

Elder Mistreatment in an Aging America: An Urgent Need for Research

Statement of

Richard J. Bonnie

Chairman, Panel to Review Risk and Prevalence of
Elder Abuse and Neglect
National Research Council/National Academy of Science

and

Schools of Law and Medicine, University of Virginia

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Mr. Chairman and members of the Committee:

My name is Richard Bonnie. I am John S. Battle Professor of Law, Professor of Psychiatric Medicine, and Director of the Institute of Law, Psychiatry and Public Policy at the University of Virginia. I am a member of the Institute of Medicine of the National Academy of Sciences, and I am appearing before you today in my role as the chair of a study on elder abuse and neglect recently conducted by the National Research Council, the operating arm of the Academy. Our study committee was established in the spring of 2001, in response to a request by the National Institute on Aging, to assess the state of knowledge in this field, and to make recommendations for future research. Our report was released yesterday, and I am immensely pleased to have the opportunity to present our conclusions and recommendations to you and the American people today.

I have given the Committee's staff a pre-publication copy of the report, entitled *Elder Mistreatment: Abuse, Neglect and Exploitation in an Aging America*, and am appending to my written statement the Executive Summary of that report. In my testimony here today, I would like to make five points:

Very Little is Known

First, it is genuinely amazing how little we know about this important subject. A thorough search of the scientific literature turns up fewer than 50 peer-reviewed studies. No major foundation has identified elder mistreatment as one of its priorities, and federal investment has been modest at best. For example, fewer than 15 studies on this subject have been funded by the National Institute on Aging since 1990, and support from other agencies has been episodic. As a result, very little is known about the nature and magnitude of elder abuse and neglect, its causes and consequences, the effectiveness and cost of current interventions, or measures that could successfully be taken to prevent it or to ameliorate its effects. The best metaphor to describe current knowledge is a nearly blank slate, a *tabula rasa*. The gaps in our knowledge are enormous.

Prevalence Data are Urgently Needed

Second, there is an urgent need for studies on the prevalence of abuse, neglect and exploitation. I have participated in ten studies on behalf of the National Academy of Sciences. Reports in this genre typically begin by calling attention to the magnitude and social cost of the problem being explored, before going on to identify opportunities and priorities for research, programmatic action and policy initiatives. There is simply not enough information to describe the magnitude and social cost of elder mistreatment. That fact is a telling indication of the compelling need for the panel's report, as well as for an intensified program of research.

No survey of the U.S. population has ever been undertaken to provide a national estimate for the occurrence of any form of elder mistreatment. The magnitude of the problem--among community-dwelling elders, as well as those residing in long-term care facilities--is basically unknown. Most of the research thus far conducted in this field has

relied on records of social service agencies. But valid prevalence data (rates of abuse, neglect and exploitation) can be developed only by studying populations (in communities or institutions, or wherever people are found). Studying reported cases is not sufficient, because only a very small proportion of cases reach agency attention -- and we have no idea what proportion it is. Only a handful of population-based studies have been conducted, and most of them have been fielded in other countries.

The panel's report offers a sequential strategy for prevalence research:

- Improved definition, measurement and instrument development for each of the various forms of mistreatment;
- Methodological studies to identify the best methods for ascertaining occurrence rates among different populations in different settings (e.g., in the home, in assisted living locations, and in nursing homes), taking into account variations in cognitive capacity of the elder subjects, and the availability and reliability of proxy respondents;
- Local area studies using multiple modes of case ascertainment for different settings (e.g., family homes, assisted living facilities, nursing homes).
- Adding small modules on aspects of elder mistreatment to ongoing national surveys of the elderly population; and
- Eventually, a full-scale national prevalence study.

Though Unquantified, the Problem is Serious and Likely to Grow

Even in the absence of adequate prevalence data, available information from clinical and social service settings and agency records gives us a sound basis for believing that abuse, neglect and exploitation of elders are significant problems. In terms of magnitude, rough estimates, based on figures extrapolated from local studies, suggest that the national prevalence of elder mistreatment (including physical abuse, psychological abuse, and neglect) is likely to be between 2% and 4% of the older population, and perhaps twice that high if financial exploitation is included. At any point in time, between one and two million vulnerable elders may be experiencing (or are at high risk of experiencing) mistreatment.

