The Availability and Utility
of Interdisciplinary Data on Elder Abuse:
A White Paper for the
National Center on Elder Abuse

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for the
National Center on Elder Abuse

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The National Center on Elder Abuse (NCEA) serves as a national resource for elder rights advocates, law enforcement and legal professionals, public policy leaders, researchers, and citizens. It is the mission of the NCEA to promote understanding, knowledge sharing, and action on elder abuse, neglect, and exploitation.

The NCEA is administered under the auspices of the National Association of State Units on Aging.

National Center on Elder Abuse

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Executive Summary

There is wide consensus that currently a clear picture of the incidence and prevalence of elder abuse in the United States is sadly lacking—and that such a picture "is essential if social policy is to be created to impact prevention and treatment" (National Institute on Aging, 2005). While the National Center on Elder Abuse (NCEA) has collected and analyzed state adult protective services data, the penumbra of additional data elements that might be available through health care, long term care, criminal justice, fiduciary, and legal services networks has remained largely unexplored. Therefore, the NCEA sought the development of a white paper examining such data elements, their scope and limitations, and outlining their potential use by the U.S. Administration on Aging (AoA), other federal agencies, and elder abuse professionals and advocates. In response, the American Bar Association Commission on Law and Aging (ABA Commission) conducted exploratory research on a wide range of possible data sources. This white paper presents and evaluates the results.

The seminal work on the state of knowledge about elder abuse and the substantial lack of data is the National Research Council's *Elder Mistreatment: Abuse, Neglect, and Exploitation in an Aging America*, the report of the Panel to Review Risk and Prevalence of Elder Abuse and Neglect. The report served as the starting point for the ABA Commission research. The research methodology focused on Internet and telephone research, including a broad-based Web scan and telephone discussions with 35 key informants.

A blatant difficulty in elder abuse research is widely differing definitions and terminology (National Research Council, 2003). For example, according to the NCEA:

> elder abuse is a term referring to any knowing, intentional, or negligent act by a caregiver or any other person that causes harm or a serious risk of harm to a vulnerable adult. The specificity of laws varies from state to state, but broadly defined, abuse may be: physical abuse, emotional abuse, sexual abuse, exploitation, neglect, abandonment (the NCEA Web site

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defines each subcategory at
http://www.elderabusecenter.org/default.cfm?p=faqs.cfm).

The National Research Council report uses the term "elder mistreatment," defined
as:

(a) intentional actions that cause harm or create a serious risk of harm
(whether or not harm is intended) to a vulnerable elder by a caregiver or
other person who stands in a trust relationship to the elder, or (b) failure
by a caregiver to satisfy the elder's basic needs or to protect the elder from
harm (National Research Council, 2003).

The report explains that the term "mistreatment" is meant to exclude cases of self-
neglect, as well as cases of victimization by strangers.

Although inconsistent terminology and definitions—or lack of definition—of
elder abuse clearly are a research impediment, this study did not use any specific
definition to guide its research, but rather looked as broadly as possible, seeking to
identify any data at all that related to elder abuse. This white paper uses the term "elder
abuse," rather than "elder mistreatment" to refer generically to the various forms of
abuse, neglect, and exploitation, unless otherwise indicated.

Databases that might yield information on elder abuse fall into two categories—
data regularly coded for either claims or regulatory purposes, and data collected for
research, evaluation, and policymaking purposes. The white paper findings on both kinds
of data sources are summarized in the chart below, and described in greater detail with
references throughout the text. The chart gives a quick overview of the panoply of
"alphabet soup" databases with varying—and all too frequently, little—potential for
shedding light on the incidence and prevalence of elder abuse. *The chart should not stand
alone, but should be read along with the full narrative*. It is difficult to gauge which, if
any, of the items listed in the column on "Potential for Use or Action" are viable and
cost-effective. Several appear more timely and doable than others, and these are set out in
the conclusions.

While each of the listed actions offers some potential to fill in the blanks in the
national picture of elder abuse, taken together they are nonetheless insufficient and
piecemeal. Indeed the examination of data sources for this white paper supports the need
for a national incidence and prevalence study as recommended by the National Research
Council (National Research Council, 2003), as well as the development of scientific

research on elder abuse under proposed projects supported by the National Institute on
Aging.

