White Paper

Research Directions in Elder Mistreatment Research

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It was a distinct pleasure to testify on suggested research directions before on the Elder Justice Coordinating Council in Washington, DC on October 11, 2012. This "white paper" is an elaborated version of my comments, and offers suggestions on how where the field of elder mistreatment should go and some ideas on how to get the most from available research funds. The paper is in two parts: the first deals with directions in research policy; the second suggests a number of targeted, specific research directions.

Federal Research Policy on Elder Mistreatment (EM)

It is important to start with some suggested directions in federally-sponsored research policy, because the US federal government sponsors most of the health and related social research in the US and at the present time research funds are scarce. Therefore funds distribution should be done with extreme care. The following are some suggestions to research policies that may maximize research output and results:

1. Catalog existing research on EM.

Careful cataloging of existing research and related policy interventions should be carefully gathered and cataloged, to avoid duplication or pursuing less fruitful methods or themes and maximize productivity. It might be of value to conduct systematic reviews and even meta-analyses where enough sound studies are available. This should include not only direct elder mistreatment, but also related knowledge from all dimensions of domestic and institutional mistreatment and violence. It should be noted that not all important work have been

performed in the US; important studies performed elsewhere can have an important impact on our knowledge of causes and potential interventions.

2. Specifically target research themes.

In my view, a substantial portion of federally funded research should be targeted to the most important research themes, where knowledge is lacking and issues are unsolved. While there are such themes suggested below, the list should be developed by a panel of investigators along with federal officials involved with EM policy. Of course, there should always be some funds available for new ideas and previously unidentified problems, but in the case of EM, many of these problems have been identified.

3. Promote new investigators in EM.

Consider targeted funding to increase the size and scope of the investigative workforce in important research areas related to EM. An important example might be training and coordinated research in forensic medicine and practice. Working with appropriate professional organizations, plans could be made to provide modules of training and possibly pilot research funding. This needn't be limited to health professionals, as other scientists working in sociology, psychology, justice or criminology might be important recipients of such research and training funding. It is not a great stretch to consider starting fellowships in EM research, perhaps in part with funding from voluntary organizations.

4. Facilitate EM research by means in addition to providing extramural research funding.

There are a number of important activities that federal agencies can do to promote effective EM research besides providing funds. Perhaps most important is facilitating the sharing of federal data relevant to mistreatment and EM research, including information collected on justice matters, social and environmental matters, housing policies relevant to EM, urban design and structure, and informative clinical information that may be in its possession. It is appreciated that sharing such information may have legal and logistical impediments, it is critical to for various types of policy research. Federal agencies should also facilitate research in the private sector, particularly the banking and financing industries, in order to improve progress with respect to detection and prevention of financial mistreatment. Finally, and also challenging, federal agencies should conduct internal evaluations of their own EM policies, to determine their own efficacy and effectiveness and to promote and accommodate new and promising policy initiatives. Too often, the value of many well-meaning and potentially important policies is never determined.

Selected Research Themes on Elder Mistreatment

The following are some potential research themes that the author believes are central to improving the prevention and control of EM in the community and institutions. Some research has been performed in each of these areas, and other research directions are possible, but in the author's view the suggestions below are likely to be among the most fruitful in the short and medium terms:

 Develop and pilot improved qualitative methods for understanding how EM in the community reveals itself to social agencies and institutions.

Among the most important elements of research directions that should be funded now is to conduct new studies, beginning on a small scale, on how to get closer to "truth" on rates of EM occurrence rates in American society. This not for the sake of accuracy alone, but because it is likely that the rates we cite are not very accurate, and the economic basis for research and EM control may be mischaracterized. This potential inaccuracy is suspected because of the complexity of EM, which in the community takes place mostly in intimate personal and family settings, where accurate observation is extremely limited and many family secrets are never revealed. Truer rates may only be revealed by triangulation of multiple sources of data collection and a combination of quantitative and qualitative studies. Without this fundamental work, there will be no credible benchmarks for federal EM control and program evaluation, and will deter further advances in clinical screening for EM, which has been an important prior goal of EM research. Methods might include clinical interviewing of victims, family and household members, other persons in relevant social networks, including health, social and justice professionals, and perpetrators.

2. Promote research to develop a consistent federal taxonomy and nomenclature of EM for use in research and administrative matters.

