
1	national incidence and prevalence research to measure all types of elder abuse.	3.99
2	protection from retaliation of individuals who report elder abuse in any setting.	3.74
3	affordable and accessible services to help older adults manage their finances, thereby reducing the risk of financial exploitation.	4.01
4	ethicists and philosophers to partner with policymakers, researchers, and practitioners in addressing ethical issues that arise in elder abuse cases, including how best to balance autonomy and safety.	3
5	to translate the questions and dilemmas faced by practitioners into research that can assist them.	3.43
6	research into the long term (longitudinal) nature of elder abuse for victims and perpetrators, and contextual factors (such as poverty or isolation) that can affect elder abuse.	3.55
7	to increase investigation and prosecution by State Attorneys General and Medicaid Fraud Control Units of elder abuse-related violations, such as Medicaid fraud, abuse and neglect in facilities, consumer protection initiatives targeting financial exploitation, and others.	4.02
8	to train practitioners to use evidence-based and promising screening and interventions that detect and address trauma and other mental health, behavioral health, and substance abuse issues.	4.17
9	prosecutors and prosecution units dedicated to pursuing elder abuse.	4.08
10	a vast increase in the number of health care professionals qualified to care for older people and to identify, address, and prevent elder abuse.	4.06
11	to provide caregivers with adequate support and services to develop competency and reduce stress.	3.73

12	to increase initiatives for primary and secondary prevention (such as social supports for older people).	3.71
13	the aging network to assign higher priority and more resources to addressing elder abuse, including through the integration of elder justice measures in all appropriate programs and initiatives.	4.01
14	less restrictive alternatives to guardianship and conservatorship that maximize autonomy while promoting security.	3.35
15	to test and integrate promising practices and research from related fields, such as child abuse and domestic violence, in elder justice work.	3.56
16	a well-funded national center on elder abuse with resources similar to those allocated for child abuse centers, and specialized resource centers for entities like Adult Protective Services, older victim services, the ombudsman program, legal services, guardianship, etc.	4.05
17	to evaluate the experience of older victims to assess how well victim safety is addressed, whether services are coordinated and seamless, and whether offenders are held accountable in a consistent way (similar to safety planning audits used in the domestic violence field).	3.75
18	courts to improve how they handle elder abuse cases and accommodate the needs of older people.	4.15
19	to develop curricula on aging for K-12 and higher education that emphasize the value of older adults, that well being in old age is of universal concern, and that other forms of family violence have a nexus to elder abuse.	3.05
20	research on the nexus between mental health and elder abuse, both for victims and perpetrators.	3.27
21	individuals and entities that address mental health, dementia, women's, and disability rights issues, as well as other related issues, to improve how they respond to the needs of elder abuse victims who also are their constituents.	3.56
22	research the rates of and connections between abuse, neglect, and exploitation at home and in facilities, and develop policy accordingly.	3.27
23	to ensure that quality information about preventing, identifying, and responding to elder abuse, (such as curricula and tool kits) is disseminated to professionals and the public.	3.91
24	to include older people's input in all aspects of elder justice efforts.	4.15
25	to develop and implement standards for the treatment of older inmates and suspects to prevent abuse.	2.94
26	the Centers for Disease Control and Prevention to recognize and address elder abuse as a serious public health issue, like child abuse and intimate partner violence, warranting comparable surveillance, prevention, and treatment programs.	4.14
27	systemic evaluation of existing laws and implementation practices to develop model laws and policy.	3.78
28	to research the impact and value of mandatory reporting.	3.09
29	research into the consequences of elder financial exploitation, such as potential declines in health and increased risk for other types of elder abuse.	3.64

30	to identify and resolve impediments to multidisciplinary coordination in elder abuse matters due to confidentiality, privacy, and other laws, regulations and protocols.	3.85
31	to improve law, policies, training, oversight, and data collection related to abuse of powers of attorney.	3.72
32	research to identify forensic markers to assist in the detection of elder abuse.	3.7
33	to ensure effective training on elder justice issues by developing, evaluating, and continuously updating curricula, and by training trainers to cultivate expertise.	3.85
34	to include questions about elder abuse on relevant professional licensing exams to encourage training and competency on elder justice issues.	3.81
35	more multidisciplinary teams throughout the country that have adequate support for facilitators and operations.	3.78
36	to test and develop a range of effective emergency and transitional housing and shelter options to better meet older victims' needs.	3.82
37	the Coordinating Council created by the Elder Justice Act to identify priorities, allocate resources, and coordinate efforts by the federal government in addressing elder abuse.	3.83
38	to increase scrutiny and accountability of representative payees and develop appropriate responses to abuse of the representative payee system.	3.64
39	research and policy regarding the role of diminished, variable or questionable capacity in increasing the risk of elder abuse.	3.44
40	to improve reporting by mandatory reporters.	3.36
41	to review existing systems, programs, and protocols to identify and address systemic gaps and overlaps.	3.52
42	to educate all types of caregivers about elder abuse.	3.78
43	research to identify perpetrator characteristics, including why they abuse and how to develop preventive interventions.	3.38
44	to develop initiatives to translate research into policy and practice that more effectively addresses elder abuse.	3.69
45	increased awareness of and efforts to detect, prevent and respond to elder sexual assault in all settings.	3.92
46	to raise awareness about diminished cognitive capacity and its high correlation with elder abuse to inform research, policy, and practice.	3.79
47	a federal Office of Elder Justice, comparable to federal offices dedicated to addressing child abuse and violence against women.	3.89
48	better methods for investigating and measuring the prevalence of elder abuse in residential care facilities, and other non-nursing home settings.	3.77
49	research on elder abuse in different cultures (such as definitions, risk factors, interventions, prevention, and prevalence) to inform policy and practice.	3.43
50	research to understand the causes of elder abuse and conceptual models that inform practice, such as greed, power and control, and caregiver stress.	3.3
51	improved identification and tracking of elder abuse cases by law enforcement and prosecutors.	4.06

52	to develop comprehensive, consistent definitions of elder abuse, neglect, and exploitation to be used in various contexts such as in laws, critical care, and services.	3.9
53	long term care facilities to be staffed by sufficient numbers of adequately trained, compensated, supervised, and screened staff.	4.15
54	to increase access to and monitoring of home care to promote quality care at home and prevent elder abuse.	3.93
55	to create an adequately funded national infrastructure for APS that includes a national resource center, data collection, program evaluation, training, technical assistance, and resources for adequate staffing.	4.09
56	to identify and implement interventions that respond to the needs of low income people at risk for elder abuse.	3.59
57	to collect and aggregate data about elder abuse cases that is comprehensive, consistent, accurate, current, and available to the public.	3.8
58	to increase research, policy, and practice that addresses neglect of older people.	3.67
59	to develop better ways to use technology in the prevention and detection of elder abuse.	3.44
60	to establish a national elder abuse hotline.	3.18
61	to raise awareness among trusts and estates, family, and elder law attorneys about how to better identify and prevent elder abuse.	3.63
62	research, including program evaluation, to determine the effectiveness of interventions that are used to address elder abuse, such as which Adult Protective Services and ombudsman models are most effective.	3.92
63	probation, parole, and community corrections systems to address elder abuse considerations in the release and placement arrangements of inmates of all ages.	3.21
64	to clarify the roles and responsibilities of entities responding to elder abuse (such as Adult Protective Services, ombudsman, guardians, law enforcement, legal services, victim advocates, and others) to identify conflicts of interest, gaps, and overlaps in services.	3.68
65	validated methods and instruments to collect data about elder abuse from various systems.	3.56
66	private foundations, religious and corporate philanthropies, and private donors to support research, policy, and programs related to elder abuse.	3.65
67	local, state, and national entities to create and implement strategic plans to address elder abuse.	3.71
68	public education to provide accurate information about elder abuse and to correct misperceptions and raise awareness about aging.	3.95
69	professionals, in gathering information from older people, to know how to ask screening questions sensitively and how to follow up appropriately.	3.9
70	law enforcement officers and units dedicated to addressing and investigating elder abuse.	4.08
71	Aging and Disability Resource Center (ADRC) staff to assist in coordinating multidisciplinary efforts to address elder abuse and to provide appropriate information and referrals.	3.4

72	focus groups and other methods to determine what types of communications are most effective in preventing elder abuse.	2.86
73	to foster person-centered approaches in all aspect of services and prevention targeting elder abuse (such as client-centered, victim-centered, and patient-centered approaches).	3.62
74	to measure the economic cost of elder abuse (e.g., facility placements, hospitalizations, trips to the emergency room, lost assets, and wages, etc.) in order to identify areas of costs savings gained by addressing the problem.	3.79
75	to cultivate greater interest in and commitment to reducing elder abuse among political leaders.	4.09
76	to fully fund and implement elder justice provisions in existing laws, such as the Elder Justice Act, the Older Americans Act, and the Violence Against Women Act.	4.54
77	the financial industry to create and implement initiatives to address and prevent elder financial exploitation.	3.92
78	to clearly define what constitutes successful outcomes in elder abuse interventions and prevention efforts.	3.75
79	to improve laws, policies, training, monitoring, oversight, and data collection related to guardianship and conservatorship.	3.63
80	well-funded, effective advocacy networks and coalitions to increase funding and inform policy and legislation that coordinate at the local, state, and national level.	3.92
81	faith leaders and faith-based organizations to be more informed about and engaged in addressing elder justice issues.	3.49
82	to train and fund more forensic experts to aide in the detection, analysis, investigation, and prosecution of elder abuse cases.	3.77
83	to develop and fund multidisciplinary centers of excellence on elder abuse that coordinate with one another.	3.55
84	to cultivate new diverse leaders with varied perspectives in the elder justice field.	3.39
85	to increase resources for and capacity of long term care ombudsmen to address elder abuse.	3.44
86	an annual national elder justice conference.	3.04
87	to train relevant professionals to serve as expert witnesses in elder abuse cases.	3.34
88	to address issues that arise when elder abuse cases extend beyond state boundaries, for example through interstate compacts, abuse registries, and full faith and credit provisions.	3.34
89	better ways to identify and respond to high-risk transitions that create unsafe conditions, such as when certain types of offenders move into the homes of older, frail relatives or when sexual predators are placed in nursing homes.	3.65
90	to improve the standards and evaluate and validate the methods used by various entities (such as surveyors, Adult Protective Services, ombudsman, and others) to confirm or substantiate elder abuse allegations.	3.77