Profile of Data Sources
Concerning Incidence and Prevalence of Elder Abuse

Data Set	Description	Frequency & Consistency of Collection	Gaps/Limitations	Potential for Use or Action
Adult Protective Services (APS)	State APS programs maintain data on reports and investigations.	NCEA has collected and analyzed state APS data for several years.	NOT STUDIED IN THIS REPORT	NOT STUDIED IN THIS REPORT
International Classification of Diseases (ICD) Coding on Abuse	ICD coding gives statistics on diseases and health conditions. ICD-9 has codes for "adult maltreatment." ICD-10, not yet in use, has codes for suspected and confirmed adult abuse. E-codes (external cause of injury) describe nature of abuse and perpetrator.	ICD coding by health care providers is not in itself a database, but rather serves as a basis for national surveys and databases (see below).	ICD abuse codes rarely used—health care providers code injury or condition as primary diagnosis; have limited training in recognizing elder abuse; may be unaware of abuse codes or reluctant to report abuse. Adult abuse codes not age-specific; must be correlated with age. Frequently no indication of perpetrator. Deficiencies in E-coding.	►Submit comment in proposed rulemaking for ICD-10 recommending elder abuse as distinct category. ►Look for ICD codes showing medical patterns flagging abuse and correlate with age, rather than rely on ICD abuse codes. ►Educate physicians and other health care providers about elder abuse and importance of coding it.
Centers for Disease Control and Prevention (CDC) National Center for Health Statistics (NCHS)—National Hospital Ambulatory Medical Care Survey (NHAMCS)	Survey samples visits to 500 hospital outpatient and emergency departments.	Annual survey.	Relies on ICD data; usage of adult abuse codes very low. Sample, not universe.	►Request NCHS to do correlation of age data and ICD-9 codes on abuse from NHAMCS database.

Data Set	Description	Frequency & Consistency of Collection	Gaps/Limitations	Potential for Use or Action
CDC NCHS National Ambulatory Medical Care Survey (NAMCS)	Survey samples visits to physicians' offices. Participating physicians complete forms for a one-week reporting period.	Annual survey.	Relies on ICD data; usage of adult abuse codes very low. Sample, not universe.	► Request NCHS to do correlation of age data and ICD-9 codes on abuse from NAMCS database.
CDC NCHS National Hospital Discharge Survey (NHDS)	Collects data from 500 hospitals and 270,000 patient records on patients discharged from non-federal short-stay hospitals in United States.	Annual survey.	Relies on ICD data; usage of adult abuse codes very low—"too infrequent to show up."	►Contact project officer for upcoming redesign of NHDS (collection of more in-depth data) to discuss input on elder abuse.
CDC NCHS National Nursing Home Survey (NNHS)	Survey based on national sample of 1,500 nursing homes—uses resident data and interviews with residents and staff.	Conducted periodically, most recently 2004. Next conducted 2009.	No questions currently pertain to abuse.	►Request an interview question be added to NNHS on elder abuse. Barriers = added cost and conflicted facility staff.
CDC NCHS National Home and Hospice Survey (NHHS)	Survey samples 1,500 home health and hospice care agencies. Interviews agency staff, collecting information on six current patients and six discharges.	Conducted periodically. Next conducted 2007.	No questions currently pertain to abuse, although currently a question being added about recognizing elder abuse.	►Request an interview question be added to NHHS on agency staff encounters with elder abuse. Barriers = added cost. Conflict if information also sought on abuse by agency staff as well as abuse by others observed by agency staff.
CDC NCHS Individual Health Care Surveys— National Health Interview Survey (NHIS)	NHIS interviews members of 43,000 households on health matters.	NHIS conducted annually.	No questions on elder abuse; only general questions on injury.	Survey currently has no useful information on elder abuse; age correlations with injury would yield little. Adding question on elder abuse difficult because of cost, reluctance of respondents to report.
CDC National Violent Death Reporting System	National Center for Injury Prevention and Control (NCIPC)	Began in 2003. Additional states to be added each year.	Currently only 17 states participating.	►Obtain data that will be released soon regarding violent

Data Set	Description	Frequency & Consistency of Collection	Gaps/Limitations	Potential for Use or Action
(NVDRS)	funds state health departments to collect data on violent deaths from death certificates, medical examiners, police records, crime lab data, and news reports.		Does include data elements on age and perpetrator, but this data not consistently provided; database currently not available for public use.	deaths of elders due to acts by family/caregivers in participating states. ►Explore potential for NVDRS to draw upon elder fatality review team data and APS data.
CDC National Electronic Injury Surveillance System, All Injury Program (NEISS-AIP)	Consumer Product Safety Commission collects data from hospital emergency rooms on product-based injuries, and the National Center for Injury Prevention and Control (NCIPC) expands this to all injuries. Survey samples 500,000 medical records from 66 hospital emergency departments. Includes information on assaults and age. Uses narrative verbatim from medical records. NEISS-AIP and NVDRS make up WISQARS, a Web-based injury statistics query and reporting system.		Has good information on assaults of elders, but perpetrator data not always noted in medical record and thus not coded.	►Obtain NEISS-AIP data on elder assaults as background. Explore whatever perpetrator data is available.
CDC Chronic Disease Behavioral Risk Factor Surveillance System (BRFSS)	Survey is state-based, using CDC core questionnaire on personal health risk behaviors.		Had preliminarily added questions on elder abuse in new caregiver survey being implemented as part of BRFSS, but these questions eliminated in final version due to potential conflict	Could request the addition of elder abuse questions; but questions problematic, as caregivers may be unlikely to report elder abuse.