In keeping with Recommendation #1, above, the federal government should promote research on creating a standardized and consistent clinical and administrative EM taxonomy and nomenclature for diagnosed and suspect cases of EM. This would be applied in all research and

related administrative communications and measurement assessments across all departments and agencies dealing with EM. All important EM domains, such as physical and psychological abuse, institutional abuse, financial abuse, and elder neglect should be considered. This will require some research on linguistics, disease taxonomy and nomenclature and natural language processing. This could be supported by National Library of Medicine, which supports medical linguistic activies such as the Unified Medical Language System. Related to this are informatics issues on how to detect EM in federal programs and activities. Without this harmonization of nomenclature in federal data bases, further work will be difficult.

3. Conduct conceptual and community-based research on the nature and outcomes of "neglect" among EM victims.

Particularly important is the need to revisit and reconceptualize the entire notion of the EM labels of "neglect" and "self-neglect." It is probably the most common of EM situations in the US where older persons disabled by mental and physical illness to the point of limited ability for self care; usually, others in the social environment are unwilling or unable to assist that person. But this is a complex "diagnostic" social problem and in most instances the label is not productive from a policy perspective. The central issue is defining need, whatever its orgins. Important factors that need to be evaluated include poverty, limited literacy and self-efficacy, lifelong intellectual disability, the presence of equally impaired family members, and unresponsiveness by the social and health care systems. Each of these situations requires very different remedies, but perhaps underlying this complex and diverse syndrome is a person with basic human needs. This syndrome needs accurate characterization (diagnosis) and evidence-

based management. The use of current EM labels may becloud appropriate management of what might be the largest EM problem of all: impoverished, sick, disabled persons unable to engage in self-preservation. The most important thing that can be done now is to determine the role of poverty (and its encumberances) and the lack of social and medical support as the fundamental causes of this syndrome of "neglect." Only then can appropriate actions and remedies can be taken.

4. Conduct research on modern technological ways to detect possible EM in both community and institutional settings.

There is a need to promote research on ways in which putative EM can be "automatically" suspected or detected in home and institutional circumstances, applying a variety of modern, technologically-driven detection and surveillance devices. In the era of the "smart home" and highly monitored institutional settings, this should be increasingly possible. Positive signals can then be detected and at least related to the clinical picture of potential victims. There is already a precedent for assessing the quality of social interactions electronically with electronic sensors.

5. Fund research on the potential for community-based interventions to <u>prevent</u> EM, including those conducted by formal health departments.

There is very little research on community-based interventions that have the potential to prevent EM before it starts. As an exercise, research funders should try to identify and count the number of public service announcements over a given time period concerning the problem

of EM. There has been research on the secondary prevention of EM, suggesting that interventions within individual homes where EM has occurred can deter subsequent EM episodes, affecting both perpetrators and victims. These might include, for example, respite care and educational programs. Further research in this area is likely to be fruitful, but there is almost no research on *broadly-based community interventions* on decreasing EM rates. A critical issue is the role of formally constituted public health departments at the state and local levels. How EM might be mitigated at the community level is all but unanswered. Would community education programs be of value? Could school-based education encumber children as agents against physical or psychological mistreatment? Could potential perpetrators with histories of alcoholism or illicit drug abuse be identified in advance of crimes with useful interventions? Pilot interventions that are well-grounded in both behavioral theory and community intervention methodology should be tested in a variety of geographic and cultural settings.

6. Experiment with new prevention and intervention programs in populations served by federally-administered health programs, such as the Veterans Affairs Health System, the Indian Health Service and federally-sponsored health community health centers.

As noted in #5 immediately above, prevention is all by untested. Some venues for health

services delivery, where the federal government has jurisdiction, see many older patients where elder mistreatment incidence and prevalence are among the most common documented in the United States, and these may be among the most important for testing the role of prevention. Some important venues are the Veterans Affairs Health System, federally-

sponsored community health centers and the Indian Health Service. Within these programs, there is a need for greater emphasis on research programs that: a) lead to more complete and accurate recognition of EM; b) document the special clinical consequences of EM in patient-victims; and c) develop more efficient and effective methods for addressing and mitigating the problems through a combination of health and social interventions. Because of available data and committed health professionals and administrators, these venues could provide leadership in understanding community approaches to EM.

7. Federal agencies should strengthen forensic research aimed at detecting EM in state and local jurisdictions.

Forensic techniques to detect physical abuse among potential EM victims are severely underdeveloped, and rigorous research is needed to identify such abuse in the clinic, the pathology suite and other important community settings. Biomarkers and radiographic, toxicological and other techniques are needed to define the differences between naturally-occurring illnesses and injuries and the trauma associated with EM. Whether in the clinic or in the autopsy suite, there are very few validated modern tools to discern the role of EM in causes of stress-related conditions, promotion of co-morbid illnesses, and death. The forensic services of the US are desperately in need of new and concerted research in this area. This will assist both the health and justice EM communities.