91	to develop validated tools and methods for those on the front lines to screen for elder abuse in various settings.	4.04
92	to improve screening, training, monitoring of and support for direct care workers to reduce the incidence of abuse, neglect, and exploitation.	4.08
93	to address and prevent elder abuse that occurs during or as a result of care transitions (i.e. from a hospital to nursing home).	3.37
94	more elder abuse forensic centers and other similar multidisciplinary entities that bring a coordinated approach to elder abuse cases.	3.52
95	a national think tank or comparable entity to analyze and disseminate information about complex elder justice issues and provide leadership on communication and policy issues.	3.28
96	to 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.	3.89
97	Medicare, Medicaid, and other insurance reimbursement for elder abuse screening, detection and intervention.	3.86
98	services and education for abusers and potential abusers that prevent or mitigate abuse.	3.35
99	effective responses and prevention efforts tailored to marginalized and underserved populations.	3.72
100	to draft, enact, and fund new elder justice legislation to address current gaps in the law.	3.62
101	an equivalent or expansion of the long term care ombudsman program to advocate for people who receive care in settings other than nursing homes.	3.39
102	effective survey and certification/state regulatory agencies and trained surveyors to enforce standards and investigate abuse, neglect, and exploitation in nursing homes, assisted living, and other residential settings.	3.66
103	a strong movement to advance elder justice, informed by key teachings from other social movements.	3.58
104	training for individuals who come into contact with older people (such as postal workers, Meals on Wheels staff, emergency room nurses, etc.) on how to recognize, respond to, and refer suspected elder abuse at the local, state, and national level.	3.93
105	to convene the Elder Justice Act's Advisory Board.	3.59
106	discipline-specific training on elder justice issues, repeated at regular intervals, for individuals working in field at the local, state, and national level.	3.84
107	ongoing multidisciplinary training (bringing together professionals from various disciplines) about effective approaches, collaboration, and other matters, at the local, state and national levels.	3.96
108	more funds for elder abuse victims' services.	4.34
109	to identify compelling spokespersons for the issue who will attract public attention.	3.52
110	prevention, intervention, and surveillance methods tailored to protect cognitively impaired older people in all settings.	3.86

111	to develop effective responses to resident-on-resident aggression, including improved detection, intervention, and prevention by facilities and others.	3.36
112	research regarding the relationship between self-neglect and elder abuse, neglect, and exploitation.	3.06
113	more elder abuse fatality review teams to analyze suspicious elder deaths, identify systemic problems, and make recommendations, including about when autopsies should be performed.	3.62
114	AARP to assign higher priority and devote more resources to addressing elder abuse.	3.59
115	HHS to provide guidance to assist researchers in navigating abuse, consent, and other human subjects protection issues in elder abuse research, as required by the Elder Justice Act.	3.73
116	to develop national Adult Protective Services (APS) definitions and standards, including for feasible caseloads, collaborations, training requirements, and data collection.	4.08
117	high-quality, accessible civil legal services to detect, prevent and address elder abuse (including those services funded through the Older Americans Act and Legal Services Corporation).	4.06
118	to develop effective alternatives to prosecution that address elder abuse and promote justice and accountability.	3.49
119	to increase the availability of community care coordination and case management services to reduce the risk and incidence of elder abuse.	3.83
120	accessible information and services for non-abusing family and friends who are attempting to address elder abuse, including information about how to find help and how to address the impact of the abuse on their own lives.	3.68
121	to develop housing, social, and other initiatives designed to reduce the isolation of older adults.	3.88

APPENDIX E. Concept Maps Showing Clustering of Statements

The point map (Figure 1) shows each of the brainstormed ideas as a point on the map and provides a meaningful arrangement of the content. Ideas that appear closer together tended to be sorted together more frequently by participants. This map illustrates the 121 points, each representing one of the distinct ideas brainstormed by the stakeholders from the original raw list of 686 statements. As a result of hierarchical cluster analyses, a cluster point map illustrates how the individual ideas are related via higher level concepts.

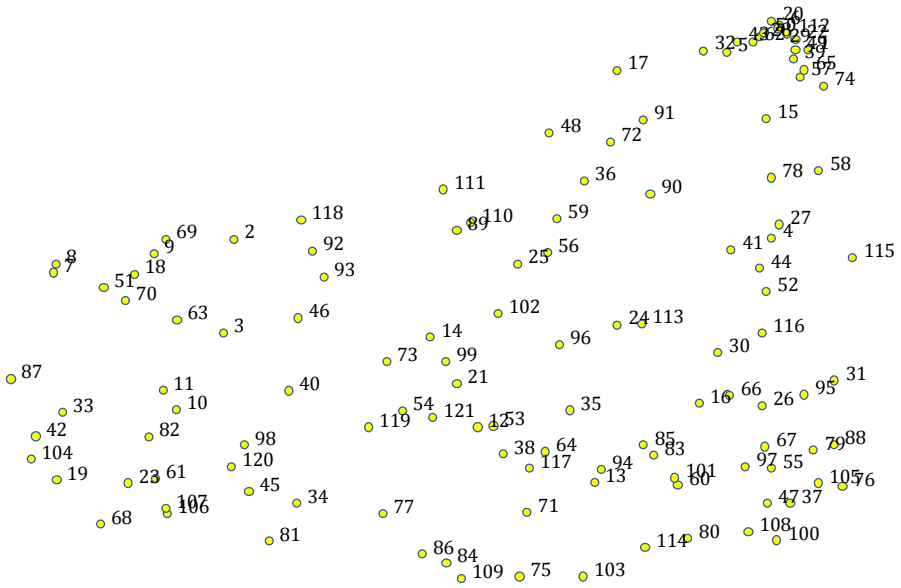


Figure 1. Point Map, indicating the array of all statements and their relationship to each other.

The cluster map shown in Figure 2 on the following page displays the nine thematic categories that emerged in sorting data from stakeholders.

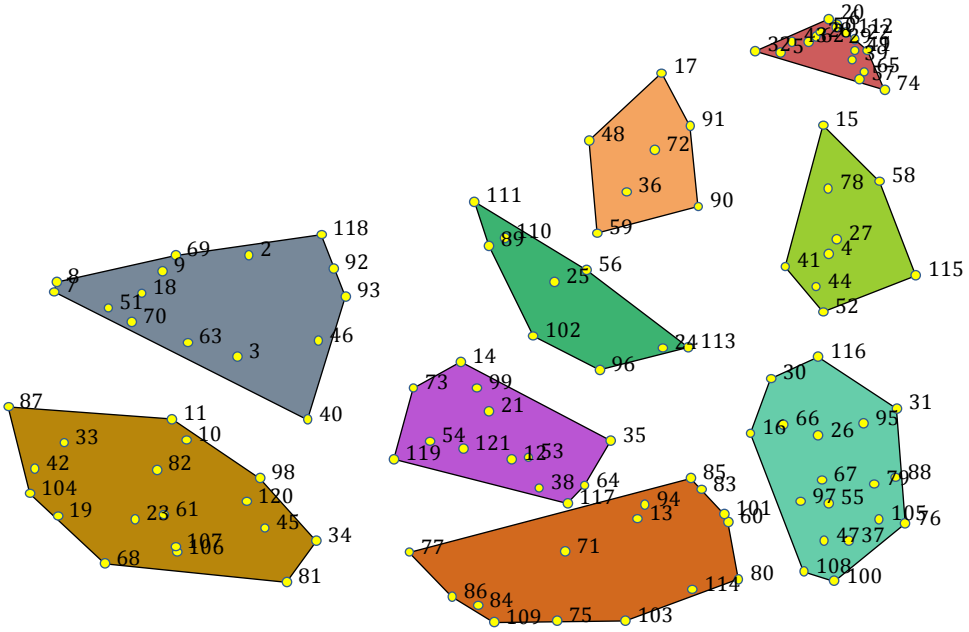


Figure 2. Point Cluster Map, showing the 121 statements grouped into nine clusters.

As a result of the stakeholders sorting the data, nine thematic categories emerged. The data suggest that these nine major themes can be employed as a meaningful framework when considering how to understand, prevent, and address elder abuse. The Labeled Cluster Map (Figure 3) shows the clusters labeled with these categorical issues. The name given to each cluster reflects the theme or topic expressed by the statements within that cluster.

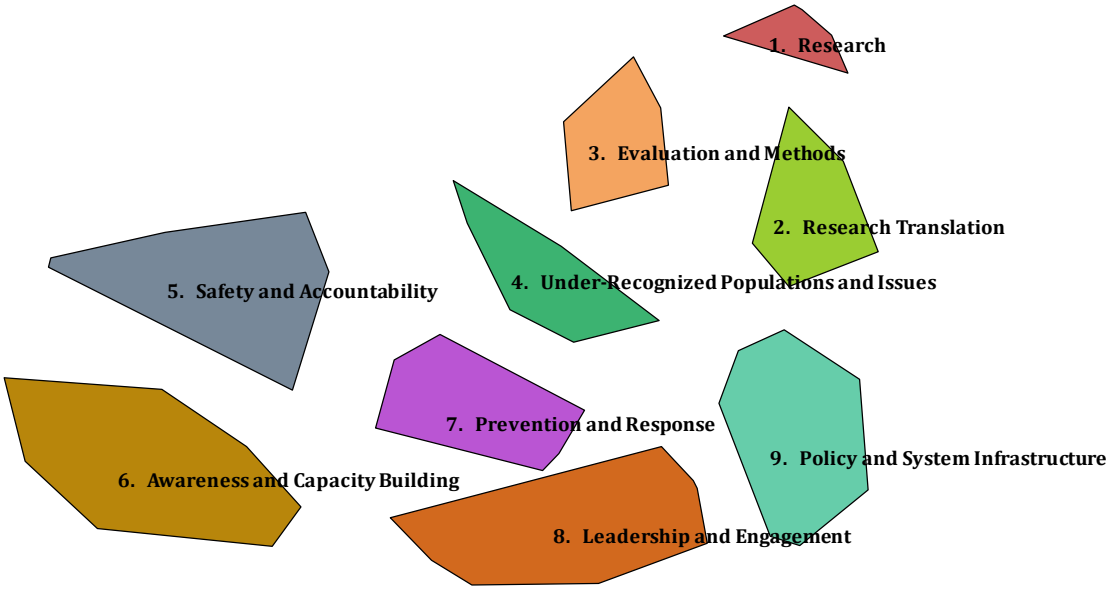


Figure 3. Labeled Concept Map. The 121 statements are grouped into a concept map with nine clusters, which indicate main topics or concepts.