Data Set	Description	Frequency & Consistency of Collection	Gaps/Limitations	Potential for Use or Action
			in caregivers reporting elder abuse.	
Medicare Claims Data	Medicare claims information available in Standard Analytical Files (SAFs) with 5 % samples of universe of Medicare claims—including files submitted by in-patient hospital providers, skilled nursing facility providers, institutional outpatient providers, home health agencies, and hospice.	Medicare SAFs are not surveys with regularly collected information. Instead they are 5 % samples of the universe of Medicare claims data, which can be requested for research.	Relies on ICD and E-coding data; usage of adult abuse codes very low.	►Submit to the Centers for Medicare and Medicaid Services (CMS) a data request packet (payment of fee required) asking that ICD-9 codes and E-codes on adult abuse in one or more SAFs be correlated with age, including all diagnoses, not just primary diagnosis. ► Use SAFs to look for ICD codes showing medical patterns flagging abuse and correlate with age, rather than rely on ICD abuse codes.
Agency for Healthcare Research and Quality (ARHQ) Healthcare Cost and Utilization Project (HCUP)	HCUP is a family of health care databases developed through federal-state-industry partnership. Collects information through state data organizations, hospital associations, private data organizations, and federal government. Includes Nationwide Inpatient Sample (NIS), which samples over 1,000 hospitals; State Inpatient Database (SID), including inpatient discharge abstracts from participating states; and State Emergency	Annual surveys.	Relies on ICD data; usage of adult abuse codes very low.	Age correlation with hospital discharges in which a diagnosis was abuse shows only tiny number, not very useful.

Data Set	Description	Frequency & Consistency of Collection	Gaps/Limitations	Potential for Use or Action
	Department Database (SEDD), with data from hospital emergency visits.			
DHHS Office of the Inspector General (OIG) Report on State Medicaid Fraud Control Units (MFCUs)	OIG reports on state MFCUs indicate aggregate number of cases opened on "patient abuse and neglect" by Medicaid providers.	Annual OIG reports.	Data is aggregate figure only. No indication of types of abuse, neglect; or types of providers. No indication of whether MFCUs report these cases to APS.	Obtain MFCU reports to OIG to determine whether there is additional useful information.
Nursing Home Enforcement Data–Online Survey, Certification, and Reporting System (OSCAR).	OSCAR database includes deficiencies identified by state surveyors, including F-223 on resident abuse and F-224 on mistreatment of resident's property.	Ongoing database showing deficiencies and enforcement actions by year.	Percent of facilities with deficiency on abuse is very tiny, not useful. Data indicates only whether there was a deficiency citation for F-223 on abuse, but not the kinds of abuse, frequency, number of instances, perpetrator. Lack of surveyor training in identifying abuse; lack of consistent facility documentation of abuse. May be duplicative reporting of instances of abuse to APS.	Recommend that F-223 and F-224 instructions to surveyors be clarified to include number of instances of abuse, but this may not be possible in survey setting.
Aspen	ACTS is a database	Ongoing; initiated	ACTS includes	►Contact CMS staff

Data Set	Description	Frequency & Consistency of Collection	Gaps/Limitations	Potential for Use or Action
Complaints/Incidents Tracking System (ACTS)	designed by the Centers for Medicare and Medicaid Services (CMS), used by state survey agencies and regional offices to track, process, and report on complaint and incidents concerning skilled nursing facilities, hospitals, home health agencies, and other health services providers.	in 2004.	allegations of abuse that may or may not end up as deficiencies. ACTS is currently not available to the public.	to learn more about the potential of ACTS.
National Ombudsman Reporting System (NORS)	NORS is the national long term care ombudsman reporting system. A category of reported complaints includes seven subcategories of abuse.	Annual reports by long term care ombudsman programs (LTCOP).	Complaint definitions and use of NORS complaint categories inconsistent across states. NORS abuse complaints may be duplicative of reports to APS.	►Explore use of NORS abuse complaint information; and approaches to clarify NORS abuse data.
Nurse Aide Registry	States must maintain registry of nurse aides prohibited to work in long term care facilities because of substantiated findings of abuse.	Ongoing state registries, information by year.	Registries report only number of abusive aides, not number of abusive incidents. Some states do not consistently update registries. Some individuals with adverse findings in one state are certified in other states.	Because of limitations, state registry information not of significant use.
National Aging Program Information System (NAPIS)	Administration on Aging (AoA) collects information from state units on aging on client characteristics and home-	Annual reports.	Data on client characteristics and services provided does not include information on abuse.	Explore potential for collecting information on clients who have been abused—but definition and costs could be substantial

Data Set	Description	Frequency & Consistency of Collection	Gaps/Limitations	Potential for Use or Action
	/community-based services provided under Title III of Older Americans Act.			barriers.
Bureau of Justice Statistics National Crime Victimization Survey (NCVS)	Survey collects information on criminal victimization from 76,000 respondents in about 42,000 households.	Annual survey.	Survey includes no specific question on elder abuse. Survey does not include crimes in institutional settings.	►Explore feasibility of adding to NCVS a question on elder abuse. Barriers = victims may be reluctant or unable to report abuse on survey.
FBI Uniform Crime Reports (UCR)	UCR collects crime data reported by law enforcement officers.	Ongoing reporting by year.	No specific item on "elder abuse." Elder abuse *per se* not a crime in all jurisdictions. Police may not recognize and report elder abuse. While acts that make up "elder abuse" may be crimes, these would need to be correlated with age and perpetrator data. Does not include perpetrator information. Includes only the most aggravated crime and only crimes reported to police.	►Consider requesting that elder abuse be added as specific item under UCR, but barriers significant as noted in previous column.
FBI National Incident-Based Reporting System (NIBRS)	NIBRS goes beyond UCR to collect additional data, including information on perpetrator. Reports each incident rather	Ongoing reporting by year.	No specific item on elder abuse. Elder abuse *per se* not a crime in all jurisdictions.	►Consider requesting that elder abuse be added as specific item under NIBRS. Potential use greater than for UCR, but