8. Federal agencies should partner with the financial and banking industries to do research on developing signals indicating possible financial abuse.

This is a critical need to better understand the occurrence and circumstances of financial mistreatment, since the episodes rarely lead to scrutiny by any social or protective agencies. This may also include so-called "POA abuse" (power of attorney abuse). There are many possible dimensions to this, but creative remedies are not well-developed, even though some banking and trust systems have experimented with signal detection of misuse of funds belonging to older persons. The federal government should partner with the financial industry and the private legal communities to explore systematic research that might include: a) developing new controls on the disposition of financial assets of impaired elders, such that signals occur if untoward flows of funds occur; b) monitoring the flow of funds by those who have medical or durable power of attorney to look for signs inappropriate monetary acquisition or expenditures; and c) developing model research programs to test the efficacy and enforceability of criminal penalties in deterring financial mistreatment.

9. Conduct evaluation research on the efficacy, including outcomes, of the basic practices of Adult Protective Services (APS).

APS is a critical part of the fabric of screening, investigating and intervening in EM cases. As with other such EM control programs, however, many of the practices vary from one jurisdiction to the next, and whether resources are optimally employed is uncertain.

Immediate, federally supported evaluation research needs to be conducted on the most efficient practices, with outcomes that reflect both specific APS clients and for community as a whole. Multiple evaluative endpoints can be pursued, but in the end lowering the rates of EM in defined populations will be the ultimate benchmark of success.

10. Federal data bases should be made available to do more critical work on identifying EM perpetrators.

These might include bringing to bear such data as prior histories of arrest and conviction, work-related social malfunction, divorce and family violence histories in past records, behavioral disorders in federal medical record data bases, disciplinary problems in the military, excessive numbers of automobile citations, and related clues that may identify EM perpetrators. The federal government can provide or assist the states in acquiring such information on known perpetrators. This approach may turn out to be ineffective, but it needs to be explored. An analogy to how convicted pedophiles are handled may be useful here if the risk situation is discovered. As has been discovered in many types of criminal behavior, a substantial amount of crime may be perpetrated by a smaller number of repeat offenders. In his testimony at the EJCC, Dr. Lachs also made a plea for having federal data available for research.

11. Explore urban and regional planning models and architectural housing design alternatives to determine if various designs promote or deter EM.

The federal government has oversight of a substantial amount of housing in the US, and it is important to determine whether various designs of cities, neighborhoods and housing have an impact, negative or positive, on the rates of EM, which itself must in part be determined by the degree and quality of social interaction of older persons.

12. Explore the efficacy of various state policies, regulations, laws and programs in deterring and controlling EM.

There is a comparative lack of empirical research evaluating the role of state public policies in advancing the public effort to identify, investigate, and prosecute EM. This oversight is problematic because, on one hand, there is clear and direct link between state policies and the protection of older adults and, on the other hand, the modification of state policies may be the most effective and efficient way to reduce the occurrence of EM. Important agencies such the DHHS and DOJ support research proposals that are guided by an over-arching theoretic model hypothesizing that outcomes pertaining to the identification, investigation, and prosecution of EM are shaped variably by state policies and enforcement structures. Consistent with this, priority should be assigned to research proposals that aim to: (a) account for targeted EM policy outcomes (e.g., increasing the number of prosecuted cases), (b) evaluate legislation, regulation, and case law which comprise the foundation of state EAN policies; (c) examine pertinent state agency enforcement structures, and (d) statistically test models in which the outcomes are linked to state policies and enforcement structures nested within contexts where interest groups and other extrinsic variables.

Conclusion

A multifaceted approach to research is needed in order to control or deter elder mistreatment in the community. Such approaches must include research funding, but it also requires a series of steps by relevant federal agencies to facilitate effective research programs, conduct detailed

evaluations of existing important policies and programs and partner with the private sector to identify and execute more effective solutions. The steps suggested above may not be the only ones available, but they should be considered as a way of going forward in this neglected area.

DISCLAIMER:

This White Paper reflects the opinions and thoughts of the author as submitted to the Elder Justice Coordinating Council. It does not represent the interests or positions of the Elder Justice Coordinating Council nor any of the federal agencies that are members of the Council. The Council has reviewed this White Paper and has taken its contents under advisement, but does not endorse nor adopt it wholly or in part as representing the policies or positions of the federal government.