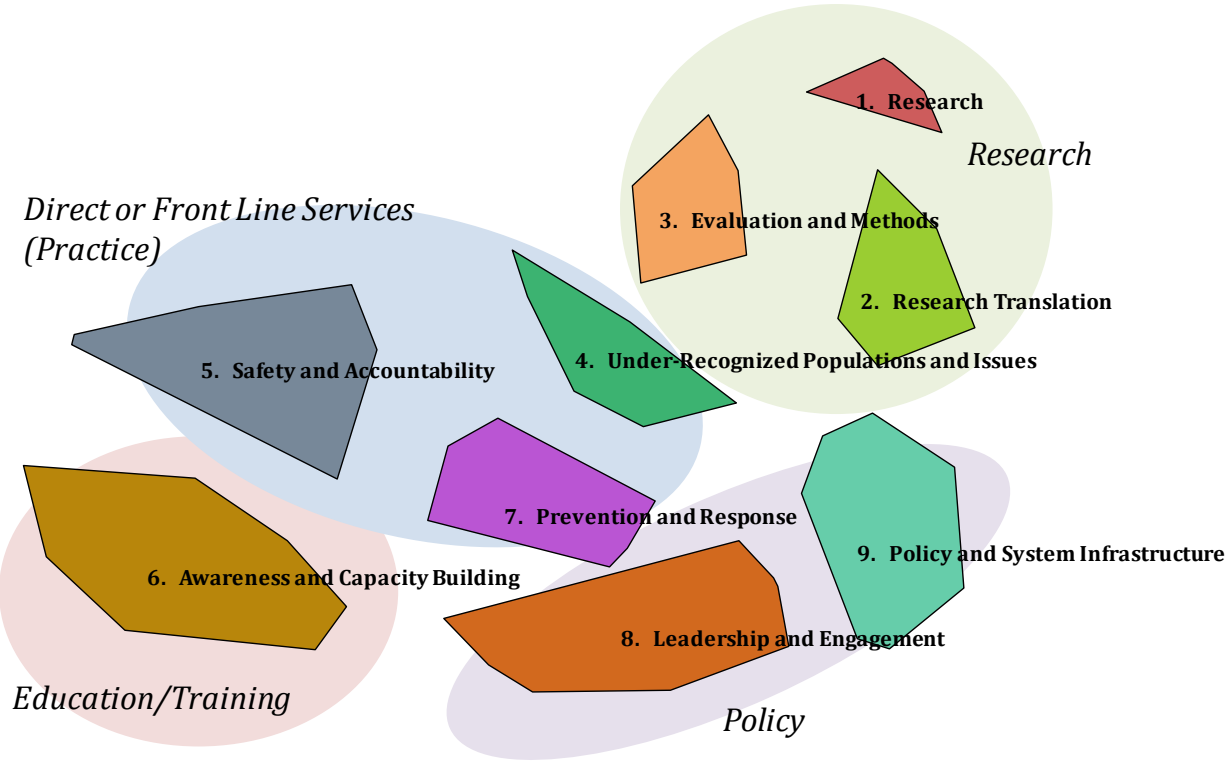


Figure 4. Domains Map. The nine clusters from figure 3 are grouped into four Domains

Appendix F. Charts Showing Ratings by Importance and Feasibility

Pattern Matches were created to compare the *Importance* and *Feasibility* ratings at the cluster level and statement level, respectively.

Concept mapping results include analyses for each cluster represented on the map as shown in Figure 5. These analyses are bivariate plots, one for each cluster, that show the average *Importance* and *Feasibility* rating of each statement within a cluster. These "zone" analyses enable stakeholders to keep the larger conceptual view in mind, while returning to the detailed contents of each cluster to support decision-making.

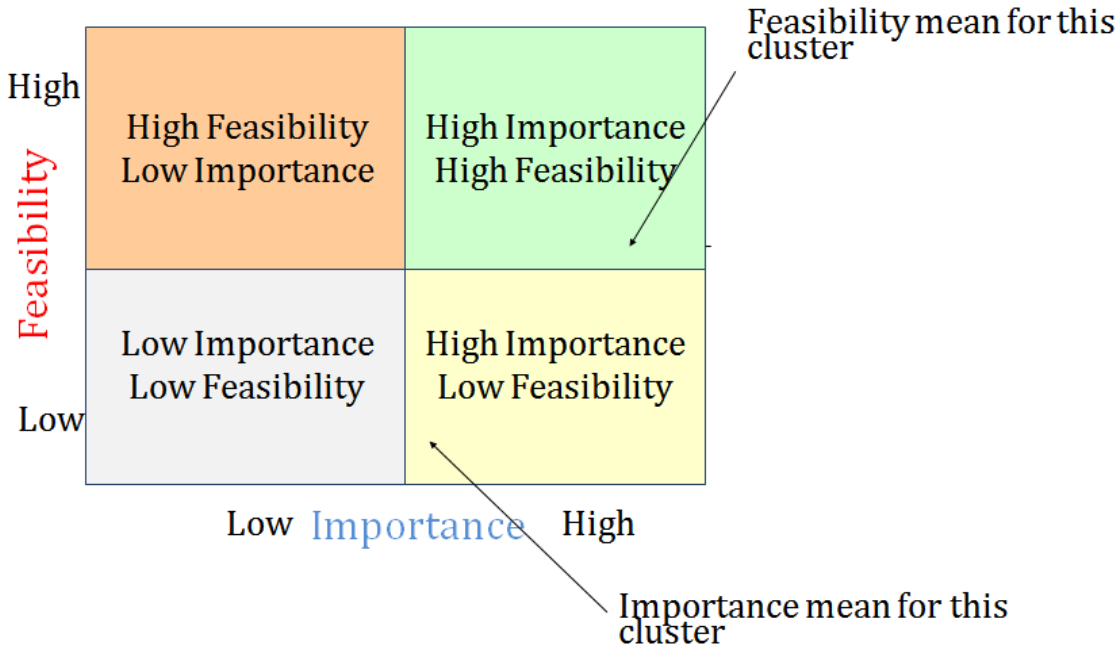
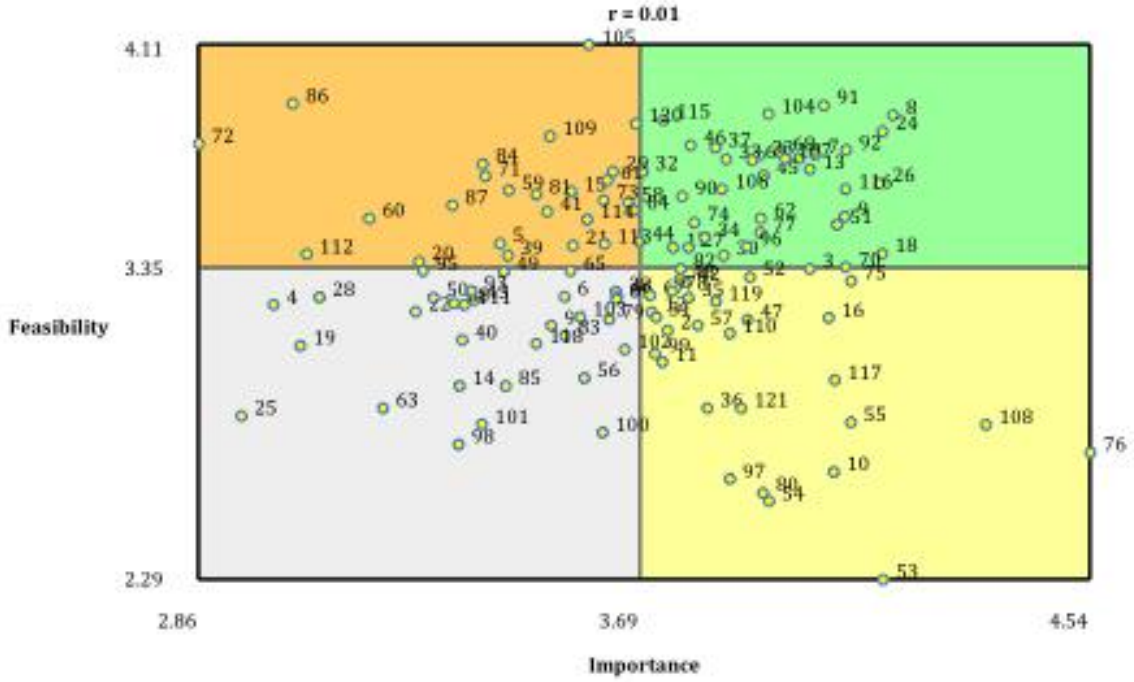


Figure 5. Example Zone Analysis

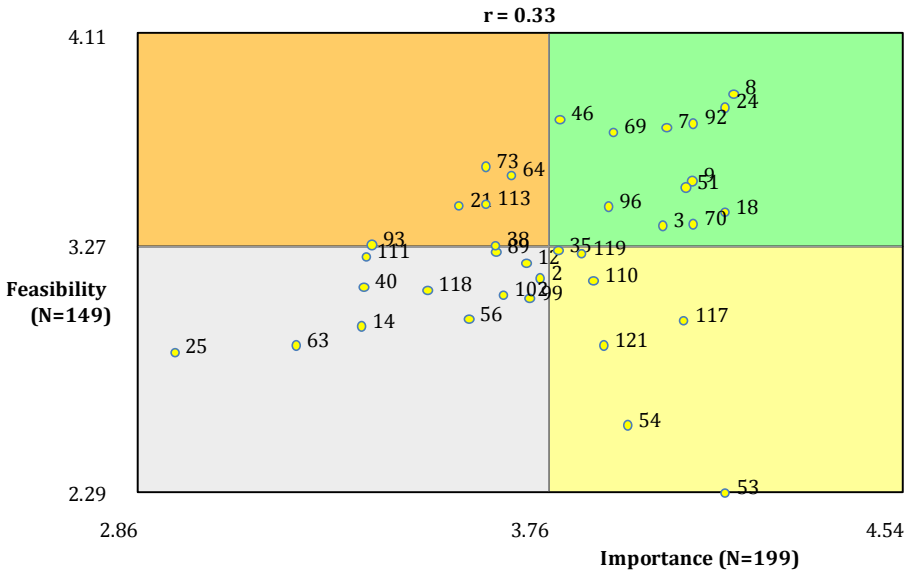
This analysis provides a way to view the data and engage in assisted dialogue about implications, utility, and ways to measure progress on such desired outcomes. Those items located in the upper right (green) quadrant – also sometimes called *the "go-zone"* – were rated higher than the mean for that grouping, on both Importance and Feasibility. Often, these ideas are the most ready for action. Items in the upper left (high Feasibility and relatively low Importance) and those in the lower right (high Importance and relatively low Feasibility) can be considered "gap" areas. These gap areas contain items for which value imbalance exists. Items in the "low importance, low feasibility" quadrant should not be dismissed, but rather be examined closely to best understand how to move forward on them.

All Statements



The following maps compare the average ratings on Importance and Feasibility for the statements ***in each Domain***. These ratings reflect the input of all ratings participants.

DOMAIN: DIRECT SERVICES (PRACTICE)



3. affordable and accessible services to help older adults manage their finances, thereby reducing the risk of financial exploitation.
7. to increase investigation and prosecution by State Attorneys General and Medicaid Fraud Control Units of elder abuse-related violations, such as Medicaid fraud, abuse and neglect in facilities, consumer protection initiatives targeting financial exploitation, and others.
8. to train practitioners to use evidence-based and promising screening and interventions that detect and address trauma and other mental health, behavioral health, and substance abuse issues.
9. prosecutors and prosecution units dedicated to pursuing elder abuse.
18. courts to improve how they handle elder abuse cases and accommodate the needs of older people.
24. to include older people's input in all aspects of elder justice efforts.
46. to raise awareness about diminished cognitive capacity and its high correlation with elder abuse to inform research, policy, and practice.
51. improved identification and tracking of elder abuse cases by law enforcement and prosecutors.
69. professionals, in gathering information from older people, to know how to ask screening questions sensitively and how to follow up appropriately.
70. law enforcement officers and units dedicated to addressing and investigating elder abuse.
92. to improve screening, training, monitoring of, and support for direct care workers to reduce the incidence of abuse, neglect, and exploitation.
96. to 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.