Data Set	Description	Frequency & Consistency of Collection	Gaps/Limitations	Potential for Use or Action
	than only most aggravated incident.		Police may not recognize and report elder abuse. While acts that make up "elder abuse" may be crimes, these would need to be correlated with age. Includes only crimes reported to police. Not yet operational in all states.	barriers still significant. ►Educate law enforcement officers about elder abuse and the importance of recording it.
Bureau of Justice Statistics National Survey of Prosecutors	Survey of all U.S. prosecutors' offices that handled felony cases in state courts of general jurisdiction, including over 2,300 offices.	Last survey 2001.	Survey asks only whether office prosecuted elder abuse cases, not how many.	►Review results for percent of offices that prosecuted elder abuse; consider requesting revision of survey to include number of elder abuse cases prosecuted.
Suspicious Activity Reports (SARs)	National banks must report known or suspected criminal offenses involving transactions over $5,000. Includes information on embezzlement/theft, check fraud, false IDs, and multiple accounts.	Ongoing reporting.	Includes no indication of age of victims.	Geared to large scale drug trafficking and money laundering. Not useful vehicle for elder abuse information.
National Domestic Violence Hotline	National hotline created through Violence Against Women Act.	Receives up to 500 calls a day and regularly maintains statistics on calls.	Tracks age of caller and whether caller is victim, interested party or information seeker. Percent of calls from elders very small. No data on violent incident involved,	Older callers constitute very small percentage, and not all of these calls concern violent incidents. Little potential for elder abuse information.

Data Set	Description	Frequency & Consistency of Collection	Gaps/Limitations	Potential for Use or Action
			or whether caller also reported to APS.	
Social Security Representative Payee System	Social Security Administration (SSA) maintains data on representative payees in Representative Payee System (RPS), started in early 1990s. Federal legislation in 2004 requires SSA to evaluate representative payee program and conduct survey of selected representative payees.	RPS is ongoing collection of data—includes all information on all representative payees since early 1990s. Mandated representative payee survey effort currently underway.	RPS payee misuse information uneven and inconsistent. A 5 % sample of misusers includes payees of minors; not publicly available now. Study will not include larger organizational payees.	►Ensure current study separates misuser payees of minors and adults, makes age correlation. ►Advocate for redesign of RPS to clearly identify misuser payees of adults, including all organizational payees.
U.S. Department of Veterans Affairs (VA) Fiduciary Program	Currently data on misuse of fiduciary funds for veterans is not aggregated. Recent federal legislation requires the maintenance of data on misuse by fiduciaries. In response, data system of fiduciary benefits program being revised.	Recent legislation requires VA to capture and maintain data on fiduciary misuse.	New data system just beginning. However, instances of fiduciary misuse may not be reported; and would need to be correlated with age of beneficiary.	►Check back with VA fiduciary program regarding data on misuse once collection is underway.
Guardianship and Conservatorship Data	Many state courts do not consistently maintain data on adult guardianship, abuse as trigger for guardianship, or abuse by guardians. NCEA/ABA survey of state court administrators on guardianship and elder abuse data underway. AARP/ABA survey on guardianship monitoring underway.	No consistent collection of data. NCEA/ABA survey and AARP/ABA surveys currently underway.	State courts have widely varying statistics on guardianship and abuse, and information may be inconsistent, outdated, problematic, missing. Information on abuse in guardianship may or may not be at local court level, but is not reported	Encourage more consistent and detailed collection of guardianship data. ►Eventually, check with NGA and state certification programs for data on complaints and decertification.

Data Set	Description	Frequency & Consistency of Collection	Gaps/Limitations	Potential for Use or Action
	NGA national guardian certification program and emergent state programs may offer data on abuse.	No data from certification programs yet.	to state court administrative offices. Certification programs just getting underway; few instances of complaints and decertification yet.	
Legal Services Program Data	Legal Services Corporation (LSC) uses case service reporting system. In addition, individual legal services programs may maintain sub-codes refining the LSC categories. Legal programs with Older Americans Act funding may maintain additional coding categories, as is the case in Georgia. Administration on Aging database on program information, National Aging Program Information System (NAPIS), focuses only on client characteristics and numbers of cases, not types of cases.	Ongoing collection of data, reported by year.	No code specifically for elder abuse. Case code on "domestic abuse" would have to be correlated with age. Elder abuse may be coded under other topics such as debt collection, foreclosure. Local programs with additional categories of coding that might bear on elder abuse are not required to report this to LSC or the Administration on Aging.	►Contact LSC Office of Information Management to explore possible correlation of case code on domestic violence with age – but this would not include abuse by staff in institutions or other abuse not related to domestic violence. Explore potential for collecting information on clients who have been abused—but definition and costs could be substantial barriers.
Legal Hotlines for the Elderly Data	Approximately 20 senior legal hotlines keep varying types of data.	Ongoing collection of information.	Currently many hotlines do not track elder abuse; maintain differing coding systems.	►Contact hotline technical support center concerning upcoming redesign of hotline data collection system in fall 2005, concerning inclusion

Data Set	Description	Frequency & Consistency of Collection	Gaps/Limitations	Potential for Use or Action
				of elder abuse data.