It is likely that mistreatment is associated with substantial added morbidity and disability in an already vulnerable population (though, as I said, we have virtually no good data on the consequences of mistreatment). There is some evidence that mistreatment is associated with accelerated mortality.

Moreover, the occurrence and severity of elder mistreatment are likely to increase markedly over the coming decades, as the population ages, caregiving responsibilities and relationships change, and increasing numbers of older persons require long-term care.

Research is Needed to Respond Effectively to the Problem

Aside from prevalence research, here are some examples of what we need to know, and why it would help:

- *How should we define elder abuse and neglect for various policy purposes?* Although we emphasize in our report that scientific definitions need not track legal definitions, it seems clear that legal definitions and responses should be grounded in empirical understanding of the types of conduct that are most harmful and that pose the most serious risks. Right now, we have very little systematic knowledge about the phenomena that could potentially be characterized as abuse, neglect or exploitation, and about the antecedents, clinical course and outcomes of various forms of mistreatment. For all this, we need to have good longitudinal studies of vulnerable elders who have (and have not) been mistreated.
- *What data systems do we need for monitoring occurrence of mistreatment in various settings, including emergency rooms and long-term care facilities?* Issues of definition and measurement must be studied and resolved in order to implement useful surveillance systems that go beyond the APS case reports. For example, the NRC panel endorses a recent IOM recommendation concerning the need for uniform definitions and data elements for characterizing the components, processes and outcomes of long-term care across different settings of care. We emphasized that uniform data elements relating to mistreatment should be included in the outcome measures.
- *How can we identify elders who are being neglected or abused in order to intervene effectively and prevent further harm?* A key component of any effective strategy for protecting vulnerable elders from mistreatment – whether they are in the community or in nursing homes – is careful screening and, where indicated, individual assessment. Two major challenges arise in connection with screening and case-identification.. One is developing markers for otherwise hidden mistreatment to facilitate efficient screening in clinical and social service settings. The other is the development of clinical criteria for differentiating symptoms of the natural conditions and illnesses that are associated with physical frailty and aging from evidence of mistreatment. Forensic research on elder mistreatment is a high priority. Research is needed, for example, to illuminate the characteristics of common injuries, such as their etiology, natural course, distribution and severity so that the process of identifying cases of elder mistreatment can become more accurate and reliable. While certain physical signs (such as burns and ligature marks) are likely to be more reliable indicators of elder mistreatment than others (such as fractures and pressure sores), neither the challenge nor the importance of advancing knowledge in this area should be underestimated. We need to avoid both

false negatives and false positives: On the one hand, mistakenly attributing nutritional deficiencies to the course of an illness, overlooking signs of neglect, can prolong and magnify the victim's suffering. On the other hand, mistakenly characterizing a spontaneous bruise or other injury as intentionally inflicted may lead to substantial clinical, social and legal jeopardy for all concerned.

- *How can we prevent mistreatment before it occurs (or escalates in severity)?* Research on the effects of policies or programs aiming to prevent or stop elder mistreatment is urgently needed. (The panel uses the term “interventions” in the broad sense to refer to the full array of activities aiming to prevent mistreatment from starting, to prevent it from continuing or escalating, and to protect a victim or remove a perpetrator.) Existing community interventions to prevent or ameliorate elder mistreatment have not been evaluated, and it is possible that some programs make things worse. In the NRC panel's view, agencies funding new intervention programs should require and fund a scientifically adequate evaluation as a component of each grant. The panel also recommends research on the effectiveness of APS interventions, and encourages the development of APS/university research teams whose mission would be to evaluate existing data, recommend improvements in the collection of data, analyze incident reports, and design studies to assess outcomes. Another important research priority concerns the effects of nursing home staffing levels and configurations on the occurrence of mistreatment.
- *Are preventive and protective interventions cost-effective?* Ultimately, it will be important to know whether preventive and protective interventions reduce morbidity and mortality, including Medicare and Medicaid expenditures. Our capacity to answer ultimate policy-relevant questions of this kind depends on systematic longitudinal research in various settings, with appropriate comparison groups. This research is feasible, but not in the short term. The groundwork first needs to be laid.