DOMAIN: DIRECT SERVICES (PRACTICE)

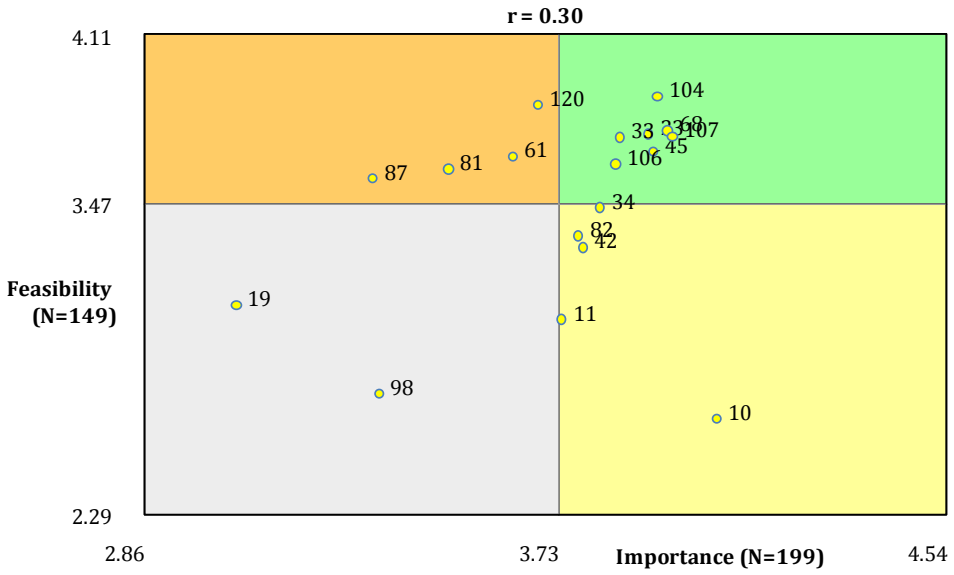
21. individuals and entities that address mental health, dementia, women's, and disability rights issues, as well as other related issues, to improve how they respond to the needs of elder abuse victims who also are their constituents.
38. to increase scrutiny and accountability of representative payees and develop appropriate responses to abuse of the representative payee system.
64. to clarify the roles and responsibilities of entities responding to elder abuse (such as Adult Protective Services, ombudsman, guardians, law enforcement, legal services, victim advocates, and others) to identify conflicts of interest, gaps, and overlaps in services.
73. to foster person-centered approaches in all aspect of services and prevention targeting elder abuse (such as client-centered, victim-centered, and patient-centered approaches).
93. to address and prevent elder abuse that occurs during or as a result of care transitions (i.e. from a hospital to nursing home).
113. more elder abuse fatality review teams to analyze suspicious elder deaths, identify systemic problems, and make recommendations, including about when autopsies should be performed.

35. more multidisciplinary teams throughout the country that have adequate support for facilitators and operations.
53. Long-term care facilities to be staffed by sufficient numbers of adequately trained, compensated, supervised and screened staff.
54. to increase access to and monitoring of home care to promote quality care at home and prevent elder abuse.
110. prevention, intervention, and surveillance methods tailored to protect cognitively impaired older people in all settings.
117. high-quality, accessible civil legal services to detect, prevent, and address elder abuse (including those services funded through the Older Americans Act and Legal Services Corporation).
119. to increase the availability of community care coordination and case management services to reduce the risk and incidence of elder abuse.
121. to develop housing, social, and other initiatives designed to reduce the isolation of older adults.

DOMAIN: DIRECT SERVICES (PRACTICE)

2. protection from retaliation of individuals who report elder abuse in any setting.
12. to increase initiatives for primary and secondary prevention (such as social supports for older people).
14. less restrictive alternatives to guardianship and conservatorship that maximize autonomy while promoting security.
25. to develop and implement standards for the treatment of older inmates and suspects to prevent abuse.
40. to improve reporting by mandatory reporters.
56. to identify and implement interventions that respond to the needs of low income people at risk for elder abuse.
63. probation, parole, and community corrections systems to address elder abuse considerations in the release and placement arrangements of inmates of all ages.
89. better ways to identify and respond to high-risk transitions that create unsafe conditions, such as when certain types of offenders move into the homes of older, frail relatives or when sexual predators are placed in nursing homes.
99. effective responses and prevention efforts tailored to marginalized and underserved populations.
102. effective survey and certification/state regulatory agencies and trained surveyors to enforce standards and investigate abuse, neglect, and exploitation in nursing homes, assisted living, and other residential settings.
111. to develop effective responses to resident-on-resident aggression, including improved detection, intervention, and prevention by facilities and others.
118. to develop effective alternatives to prosecution that address elder abuse and promote justice and accountability.

DOMAIN: EDUCATION



23. to ensure that quality information about preventing, identifying, and responding to elder abuse, (such as curricula and tool kits) is disseminated to professionals and the public.
33. to ensure effective training on elder justice issues by developing, evaluating, and continuously updating curricula, and by training trainers to cultivate expertise.
45. increased awareness of and efforts to detect, prevent, and respond to elder sexual assault in all settings.
68. public education to provide accurate information about elder abuse and to correct misperceptions and raise awareness about aging.
104. training for individuals who come into contact with older people (such as postal workers, Meals on Wheels staff, emergency room nurses, etc.) on how to recognize, respond to, and refer suspected elder abuse at the local, state, and national level.
106. discipline-specific training on elder justice issues, repeated at regular intervals, for individuals working in field at the local, state, and national level.
107. ongoing multidisciplinary training (bringing together professionals from various disciplines) about effective approaches, collaboration, and other matters, at the local, state, and national levels.

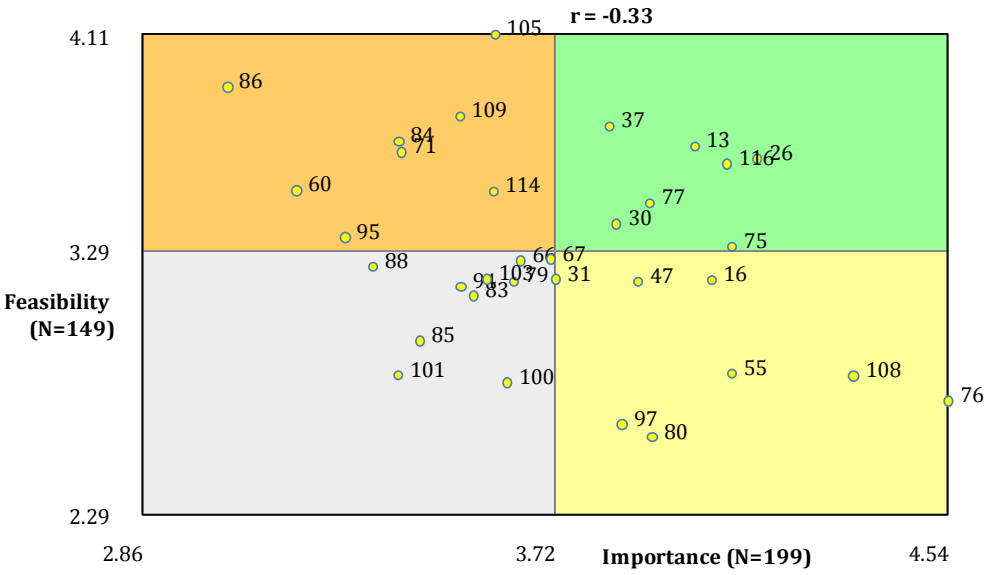
61. to raise awareness among trusts and estates, family, and elder law attorneys about how to better identify and prevent elder abuse.
81. faith leaders and faith-based organizations to be more informed about and engaged in addressing elder justice issues.
87. to train relevant professionals to serve as expert witnesses in elder abuse cases.
120. accessible information and services for non-abusing family and friends who are attempting to address elder abuse, including information about how to find help and how to address the impact of the abuse on their own lives.

DOMAIN: EDUCATION

10. a vast increase in the number of health care professionals qualified to care for older people and to identify, address, and prevent elder abuse.
11. to provide caregivers with adequate support and services to develop competency and reduce stress.
34. to include questions about elder abuse on relevant professional licensing exams to encourage training and competency on elder justice issues.
42. to educate all types of caregivers about elder abuse.
82. to train and fund more forensic experts to aide in the detection, analysis, investigation, and prosecution of elder abuse cases.

19. to develop curricula on aging for K-12 and higher education that emphasize the value of older adults, that well being in old age is of universal concern, and that other forms of family violence have a nexus to elder abuse.
98. services and education for abusers and potential abusers that prevent or mitigate abuse.

DOMAIN: POLICY



13. the aging network to assign higher priority and more resources to addressing elder abuse, including through the integration of elder justice measures in all appropriate programs and initiatives.
26. the Centers for Disease Control and Prevention to recognize and address elder abuse as a serious public health issue, like child abuse and intimate partner violence, warranting comparable surveillance, prevention, and treatment programs.
30. to identify and resolve impediments to multidisciplinary coordination in elder abuse matters due to confidentiality, privacy, and other laws, regulations and protocols.
37. the Coordinating Council created by the Elder Justice Act to identify priorities, allocate resources, and coordinate efforts by the federal government in addressing elder abuse.
75. to cultivate greater interest in and commitment to reducing elder abuse among political leaders.
77. the financial industry to create and implement initiatives to address and prevent elder financial exploitation.
116. to develop national Adult Protective Services (APS) definitions and standards, including for feasible caseloads, collaborations, training requirements, and data collection.