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I. Introduction—Through a Glass Darkly

There is wide consensus that currently a clear picture of the incidence and prevalence of elder abuse in the United States is sadly lacking—and that such a picture "is imperative to enable society to . . . mount an effective response (National Research Council, 2003; also see National Institute on Aging, 2005; Federal Interagency Forum, 2004). Indeed, without solid information, policymakers and practitioners are looking "through a glass darkly" in addressing the problem.

While the NCEA has collected and analyzed state adult protective services data (Teaster & Otto et al, 2006), the penumbra of additional data elements that might be available through health care, long term care, criminal justice, fiduciary, legal services, and aging networks has remained largely unexplored. Therefore, the NCEA sought the development of a white paper examining existing and possible data elements, their scope and limitations. In response, the American Bar Association Commission on Law and Aging conducted exploratory research on a wide range of possible data sources. This paper presents and evaluates the results and the potential of these data sources for use and action by the AoA, other federal agencies, and elder abuse professionals and advocates. The white paper findings support the compelling need and offer a useful platform for a national incidence and prevalence study, as well as the development of scientific research on elder abuse under proposed projects supported by the National Institute on Aging.

II. Background and Methodology

The seminal work on the state of knowledge about elder abuse and the substantial lack of data is *Elder Mistreatment: Abuse, Neglect, and Exploitation in an Aging America*, the 2003 National Research Council report of its Panel to Review Risk and Prevalence of Elder Abuse and Neglect. The report outlines the need and lays a comprehensive foundation for further study on the incidence and prevalence of elder

abuse. It summarizes empirical research and the collection of epidemiological data to date. Following the report, the National Institute on Aging has called for research to "provide the scientific basis for understanding, preventing, and treating elder mistreatment" (National Institute on Aging, 2005). The National Research Council report and its extensive appendices served as the starting point for this paper.

The methodology for the development of the white paper focused on Internet and telephone research. After a baseline discussion with the NCEA partner organizations, the project began with a Web scan of data sources listed in the NCEA Request for Proposals for development of this white paper, including the Centers for Medicare and Medicaid Services (CMS), the Centers for Disease Control and Prevention (CDC), the AoA, the Medicaid Fraud Control Units, the U.S. Department of Justice, the National Institutes of Health National Library of Medicine's *PubMed*, and other leads. In addition, the librarian at the AoA provided results of her preliminary research on possible sources of elder abuse data. The project then sought to examine other sources of data such as the Social Security Administration, the U.S. Department of Veterans Affairs, state probate courts, state quality improvement organizations, legal services programs, and more. Telephone interviews with key informants supplemented on-line Internet research. In total the project interviewed 41 key informants, primarily by telephone, but in some cases by e-mail (see List of Key Contacts)—and also made a number of additional "blind alley" contacts that ultimately did not yield useful information.

The investigation sought both data on the "incidence" and "prevalence" of elder abuse. The incidence rate is the number of new instances of abuse within a specific time period; whereas the prevalence rate tells how frequently abuse occurs at a given point, regardless of the time of onset (National Research Council, 2003). The investigator conceived of the project as a "treasure hunt" for relevant data and kept a detailed research record. Overall, the investigator encountered more "blind alleys" and "dead ends" than "finds," yet explored several critical areas with varying potential for shedding light on the incidence and prevalence of elder abuse, as summarized throughout the paper (and in the Executive Summary chart).

A blatant difficulty in elder abuse research is the disparity of definitions of "elder abuse" (Lachs & Pillemer, 1995). The National Research Council report's background paper *Epidemiological Assessment Methodology* (Acierno, 2003) stresses that while various agency records offer possible sources of information, "the definitions for particular forms of elder mistreatment vary widely across social service agency, county, and state." Similarly, the background paper *Elder Abuse in Residential Long-Term Care Settings* (Hawes, 2003) notes that "agencies use different definitions and have different

standards and practices for . . . classifying an allegation as substantiated." An additional background paper, *The Epidemiology of Elder Abuse and Neglect,* not included in the Panel report, concludes that "preliminary to generating a national estimate [of the magnitude of the problem] is the need for consensus on the operational definitions of elder abuse and neglect for the purpose of uniform ascertainment and comparisons across studies" (Branch, 2001).

This problem is illustrated by the different definitions and terminology used by the NCEA and the National Research Council. According to the NCEA:

> elder abuse is a term referring to any knowing, intentional, or negligent act
> by a caregiver or any other person that causes harm or a serious risk of
> harm to a vulnerable adult. The specificity of laws varies from state to
> state, but broadly defined, abuse may be: physical abuse, emotional abuse,
> sexual abuse, exploitation, neglect, abandonment (the NCEA Web site
> defines each subcategory at
> http://www.elderabusecenter.org/default.cfm?p=faqs.cfm).