We Need to Build an Infrastructure for Research

In *Understanding Child Abuse and Neglect* (1993) and *Violence in Families* (1998), the National Research Council was able to map out a comprehensive blueprint for research in the adjacent domains of child mistreatment and intimate partner violence. However, so little is now known about elder mistreatment that it would be premature to draw up detailed research agenda. Instead, the panel's report is best seen as laying the foundation for a much-needed effort to “jumpstart” this nascent field of scientific investigation.

An important part of this effort is to establish an infrastructure for research, and to recruit researchers from the range of disciplines whose collaboration is needed. Here are a few ideas about how we might propel this field forward at a sensible and productive pace:

- A one-time investment will not do the job. *An adequate long-term funding commitment to research in elder mistreatment must be made* by relevant federal, state, and private agencies to support research careers and to develop the next generation of investigators in the field.
- *Research on elder mistreatment should be connected to the mainstream research agendas of agencies other than those already in the field.* Most research on elder mistreatment has been supported by the National Institute on Aging, the Administration on Aging, and a few other agencies in DHHS and DOJ. Funding agencies with interests in aging or disabled or vulnerable populations, or in health care delivery (especially long-term care) and health/social policy research, should invest in research in this important and understudied domain affecting older adults.
- *Some aspects of elder mistreatment research require agency collaboration.* Recognizing that elder mistreatment crosses categorical boundaries in both health research and social science research, federal funding agencies (e.g., the National Institute on Aging, the Administration on Developmental Disabilities and Rehabilitation Research, and the National Institute of Justice) should work collaboratively to promote research on the abuse and financial exploitation of vulnerable adults, including older persons as well as younger adults with disabilities.
- *Another promising idea would be to locate aspects of elder mistreatment research relating to caregiving in the domain of quality assurance in long-term care.* According to the prevailing conceptualization of healthcare quality (easily extended to other human services), patient (or client) safety is one of the four components of quality in services (together with effectiveness, patient-centeredness, and timeliness). It is already understood that prevention of mistreatment is a core element of quality assurance in nursing home regulation. However, 80 percent of vulnerable elderly persons live in community settings, not in nursing homes. Protecting elderly people in these settings, including their own homes, represents a parallel challenge for public policy and an overlapping agenda for researchers aiming to understand the phenomenology, etiology, and consequences of mistreatment and the interventions that can reduce it. By viewing elder mistreatment through the prism of quality assurance (safety and security) in long-term care, it is possible to draw together the frameworks and methods of researchers studying the needs of, and services provided to, vulnerable elderly people in various long-term care

settings, as well as those used by researchers studying power and conflict in human relationships

- In other fields of research needing a “jumpstart,” *one particularly useful device for infrastructure-building has been the creation of multi-disciplinary research centers*. This mechanism has been used effectively in the field of injury prevention and treatment, as I learned in chairing an IOM study on this subject. (See IOM, *Reducing the Burden of Injury*, 1999). Although the NRC elder mistreatment panel did not discuss this idea, I personally believe that creation of three to five Centers for Research on Elder Mistreatment – drawing together researchers and service agencies – could quickly propel the field forward.

Concluding Comment

Although the magnitude of elder mistreatment is unknown, its social importance is self-evident. Abuse and neglect of older individuals breaches a widely embraced moral commitment to protect vulnerable people from harm and to ensure their well-being and security. To carry out this commitment, society cannot rely on good intentions alone. A substantial investment in scientific research along the lines outlined in the NRC panel’s report is an essential component of a comprehensive and effective national response.