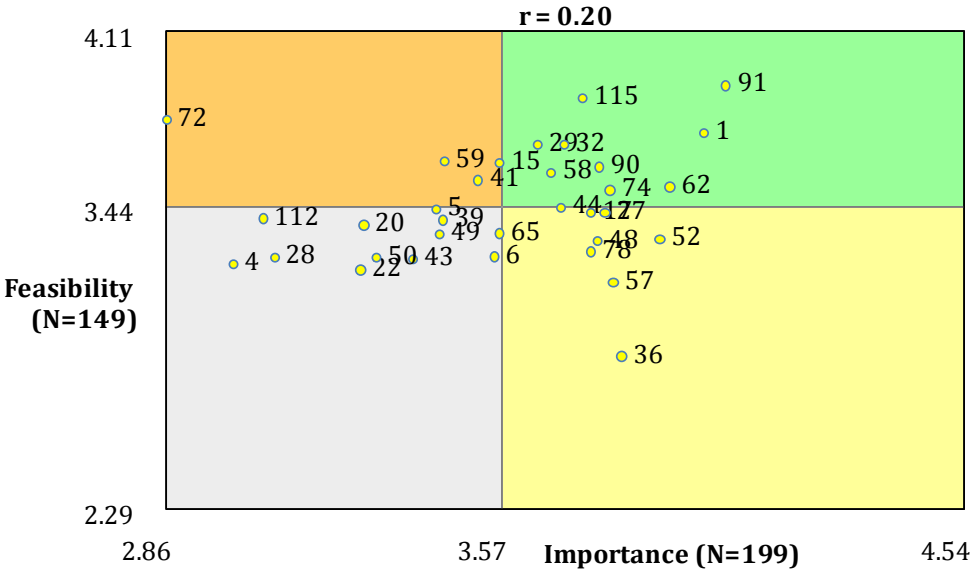
60. to establish a national elder abuse hotline.
71. Aging and Disability Resource Center (ADRC) staff to assist in coordinating multidisciplinary efforts to address elder abuse and to provide appropriate information and referrals.
84. to cultivate new diverse leaders with varied perspectives in the elder justice field.
86. an annual national elder justice conference.
95. a national think tank or comparable entity to analyze and disseminate information about complex elder justice issues and provide leadership on communication and policy issues.
105. to convene the Elder Justice Act's Advisory Board.
109. to identify compelling spokespersons for the issue who will attract public attention.
114. AARP to assign higher priority and devote more resources to addressing elder abuse.

DOMAIN: POLICY

16. a well-funded national center on elder abuse with resources similar to those allocated for child abuse centers, and specialized resource centers for entities like Adult Protective Services, older victim services, the ombudsman program, legal services, guardianship, etc.
31. to improve law, policies, training, oversight, and data collection related to abuse of powers of attorney.
47. a federal Office of Elder Justice, comparable to federal offices dedicated to addressing child abuse and violence against women.
55. to create an adequately funded national infrastructure for APS that includes a national resource center, data collection, program evaluation, training, technical assistance, and resources for adequate staffing.
76. to fully fund and implement elder justice provisions in existing laws, such as the Elder Justice Act, the Older Americans Act, and the Violence Against Women Act.
80. well-funded, effective advocacy networks and coalitions to increase funding and inform policy and legislation, that coordinate at the local, state, and national level.
97. Medicare, Medicaid, and other insurance reimbursement for elder abuse screening, detection, and intervention.
108. more funds for elder abuse victims' services.

66. private foundations, religious and corporate philanthropies, and private donors to support research, policy, and programs related to elder abuse.
67. local, state, and national entities to create and implement strategic plans to address elder abuse.
79. to improve laws, policies, training, monitoring, oversight, and data collection related to guardianship and conservatorship.
83. to develop and fund multidisciplinary centers of excellence on elder abuse that coordinate with one another.
85. to increase resources for and capacity of long term care ombudsmen to address elder abuse.
88. to address issues that arise when elder abuse cases extend beyond state boundaries, for example through interstate compacts, abuse registries, and full faith and credit provisions.
94. more elder abuse forensic centers and other similar multidisciplinary entities that bring a coordinated approach to elder abuse cases.
100. to draft, enact, and fund new elder justice legislation to address current gaps in the law.
101. an equivalent or expansion of the long term care ombudsman program to advocate for people who receive care in settings other than nursing homes.
103. a strong movement to advance elder justice, informed by key teachings from other social movements.

DOMAIN: RESEARCH



1. national incidence and prevalence research to measure all types of elder abuse.
29. research into the consequences of elder financial exploitation, such as potential declines in health and increased risk for other types of elder abuse.
32. research to identify forensic markers to assist in the detection of elder abuse.
44. to develop initiatives to translate research into policy and practice that more effectively addresses elder abuse.
58. to increase research, policy, and practice that addresses neglect of older people.
62. research, including program evaluation, to determine the effectiveness of interventions that are used to address elder abuse, such as which Adult Protective Services and ombudsman models are most effective.
74. to measure the economic cost of elder abuse (e.g., facility placements, hospitalizations, trips to the emergency room, lost assets and wages, etc.) in order to identify areas of costs savings gained by addressing the problem.
90. to improve the standards and evaluate and validate the methods used by various entities (such as surveyors, Adult Protective Services, ombudsman, and others) to confirm or substantiate elder abuse allegations.
91. to develop validated tools and methods for those on the front lines to screen for elder abuse in various settings.
115. HHS to provide guidance to assist researchers in navigating abuse, consent, and other human subjects protection issues in elder abuse research, as required by the Elder Justice Act.

15 . to test and integrate promising practices and research from related fields, such as child abuse and domestic violence, in elder justice work.
41. to review existing systems, programs and protocols to identify and address systemic gaps and overlaps.
59. to develop better ways to use technology in the prevention and detection of elder abuse.
72. focus groups and other methods to determine what types of communications are most effective in preventing elder abuse.

REGION: RESEARCH

17. to evaluate the experience of older victims to assess how well victim safety is addressed, whether services are coordinated and seamless, and whether offenders are held accountable in a consistent way (similar to safety planning audits used in the domestic violence field).
27. systemic evaluation of existing laws and implementation practices to develop model laws and policy.
36. to test and develop a range of effective emergency and transitional housing and shelter options to better meet older victims'needs.
48. better methods for investigating and measuring the prevalence of elder abuse in residential care facilities and other non-nursing home settings.
52. to develop comprehensive, consistent definitions of elder abuse, neglect, and exploitation to be used in various contexts such as in laws, critical care, and services.
57. to collect and aggregate data about elder abuse cases that is comprehensive, consistent, accurate, current, and available to the public.
78. to clearly define what constitutes successful outcomes in elder abuse interventions and prevention efforts.

4. ethicists and philosophers to partner with policymakers, researchers and practitioners in addressing ethical issues that arise in elder abuse cases, including how best to balance autonomy and safety.
5. to translate the questions and dilemmas faced by practitioners into research that can assist them.
6. research into the long term (longitudinal) nature of elder abuse for victims and perpetrators, and contextual factors (such as poverty or isolation) that can affect elder abuse.
20. research on the nexus between mental health and elder abuse, both for victims and perpetrators.
22. research the rates of and connections between abuse, neglect, and exploitation at home and in facilities, and develop policy accordingly.
28. to research the impact and value of mandatory reporting.
39. research and policy regarding the role of diminished, variable, or questionable capacity in increasing the risk of elder abuse.
43. research to identify perpetrator characteristics, including why they abuse and how to develop preventive interventions.
49. research on elder abuse in different cultures (such as definitions, risk factors, interventions, prevention, and prevalence) to inform policy and practice.
50. research to understand the causes of elder abuse and conceptual models that inform practice, such as greed, power and control, and caregiver stress.
65. validated methods and instruments to collect data about elder abuse from various systems.
112. research regarding the relationship between self-neglect and elder abuse, neglect, and exploitation.

Interpretation

The next step of the project was to build on the developed conceptual framework reflected in the maps and charts above in order to:

- Discuss the insight derived from the concept map and confirm the validity of the framework results with stakeholders.
- Identify topics for subsequent facilitated discussions and leadership interviews based on particular areas of the framework that demand more in-depth exploration or focused attention, and/or issues not explicitly included in the framework but of considerable importance to the elder justice field.
- Use the conceptual territories that emerged from the framework as a means for generating a list of citations that support the thematic areas of the map.
- Use the maps and charts to identify "first wave" action items, priorities by domain, and universal themes cutting across all domains and phases of the project.

Appendix G. Expert Interpretation and Analysis – Facilitated Discussions

The concept map reveals a multitude of priorities and gaps. To help interpret and understand the findings as they related to particularly complex and important topics, the subject matter experts at the September 2012 meeting identified six topics for additional input and discussion in facilitated discussions (FDs):

- *Caregiving*
- *Diminished Capacity/Mental Health*
- *Diversity and Inclusion*
- *Prevention*
- *Screening*
- *Victim Services*

Up to a dozen diverse experts were invited to participate in each of the ninety minute facilitated telephone conversations. (Only the names of those who actually were able to participate are listed.) Despite the diversity of the distinct topics discussed through the facilitated discussions, certain common themes emerged in all of the conversations.

Common Themes identified by participants in each of the Facilitated Discussions:

- **Balancing the need for services and research**: We need to serve older victims experiencing harm today, and at the same time accelerate research to determine the efficacy of prevention, intervention, and other responses.

- **Create tailored responses:** Because elder abuse involves varying types of conduct, settings, and motivating factors (e.g., greed, entitlement, power, inadequate staffing), we need a variety of screening, assessment, intervention, and prevention approaches tailored to each.

- **Diversity and inclusion:** Different populations define and experience elder abuse in distinct ways and respond differently to efforts to prevent, intervene in, and raise awareness about it. Thus, every effort should be made to recognize and address those differences and ensure cultural competence in practice, policy, research, and education.

- **Diminished capacity:** Diminished capacity and cognitive impairment pose challenges in all aspects of responding to elder abuse and requires more attention.

- **Definitions and terminology**: The varying definitions and parameters of elder abuse create unnecessary confusion in the elder abuse field, among allied professionals and with the general public. We need a consistent, clear, common sense definition of elder abuse.

Facilitated Discussion on Caregiving

When you're dealing with caregiving, you're usually dealing with family systems. There's a gap in the field in terms of communicating about caregiving. There are many proven interventions for stressed caregivers, but this isn't communicated well. Educating caregivers can do a lot to decrease the risk of elder abuse.

– Caregiving FD Participant

Discussion participants:

David Bass, PhD, *Benjamin Rose Institute on Aging*
Laura Bauer, MPA, *Rosalynn Carter Institute for Caregiving*
Tameshia Bridges Mansfield, MSW, *PHI – Quality Care through Quality Jobs*
Debra Cherry, PhD, *Alzheimer's Association*
Leisa Easom, PhD, RN, *Rosalynn Carter Institute for Caregiving*
Laura Gitlin, PhD, *John Hopkins University, Center for Innovative Care in Aging*
Kathy Kelly, MPA, *National Center on Caregiving, Family Caregiver Alliance*
Greg Link, MA, *Administration for Community Living (ACL)/Administration on Aging (AoA)*
Jane Tilly, DrPH, *Administration for Community Living (ACL)/Administration on Aging (AoA)*

Most caregivers provide extraordinary care, often under difficult circumstances, with little preparation or support, and at significant cost to their own health and financial well-being. In addition, caregiving responsibilities can take a toll on caregivers' family recreation time and responsibilities, personal leisure time, and work lives. Some caregivers, however, also abuse, neglect, and exploit. We know little about the nexus between caregiving and elder abuse – particularly in terms of how caregiving relates to preventing and responding to elder abuse. It is an issue about which we need to know more. Some research indicates that interventions targeting caregivers are more likely to prevent elder abuse than those targeting care recipients. And there is ongoing debate about the extent to which caregiver stress (in various settings) contributes to versus is used to excuse elder abuse. There is no disagreement, however, that the caregiving and elder abuse fields must find better ways to communicate, educate one another, and work together (which has rarely occurred in the past), or the rise of the aging population will exponentially increase demands on caregivers.