The National Research Council report uses the term "elder mistreatment," defined as:

> (a) intentional actions that cause harm or create a serious risk of harm
> (whether or not harm is intended) to a vulnerable elder by a caregiver or
> other person who stands in a trust relationship to the elder, or (b) failure
> by a caregiver to satisfy the elder's basic needs or to protect the elder from
> harm (National Research Council, 2003).

The report explains that the term "mistreatment" is meant to exclude cases of self-neglect, as well as cases of victimization by strangers.

Although an inconsistent terminology and definition—or lack of definition—of elder abuse clearly is a research impediment, it did not directly affect the methodology for this study. The investigator purposefully did not use any specific definition, as that might have unnecessarily narrowed the search. Instead, the inquiry was as broad as possible, seeking to identify and evaluate any data that relates to elder abuse. However, the lack of a consistent definition would make it difficult to compare the disparate data sets identified and is certainly needed "to move the field forward" (National Research Council, 2003).

III. Findings

A. Health Care Data—Background on Diagnostic Coding

1. Medical Diagnostic Codes

Physicians and hospitals use diagnostic codes for reimbursement purposes and to document the reasons for medical treatments. The World Health Organization develops an *International Classification of Diseases* (ICD) to code and classify mortality data from death certificates, and the National Center for Health Statistics in the CDC in the U.S. Department of Health and Human Services develops a "clinical modification" to code and classify morbidity data from inpatient and outpatient records, physician offices, and National Center for Health Statistics surveys (http://www.cdc.gov/nchs/icd9.htm). The ICD and the clinical modifications are revised periodically to reflect changes in the medical field. The version currently in use is ICD-9-CM. The ICD-10-CM has been developed, but is not yet in use. The diagnostic codes generally are known as "ICD codes." In addition, related "E-codes" under each ICD code classify external causes of injury. The E-codes serve as modifiers that describe the circumstances of an injury or illness.

The ICD coding provides statistical data on the incidence and prevalence of diseases and health conditions in the United States. It serves as a basis for a number of national surveys and databases. The U.S. Public Health Service and CMS require use of the ICD-9-CM for reporting diagnoses and diseases. The National Center for Health Statistics uses ICD-9-CM in its multi-faceted National Health Care Survey (see below). Hospitals use groupings of ICD-9-CM codes called "Diagnostic Related Groups" to describe types of patients and seek reimbursement. The question, then, is to what extent does or can ICD coding include information relevant to the incidence and prevalence of elder abuse.

2. Diagnostic Coding on Abuse

a ICD-9 Coding on Abuse. The ICD codes for child and adult "maltreatment" have existed since 1979 and were expanded in 1996 to include more specification of the types of abuse (Rovi & Johnson, 2003). Today, ICD-9-CM code 995.80 is "adult maltreatment, unspecified," and additional codes each identify specific kinds of adult abuse, as follows:

995.80 – Adult maltreatment, unspecified
995.81 – Adult physical abuse

995.82 – Adult emotional/psychological abuse
995.83 – Adult sexual abuse
995.85 – Other adult abuse and neglect

Research on these diagnostic codes for abuse suggests they are used very rarely, with one study of inpatient hospital admissions showing only 445 out of over 6.5 million inpatient stays with these codes (Rudman & Davey, 2000). Similarly, a study including both adult and child abuse codes analyzed four years of data from office-based physician visits, as well as visits to hospital emergency and outpatient departments, and found only 93 diagnoses for over 350,000 patient visits, noting that child abuse was diagnosed more often than adult abuse (67 incidences vs. 26 incidences) (Rovi & Johnson, 1999). There are several reasons why such coding is low:

- Reimbursement is low. "Since most reimbursement payment schedules only include the PDX [primary diagnosis] and one secondary code for reimbursement practices (*e.g.*, Medicare and Medicaid), it is not profitable or time efficient for the hospital to include these types of codes . . . ." (Rudman & Davey, 2000). Physicians in focus groups on use of the abuse codes confirmed that coding abuse is unlikely to result in insurance reimbursement. One participant noted that: "I'd use the codes if I could get some Medicare reimbursement for it. I mean, there's no incentive from an individual victim's perspective or from a system's perspective for using [the codes], really, there's no benefit" (Rovi & Johnson, 2003).

- Physicians and coding personnel may be unaware of the abuse codes (Rovi & Johnson, 1999).

- Physicians generally have little training in recognizing and addressing abuse and may feel hesitant in identifying it. They may be troubled by a "gray zone" of uncertainty, especially with older patients, as they bruise easily (Rovi & Johnson, 2002). Moreover, if physicians code a condition as abuse, they may then be required to report it under state law, and may be reluctant to do so. They may fear being asked to testify about the abuse in court, or be concerned that they are making a legal judgment (Rovi & Johnson, 2003).

- Physicians may be concerned that coding abuse could harm or jeopardize the patient. They may believe that coding abuse without patient consent is a breach of patient confidentiality. They may be concerned about insurance company discrimination against victims of abuse, including the question of whether "some HMOs might use the codes [adversely] in their selection of elderly clients" (Rovi & Johnson, 2003).