Priorities:

- **Caregivers at-risk of harm**: Some caregivers (paid and unpaid, in homes and facilities, many of them older) are abused or harmed while providing care. We need to identify scenarios where caregivers are at risk and develop programs to enhance their safety**.**

- **Caregivers at-risk for abusing or neglecting:** Not everyone has the desire, resources, or capacity to provide proper care. We need better ways to assess which caregivers are at risk for abusing, neglecting, or exploiting, and what other factors contribute to the risk. At-risk caregivers should be offered support and options that help prevent elder abuse.

- **Communication and education:** We need to deepen the understanding of abuse, neglect, and financial exploitation in the caregiving context to help the caregiving and elder abuse fields better understand the role of caregiving in elder abuse and how to prevent and address it. We need joint initiatives including forums that involve leaders in both fields, a research plan, ideas for innovative programs, curricula and toolkits.

- **Historic family violence:** The potential impact of past and ongoing abuse (e.g., child abuse and neglect, incest, sexual assault, or domestic violence) on caregiving needs to be recognized and understood. In particular, we need to develop prevention and intervention strategies for caregivers who have experienced abuse and are now in caregiving roles.

- **Joint policy initiatives:** We should promote policy initiatives with relevance to both the caregiving and elder abuse fields such as respite care; caregiver training; and assessing the impact of increasingly complex caregiving duties being shifted from the health care system to families and individuals who are often ill-equipped to assume the role. We need an analysis of intersecting policy goals and initiatives and a strategic joint response, including addressing the need for more well-trained caregivers who are adequately compensated.

Facilitated Discussion on Diminished Capacity and Mental Health

"Conceptualizing mental health and capacity issues as "brain health and functioning" is ground breaking. Clearly, diminished capacity and mental health are part of brain health and function. If the brain is not functioning properly, it can lead to impairment and lead to trouble making decisions. Calling it "brain health and functioning" also helps ease people into the conversation."

– Diminished Capacity/Mental Health FD Participant

Discussion participants:

Jason Karlawish, MD, *University of Pennsylvania*
Octavio N. Martinez, Jr., MD, MPH, MBA, FAPA, *Hogg Foundation for Mental Health*
Willard Mays, MA, *American Sociological Association (ASA) Mental Health and Aging Network*
Alixe McNeill, MPA, *National Council on Aging*
Harry Morgan, MD, *Center for Geriatric and Family Psychiatry*
Elizabeth J. Santos, MD, *University of Rochester School of Medicine and Dentistry*
Jo Anne Sirey, PhD, *Weill Cornell Medical College*
Susan Wehry, MD, *Vermont Department of Disabilities, Aging & Independent Living*

For decades, researchers and practitioners working with older victims and abusers have identified diminished cognitive capacity and mental health problems as critical and complex issues in relation to elder abuse. Yet both issues – standing alone and the interplay between them – are often not well understood or addressed in efforts to prevent, address, and understand elder abuse.

Priorities:

- **Brain health and function:** Participants supported efforts to examine diminished cognitive capacity and mental illness in the context of elder abuse, through the framework of *brain health and functioning*. Such language could help to de-stigmatize the issues of mental illness, substance abuse, dementia, and diminished cognitive capacity, and create natural bridges among the mental health, substance abuse, dementia, and elder abuse fields.

- **Education regarding the use of assessment tools:** Many practitioners on the front lines still use outdated instruments to assess diminished cognitive capacity and screen for mental health problems. We need to develop a standardized curriculum for front-line responders on what tools are validated, how to use them to assess cognitive impairment, decision-making cognitive capacity, depression, and anxiety, as well as to provide supervision and support.

- **Integration:** Key professional, consumer, and government agencies that address mental health, substance abuse, and dementia should integrate elder abuse concerns into their policy, practice, training, and research priorities.

- **Mental health networks:** In many communities, insufficient mental health services are the norm for older adults, including for those who have experienced the trauma of victimization. We need to strengthen existing mental health networks to identify and provide services to elder abuse victims, their families, and their abusers.

- **Nexus between mental health and elder abuse:** Practitioners and researchers cite mental health problems as appearing disproportionately among both victims and perpetrators of elder abuse. Mental health research, policy, and programs targeting older people should address elder abuse and how to identify and prevent it.

- **Nexus between cognitive impairment and elder abuse:** Practitioners and researchers cite cognitive impairment as a significant risk factor for elder abuse. Research, policy, and programs relating to dementia, diminished cognitive capacity, and other forms of cognitive impairment should address elder abuse and how to identify and prevent it.

"Looking at these issues together, as brain health and functioning, supports an interrelated, interdisciplinary approach. It brings areas of justice, legal, mental, transportation, housing together – the social determinants of health that impact older Americans. It really de-stigmatizes some concepts and moves away from the silo effect."

– Diminished Capacity/Mental Health FD Participant

Facilitated Discussion on Diversity and Inclusion

"As soon as we ask questions and hold people accountable to a uniform legal system, we are involved in shifting patterns of identity. As we begin to deal with questions of elder abuse within different cultural communities, we will begin to alter their perceptions as well as our own."

– Diversity and Inclusion FD Participant

Discussion participants:

David Gimbel, DPhil, *Archaeos (cultural and anthropological aspects of aging)*
Anne Marie Hunter, PhD, MDiv, *Safe Havens Interfaith Partnership Against Domestic Violence*
Evelyn Laureano, PhD, LMSW, *Neighborhood SHOPP*
Suzy Ritholz, PhD, *Services & Advocacy for Gay, Lesbian, Bisexual & Transgender Elders (SAGE)*
Sydel Samuels, *Women's Outreach Program, Nez Perce*
Kate Wilber, PhD, *USC Davis School of Gerontology*

Diversity and inclusion have long been identified as critical issues to the elder abuse field, yet we know little about the needs of diverse populations when it comes to elder abuse, and have done even less to try to tailor responses to meet those needs. This facilitated discussion focused on the needs of older victims of diverse national origin, language, race, disability, ethnicity, gender, age, religion, sexual orientation, gender identity, socioeconomic status and family structures.

Priorities:

- **Leadership:** Engage people from within underrepresented and underserved populations to conduct and participate in elder abuse-related research, education, service delivery, policy-making and in serving as elder abuse spokespersons.

- **Outreach:** Work closely with existing community and faith-based organizations, media and leaders with strong ties to older adults that other mainstream networks cannot access through traditional methods.

- **Tailored messages:** Create tailored messages and materials about elder abuse to engage each underrepresented and underserved population, and disseminate these messages in a way that targets their needs.

- **Visibility:** Ensure high visibility of voices from diverse populations in *all* policy, practice, research, and education initiatives resulting from the Elder Justice Roadmap Project**.** Diversity and inclusion are overarching concepts that touch every aspect of the concept map.

Facilitated Discussion on Prevention

"It has been 30 years and we still do not know what prevention programs work. Multi-component interventions and counseling can address potentially abusive caregivers. We need programs to prevent people from becoming abusers and from becoming victims."

– Prevention FD Participant

Discussion participants:

Georgia Anetzberger, PhD, ACSW, LISW, *National Committee for the Prevention of Elder Abuse (NCPEA)*
Melissa Brodowski, PhD, MSW, MPH, *Department of Health and Human Services, Administration for Children and Families*
Jeanette Daly, PhD, RN, *University of Iowa, Department of Family Medicine*
Martha Deevy, MBA, *Stanford Center on Longevity*
Jeff Hall, PhD, MSPH, CPH, *Centers for Disease Control and Prevention*
Candice Kane, PhD, JD, *Chicago Project Violence Prevention; University of Illinois- Chicago School of Public Health*
Bonnie Olson, PhD, *University of California- Irvine*
Karl Pillemer, PhD, *Cornell University*
Joseph Rodrigues, *State Long Term Care Ombudsman; California Department for the Aging*
Debby Tucker, MPA, *National Center on Domestic and Sexual Violence*

Prevention was identified as a critical issue for stakeholders. Although prevention is key to stemming the tide of abuse and is the first line of defense, we know almost nothing about how to successfully prevent elder abuse. We dedicate too few resources to identifying and implementing potentially successful prevention programs and strategies.

Priorities:

- **Abuser intervention programs and strategies:** We should create demonstration projects for current and potential abusers to identify and evaluate what types of interventions prevent what sorts of victimization.

- **Centers for Disease Control and Prevention:** The CDC should treat elder abuse like other serious public health issues by conducting surveillance and research, and developing strategies, interventions, and programs targeting primary, secondary, or tertiary prevention.

- **Child abuse prevention models:** Programs proven to be effective in preventing child abuse – such as home visits by health workers and child death reviews – should be studied to determine whether they can be successfully adapted to prevent elder abuse.

- **Effective models and messages:** We should conduct research to better understand which audiences need to be reached to effectively prevent elder abuse, and what models and messages effectively reach those audiences. Researchers should work with front line experts and target populations in developing such messages.

- **Risk factors:** Although some elder abuse risk factors have been identified (e.g., social isolation, shared living arrangement, dependence, cognitive impairment, physical disability), much remains unknown about risk factors and how to address them. Identifying risk factors among victims, potential perpetrators and in the environment could help guide the development of prevention programs.

- **Transitions:** Older people are made more vulnerable to victimization, and crucial information about abuse is frequently lost, as older adults move to and between health care settings. For example, health care facilities must communicate about safety measures when a victim with a restraining order is transferred from one setting to another.

Facilitated Discussion on Screening

"I have seen screening done in a waiting area where privacy and safety were not taken into consideration. Screening needs to be done in a respectful way that builds in protection, privacy, safety, and respect."

– Screening FD Participant

Discussion participants:

Jacquelyn Campbell, PhD, RN, FAAN, *John Hopkins University*
Terry Fulmer, PhD, RN, FAAN, *Bouve College of Health Sciences*
Duke Han, PhD, *Rush University Medical Center; VA Long Beach Healthcare System*
Bryan Hansen, MSN, RN, *John Hopkins University*
Catherine Hawes, PhD, *Texas A&M University*
Madelyn Iris, PhD, *Leonard Schanfield Research Institute*
Holly Ramsey-Klawsnik, PhD, *Klawsnik & Klawsnik Associates*
Debbie Lee, *Futures Without Violence*
Kathy Park, *National Council on Crime and Delinquency*
Mildred Ramirez, PhD, *Research Division, The Hebrew Home at Riverdale*

Early detection through screening may be one method to reduce elder abuse. Yet, how to best screen for elder abuse – either at the individual or population level – remains a matter of dispute. There is no consensus in the field about the best screening tools to use, although there is agreement among experts that some front line responders continue to use outdated and invalid instruments. In addition, the elder abuse field must grapple with the ethics of implementing wide-scale screening efforts for abuse when most communities lack the service capacity to respond. Further complicating the picture, the US Preventive Services Task Force concluded in 2012 that the current evidence is insufficient to assess the balance of benefits and harms of screening all elderly or vulnerable adults for abuse and neglect, an assessment that will be reviewed every five years.