They may be convinced that identifying abuse would not lead to sufficient services. Overall, it appears that at least some physicians calculate that "if we used the codes more often we might do more harm than good" (Rovi & Johnson, 2003).

Medical groups have recognized the deficiency in documentation of abuse, and coding clinic guidelines developed by both the American Medical Association and the American Hospital Association state that the abuse codes should be documented as the primary diagnosis, with the type of injury coded secondarily. In addition, proposed changes in the DRG (Diagnostic Related Groups) reimbursement rates would increase reimbursement weights for the abuse codes (Rudman & Davey, 2000, referencing AMA Coding Clinic, and at http://endabuse.org). Finally, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), which accredits hospitals, requires that health care workers document in the medical record all incidences of domestic violence (Rudman & Davey, 2000, referencing Standard P.E. 1.8, *JCAHO Manual for Hospitals 1999*).

b. <u>E-Coding on Abuse.</u> "E-codes" are "External Cause of Injury Codes." They describe the nature of the abuse and the perpetrator. E-codes are associated with specific ICD code categories. Relevant E-codes for ICD 995.80 through .85 include:

E-967.1, E-967.3, E-967.9 – Identifies perpetrator
E-960 through E-968 – Identifies nature of the abuse
E-980 through E-989 – Identifies whether injury was purposefully inflicted.
(http://endabuse.org/programs/display.php3?DocID=173)

In addition, "V-codes" give information about a patient's circumstances, history, or problem that could affect overall health status, but is not itself a current illness or injury—for instance, possibly a history of the abuse and need for counseling. Relevant V-codes include:

V15.41 – Physical abuse and rape
V15.42 – Emotional abuse
V15.49 – Other abuse
V61.11 – Counseling for victim
V61.12 – Counseling for perpetrator

c. <u>ICD-10 Coding on Abuse.</u> The ICD-10-CM, not yet in use, includes a separate set of codes at Y07 for perpetrators (currently called E-codes, as noted above). It also includes separate codes at T74 for specific kinds of adult abuse (neglect or abandonment,

physical, sexual, and psychological) that are "confirmed"–and identical codes at T76 for specific kinds of adult abuse that are "suspected." The addition of codes for unconfirmed or suspected abuse was added:

> in response to the uncertainty of identifying [abuse or] domestic violence during a specific encounter or the possible unwillingness of the healthcare worker to document suspicions and/or screen more carefully if domestic violence [or abuse] is a possibility. The suspected but unconfirmed . . . codes cannot be used in combination with any perpetrator codes since there is only suspicion, limiting the information we can learn from the data (http://endabuse.org/programs/display.php3?DocID=173).

3. Limitations of Diagnostic Codes for Elder Abuse

The most evident barrier in use of the diagnostic codes to identify elder abuse is that the abuse codes are *not age-specific*, lumping domestic violence and other adult abuse along with elder abuse. Thus, ICD data would have to be correlated with a set of data identifying those 60 years of age or older. Second, the ICD-9 codes alone do not indicate the *perpetrator*, but if an E-code showing the cause of the injury is present, the perpetrator may be noted. However, it appears that E-coding is highly variable. One informant from the National Center for Health Statistics explained that the E-codes

> are never coded very well because E-codes aim to show the source of the injury. An ambulance might come in [to the hospital] and someone might note what happened, but the physician is really more concerned about what the presenting condition is than what caused it and who did it (R. Pokras, personal communication, August 2005).

Moreover, if a care provider is the source of information, the provider will not be likely to admit to or characterize what happened as abuse. Finally, as described fully above, it would take *extensive education* of physicians and hospital staff to get them to recognize elder abuse and the rationale for using the abuse codes for elderly patients.

All of the deficiencies in medical diagnostic coding for estimating the incidence and prevalence of elder abuse were echoed in an interview with a physician who was a member of the National Research Council's Panel to Review the Risk and Prevalence of Elder Abuse and Neglect. She stated that she would "doubt if even one doctor ever used the ICD coding to indicate elder abuse. It's not in the same universe." She noted that

physicians rarely recognize elder abuse and even if they did, "the medical billing people would not know what to do with it" (L. Mosqueda, personal communication, April 2005).

The ICD-10-CM, which was developed with extensive public input over a number of years, still does not separate elder abuse from adult abuse. It does have a list of perpetrators (called "Y-codes"), which names spouse, siblings, parents, and cousins, but notably does *not* include adult children—which seems to indicate that elder abuse, at least in the family setting, was not considered in the code development. Abuse by "other family members" is Y07.49. Lumping "other family members" into one category will result in the loss of relevant elder abuse data. The list of perpetrators does, however, include abuse by care providers, designating separate codes for "at home adult care providers" and "adult care center providers." Once ICD-10 is in use, these latter codes may be of use in identifying elder abuse—but would be subject to the same variability as the current E-coding.