Priorities:

- **Dissemination and training on screening tools:** Once the best screening tools are identified for particular types of professionals or settings, they should be disseminated, and those who are expected to use the tools should be trained in how to use them.

- **Policy:** We need to address the US Preventive Services Task Force conclusion that current evidence is insufficient to assess the balance of benefits and harms of elder abuse screening. We should research elder abuse screening tools and methods, and analyze the results for policy-makers' consideration in future decisions about elder abuse screening.

- **Risks of screening:** We need to understand more about whether and to what extent screening can exacerbate the risk of abuse and how to address and reduce that risk.

- **Settings for screening:** We need to identify and prioritize the settings in which individual and population-based screening for elder abuse should take place.

- **Tailored screening:** In developing screening tools we need to consider conceptual frameworks, varying needs of different populations, setting and dynamics of abuse that affect their use. Screening should be done in a culturally competent manner. Development of screening tools and procedures should address that some people being screened lack cognitive capacity and that some proxies who respond might be abusers.

- **What happens after someone is "screened-in":** We need to think through not only *how* to screen for elder abuse, but what happens when screening indicates a problem (e.g., ongoing or risk of abuse). It is critical to think through the consequences of detecting and reporting abuse when the response is often inadequate or non-existent.

- **Validated screening tools:** We need to develop an evidence base about which screening tools are valid and suitable for different types of victims, abusers, and settings, taking into account costs in both time and money.

Facilitated Discussion on Victim Services

"We need to look at improving access and quality in victim services whether the person is APS client, in the health care or criminal justice system, and regardless of their relationship with the perpetrator. These victims often need support and linkages to services in different ways than other victims because of their relationship with or dependence on the perpetrator who is often an adult child."

– Victim Services FD Participant

Discussion Participants:

Carol Dayton, ACSW, LISW, *National Adult Protective Services Assn-National Committee on Prevention of Elder Abuse*
Mai Fernandez, JD, MPA, *National Center for Victims of Crime*
Trudy Gregorie, *Justice Solutions*
Tasneem Ismailji, MD, MPH, *Academy on Violence and Abuse*
Mary Lynn Kasunic, *Area Agency on Aging, Region One in Arizona*
Suzanne Brown-McBride, *Council of State Governments Justice Center*
Meg Morrow, JD, *Office for Victims of Crime, Department of Justice*.
Joy Solomon, JD, *Weinberg Center, Hebrew Home*
Kate Wilson, *Victim Advocate, San Diego District Attorney's Office*

Victim services are programs that work with older adults who have been victimized. Traditional victims services, i.e. domestic violence, sexual assault, and Victims of Crime Act (VOCA) programs, provide a range of services including safety planning, shelter, support groups, legal advocacy, and immigration victim assistance. In addition to traditional *victim services*, various entities and programs provide services to elder abuse victims but are not traditionally referred to as victim services. Adult Protective Services investigates and provides a range of responses to allegations of elder abuse in every state. The long-term care ombudsman advocates on behalf of long-term care residents on issues including neglect and abuse and residents' rights. And a range of aging services network providers offer services such as meals, senior centers, adult day care, and case management to older people (all of which may prevent or offer opportunities to detect elder abuse).

Priorities:

- **Adult Protective Services:** In partnership with experts and outcome measures in program evaluation, APS should develop standards. APS needs additional infrastructure and capacity to meet the needs of elder abuse victims.

- **Aging services network**: The aging services network provides a wide array of programs that could benefit older victims and detect, prevent, and ameliorate elder abuse. The aging services network must increase awareness of elder abuse and train staff to identify and respond to elder abuse. The aging services network should give elder abuse victims priority if programs have waiting lists.

- **Coordination:** All networks providing services to older victims should coordinate to reduce fragmentation and improve person-centered services to meet older victims' needs.

- **Promising and innovative programs:** We need to identify and evaluate promising and innovative practices and create programs tailored to older victims. If effective, those programs should be replicated.

- **"Patient-centered medical home":** The "patient-centered medical home" is a health care concept developed to contain costs and provide comprehensive, coordinated patient-centered care wherever the patient is. Medical home health care providers should be trained to recognize and respond to elder abuse, and the patient-centered medical home model should incorporate measures to prevent and respond to elder abuse.

- **Victim services:** Victim services providers (e.g., domestic violence and sexual assault programs, systems-based advocacy programs [in courts, law enforcement and prosecution offices], and VOCA-funded programs) must do more to tailor and offer services to older adults. National and state coalitions must address the needs of older victims in training and technical assistance. We need to encourage communication and education between existing victim services and entities responding to elder abuse.

Appendix H. Expert Interpretation and Analysis – Leadership Interviews

A critical element of the Elder Justice Roadmap Project was seeking insights and ideas from well-respected, high-level government officials, thought leaders, and heads of influential organizations regarding their views on a variety of issues with a bearing on elder abuse. The subject matter experts provided recommendations regarding both the names of leaders to interview and the areas of expertise that they should represent. Each of the leaders interviewed has broad expertise and experience that cuts across more than one relevant area. They include:

- Lorraine Cortes-Vasquez, MPA, *AARP, Executive Vice President for Multicultural Markets*
- Florence Davis, JD, *President and Director, Starr Foundation*
- John Feather, PhD, *Executive Director, Grantmakers in Aging*
- Judith Feder, PhD, *Professor, Georgetown University Public Policy Institute; Urban Institute Fellow, and member, Long-Term Care Commission*
- Ron Peterson, MD, PhD, *Mayo Clinic Department of Neurology; Director, Mayo Clinic Alzheimer's Disease Research Center; Chair, National Alzheimer's Project Act Advisory Council*
- Ron Pollack, JD, *Founding Executive Director, Families USA*
- Lynn Rosenthal, *White House Advisor on Violence Against Women, Office of the Vice President*
- Ricki Seidman, JD, *TSD Communications*
- Paul Smocer, *President, BITS, Financial Services Roundtable*
- Mike Splaine, *former Director of State Government Affairs, Alzheimer's Association; Splaine Consulting*
- Howard Spivak, MD, *Director, Division of Violence Prevention, Centers for Disease Control and Prevention*
- Christopher Stone, JD, MPhil, *President, Open Society Foundations*

The people interviewed had numerous areas of substantive expertise, including aging, caregiving, child abuse, communications strategy, dementia, criminal justice, diversity and inclusion, domestic violence, federal advisory committees, financial services, foundations, grant-making, health policy, health surveillance, impact litigation, juvenile justice, legislative and policy strategy, local, state, and national advocacy networks, outreach to multicultural populations, political strategy, population research, raising public awareness, research protocols, prevention, sexual assault, and more.

The prevailing view was that, though not a simple area, elder abuse is a problem with solutions where meaningful progress is possible. The progress that has been made in addressing other pervasive social issues is possible when it comes to elder abuse. To that end, the ideas and priorities identified in the leadership interviews fall into three broad categories: (1) priorities consistently cited in most interviews, (2) general priorities, and (3) specific priorities.

Priorities identified in the Leadership Interviews

1. Recommendations consistent among the Leadership Interviews:

Although the leaders who were interviewed came from widely divergent fields, there were some striking consistencies among their recommendations.

"It's a very difficult issue but you can't argue against saying 'it's something bad and we should fix it.…'"

– leadership Interview

- **Cultivate Allies:** "Cultivate natural allies outside the field." Develop constituencies. Figure out where the issue fits best within an administration's ongoing priorities and structures with greater prominence and clout. Find individuals inside government entities, non-profits and potential funders who might be sympathetic, then keep following up with them. Even if elder abuse is not a highly visible priority, productive work that advances the field can occur behind the scenes.

- **Develop a clear, targeted message:** Virtually all of the leaders said, in some way, that the elder justice field's messages are confusing or imperceptible and need to be clearer and more focused and targeted. One leader recommended creating one-page documents with clear, consistent, simple messages. Another said to begin by targeting people who can affect change. Others suggested enhanced use of social media. There are existing communication pathways in most sectors that might be used to raise awareness about elder abuse (for example, pairing a message about preventing elder financial exploitation with a message about financial literacy). In developing a message, it is critical to be clear about (1) the audience, (2) the goals, and (3) the best message for the particular audience. The message will differ for people who catalyze change, policymakers, researchers, varied professionals, and the general public.

- **Focus:** The elder justice field cannot do everything, especially with limited resources. Select clear priorities and focus attention. Drown out the rest of the noise. Be careful of "mission creep."

- **Fundable issue:** Most of the leaders have experience with both sides of the funding equation – both seeking funds and giving them away in public and private capacities. The prevailing view was that it is not an easy time to raise funds in general, and that elder abuse might be a bit more difficult than other issues given low levels of awareness and policy priority, but that there is no structural or other impediment to funding efforts to address elder abuse if funders are asked the right way.

- **"Gentle pressure applied relentlessly"**: Never, never give up.

- **How to Frame the Issue:** One leader cautioned against defining the issue too broadly, making it seem so pervasive and daunting to make success in tackling it seem impossible. This, however, should be balanced with another view that to portray only the most extreme cases (for example elder abuse murders) will result in some people not being able to see themselves as potentially affected by the problem, and thus not taking preventive measures against a broader range.

"I think one of the difficulties is that no one knows what elder justice is. When I say - tell me exactly what you mean by elder justice - everyone says something different. In every group I've been involved with you go round and round about the precision of language, but if the language is not compelling to the people who don't know anything about what you're doing, you're not going to convey anything to them."

– leadership Interview

2. General priorities cited in Leadership Interviews:

- **Advocacy infrastructure**: The elder justice field needs an advocacy organization with resources, staff, and a mission for which addressing elder abuse is a clear and identified priority.

- **Cost**: Develop data about the cost of elder abuse. Then get the message out, including to the financial sector, which will recognize the potential for risk management. Explore various ways to develop cost data including by developing initial cost estimates by examining case studies. This method helps to break out the cost of different phenomena (abuse, neglect, and exploitation) in different settings (home, community, and facility). But, one person cautioned, entities that "score" the cost of prevention efforts will balance the estimated amounts that might be saved with those that would be expended targeting a broader population than known victims. In other words, prevention is expensive.

- **Criminal justice:** There was a divergence of views on whether a criminal response to elder abuse should be a priority, with one person saying that the criminal justice system is unlikely to bring about meaningful change and another saying that criminal accountability is important. However, there was complete agreement regarding the importance of training and engaging law enforcement.

- **Data:** The elder justice field needs surveillance data (like that collected by CDC) to validate that elder abuse is a problem and provide additional data. The field also needs to develop information about who the perpetrators are and what is motivating them.

- **Diversity and inclusion**: It is important to reach diverse and underrepresented and underserved populations. (Some populations appear to be especially hard-hit by elder abuse.) The field needs to work with grassroots organizations and publicize those populations' trust (such as *El Diario* and *Univision*). Identify trusted *validators* (trusted individuals) to validate the messages relating

to elder abuse. It also is important to train diverse professionals and leaders from each community who bring multicultural perspectives to all aspects of practice and education.

- **Domestic violence and sexual assault:** In urging domestic violence and sexual assault fields to address the needs of older victims, begin with physical abuse and sexual assault – clearly within their ambit. Do not lead with the relatively new and unfamiliar issues of financial exploitation or neglect.

"If consciousness building is what you're trying to do at this stage and you've identified who are the most important targets, you can assess – will this analysis reach them? What do we need to do? Will it be through media or some other outlet?"

– leadership Interviewee

- **Financial exploitation:** Some informants suggested that because the public is more likely to be able to relate to (and contemplate) financial exploitation than abuse or neglect, it might make sense, for tactical reasons, to lead with that issue in raising awareness and developing policy.

- **Impact litigation:** Impact litigation can be an effective way to change systems, but it is labor intensive and more difficult to pursue successfully now than in previous decades. If it is necessary to select a single course, consider beginning with raising public consciousness.

- **Piggyback:** Integrate elder justice issues into existing structures, initiatives, regulations, protocols, research studies and so on. Piggyback onto ongoing efforts relating to aging, chronic disease, dementia, or mental health.

- **Target research:** In deciding what studies to prioritize, consider what impact they will have from a communications perspective. Will the results raise awareness, get attention, or educate the public about prevention? Also, re-analyze existing data in new ways so that the data reveal new information.

- **Training:** It is important to create training tailored to different sectors. For example, in the financial sector, develop materials educating employees for "what to look for" (to detect possible elder financial exploitation) and what they should do if they suspect elder abuse. Develop toolkits to educate older people and their caregivers about financial literacy, exploitation, and what to do if they have concerns.

- **Use existing systems:** Instead of building a new system to respond to elder abuse, strengthen and, if necessary, re-purpose existing pathways and systems to more effectively address the problem.

3. Specific priorities cited in the Leadership Interviews

- **Champions:** Identify and cultivate powerful champions. Examples include policymakers, thought and opinion leaders, potential funders and officials in Congress, the White House, government agencies, the business and financial communities, and influential advocacy groups.

- **Child abuse prevention model:** Child abuse prevention provides a good parallel for some types of elder abuse and is supported by a substantial evidence base. Programs successful in preventing child abuse involve home visits by nurses and others, nurse-family partnerships and other interventions. These are individual-based programs. Population-level prevention efforts should supplement the individual ones so that the problem is addressed at multiple levels.

- **Financial services multidisciplinary efforts:** The financial services industry should try using a multidisciplinary approach (including older persons, family members, representatives of the financial institution, and perhaps medical professionals) to develop and authorize a coordinated plan to protect assets while also respecting the older person's autonomy.

- **Prospective political candidates:** Talk to candidates early in the election cycle while they are still receptive and have time. Give them information, get them engaged, and elicit commitments.

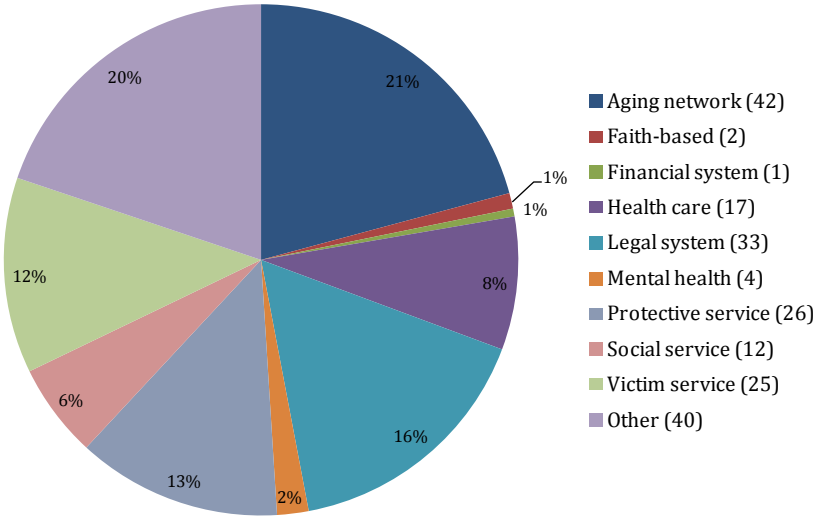
- **Story bank:** Develop a story bank describing individuals' experiences. Organize the stories by topic and location so they are available for press and politicians. This is a lot of work and requires careful vetting, follow up and organization by location and subject.

- **Technology:** Technology could be used more effectively by the financial services industry to identify scams or exploitative patterns and trouble shoot for problems.

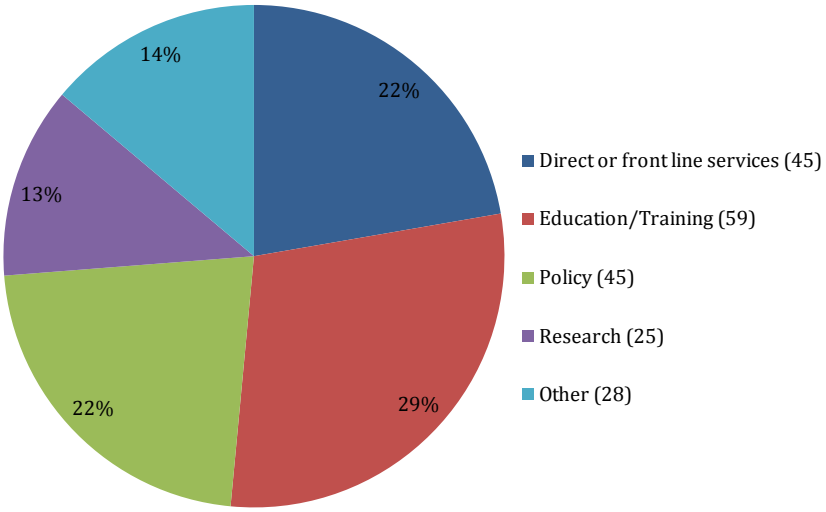
APPENDIX I. Demographics of Participants

The following charts indicate responses to the demographic questions asked of the participants who completed the sorting and rating activities.

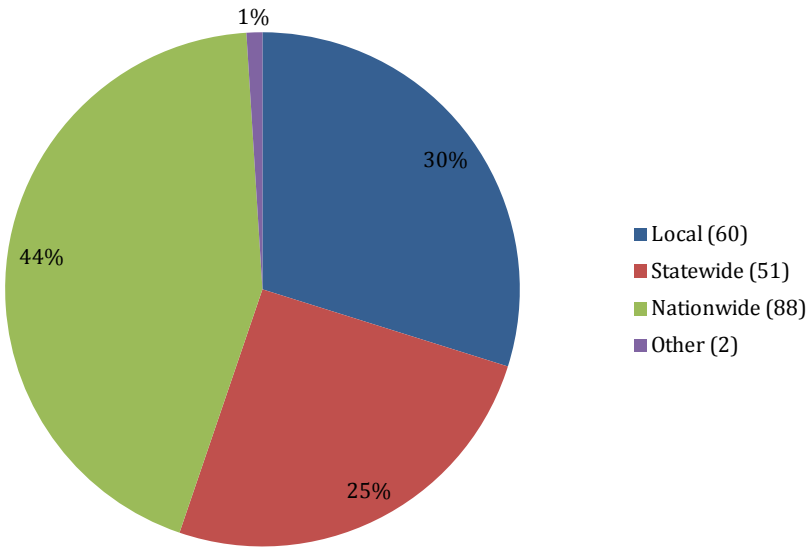
1. ***Which of the following best describes the system in which you work in relation to elder abuse?***



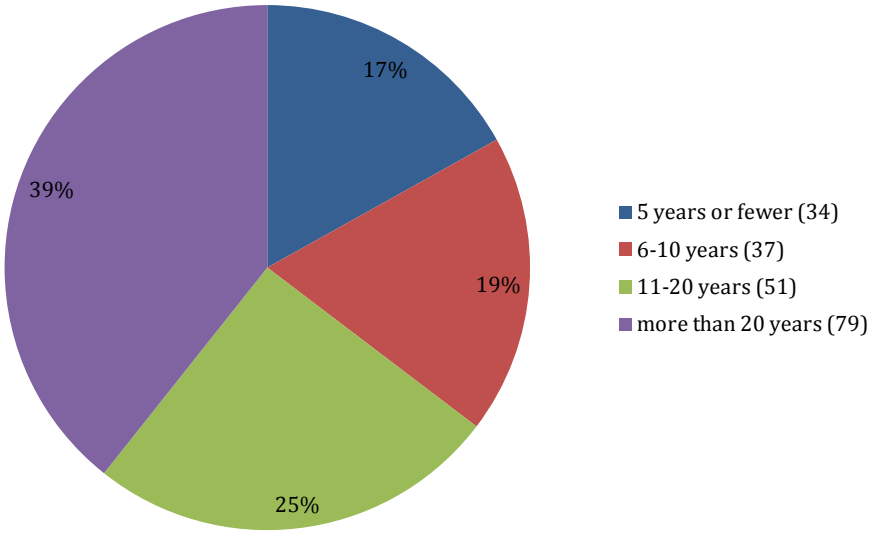
2. ***What is the principal nature of your work relating to elder abuse?***



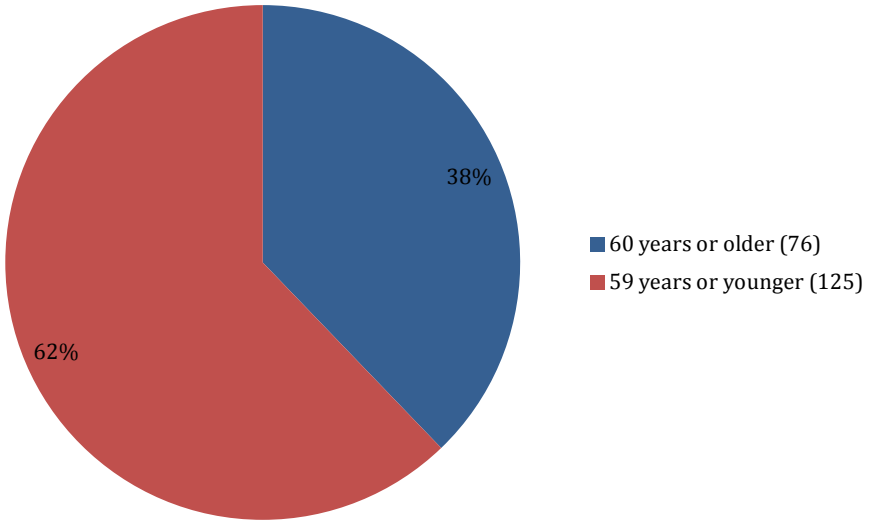
3. Which of the following best describes the primary geographic focus of your work?



4. How long have you been involved in elder abuse-related work?



5. *What was your age on your last birthday?*



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