The ICD-10 has not yet gone through a rulemaking procedure. Elder abuse professionals and advocates could submit statements during the public comment period after a notice of proposed rulemaking, recommending that elder abuse be a distinct category, as is child abuse. When questioned about the feasibility of this, a National Center for Health Statistics coding expert argued that "child abuse raises distinctly different issues," whereas elder abuse may not merit a separate category as it is similar enough to other adult abuse (D. Pickett, personal communication, August 2005). Another National Center for Health Statistics expert observed that while it might be a good idea in theory, "just because you have the coding system doesn't mean there will be data to code" for all of the reasons mentioned above. He advised focusing not so much on the ICD codes on abuse, but instead looking for certain medical patterns that might be flags of abuse in a range of other specific ICD codes—for example, using ICD codes on bruises to identify certain patterns of bruises and contusions for elderly patients over time.

Nonetheless, in response to the NCEA Request for Proposals, this study examined the potential for specific national health care databases to shed light on elder abuse by correlating the ICD diagnostic codes on abuse with age-related data, as detailed below.

B. Health Care Data—CDC Surveys and Databases

The Department of Health and Human Services CDC provides statistical information to assist in policies that improve the health of the American people. The CDC regularly conducts national surveys of health care providers and individual health

care consumers, and maintains systems to provide injury-related data. This study explored to what extent these multiple CDC sources glean any information on elder abuse.

1. National Center for Health Statistics--National Health Care Surveys

The CDC National Center for Health Statistics uses ICD diagnostic codes as well as other survey information from health care facilities in the National Health Care Survey—"a family of health care provider surveys obtaining information about the facilities that supply health care, the services rendered, and the characteristics of the patients served" (http://www.cdc.gov/nchs/nhcs.htm). The National Health Care Survey initially included four surveys: the National Hospital Discharge Survey, the National Ambulatory Medical Care Survey, the National Nursing Home Survey, and the National Health Provider Inventory. Later surveys included the National Survey of Ambulatory Surgery, the National Hospital Ambulatory Medical Care Survey, and the National Home and Hospice Care Survey.

Each survey is based on "a sampling design that includes health care facilities or providers and patient records." Data on diagnosis and treatment are collected from the providers and/or their records. The various surveys were initiated as early as 1965 (Hospital Discharge) and as late as 1994 (Ambulatory Surgery). Some of the surveys are conducted annually, and the remainder periodically. The data are used by policymakers, researchers, epidemiologists, and others. None of the National Health Care Surveys include a specific element on elder abuse, but several do include data on age.

a. National Hospital Ambulatory Medical Care Survey. This survey, conducted annually since 1992, samples visits to hospital outpatient departments and emergency departments. Each year, approximately 500 nationally representative hospitals provide data on a sample of patient visits over a four-week reporting period. Since it is a sample, it can be used for information on prevalence, but not incidence. The hospital staff in participating institutions completes a form for each case in the sample, giving information on the injury or illness and demographic characteristics of the patient, including age. About 40 percent of the time, the National Center for Health Statistics has experts from the Bureau of Census complete the forms, since hospital staff is so busy. All of the forms are then sent to a contractor for coding using the ICD-9 codes (L. McCaig, personal communication, July 2005).

Elder abuse professionals and advocates could ask the National Center for Health Statistics to do a correlation of the age data from the forms with the ICD-9 codes on adult

abuse (995.80 through 85), as well as the relevant E-codes. McCaig at the National Center for Health Statistics indicated that this could be an informal request by e-mail specifying the parameters (for example, which years, age definition, which of the abuse codes and E-codes, whether these should be broken out, etc). A limitation is that because the usage of the adult abuse codes is so low, there may not be significant numbers to produce reliable data. Also, the hospital staff, Census Bureau, and contract coders may not have been trained to recognize the importance of coding for abuse.

b. National Ambulatory Medical Care Survey. This survey, originally conducted in 1973 and conducted annually since 1989, samples visits to physicians' offices. Since it is a sample, it can be used for information on prevalence, but not incidence. Physicians are instructed in completing forms for a one-week reporting period. Data are collected on patient symptoms, diagnoses, and medications, as well as demographic characteristics of patients and services provided (http://www.cdc.gov/nchs/about/major/ahcd/namcsdes.htm). The process is similar to the National Hospital Ambulatory Medical Care Survey described above—physicians and their staff complete forms for some of the cases in the sample, Census Bureau staff complete the remainder, and the forms are sent to the same contractor for coding. Thus, the National Ambulatory Medical Care Survey data could be part of the requested National Center for Health Statistics correlation described above, and would have the same limitations.

c. National Hospital Discharge Survey. This survey, initiated in 1965, collects data from about 500 hospitals and 270,000 patient records annually. It aims to report information on "characteristics of inpatients discharged from non-federal short-stay hospitals in the United States" (http://www.cdc.gov/nchs/about/major/hdasd/nhdsdes.htm). It collects data through a manual system in which hospital staff or Bureau of Census staff on behalf of the National Center for Health Statistics abstract information from medical transcription to forms, which are then sent to a coding contractor.

According to a key informant at the National Center for Health Statistics, the ICD codes on adult abuse do not even show up on the National Hospital Discharge Survey summary, because they are used too infrequently and the sample size is not large enough. He noted that it would be likely that if an elderly person came in with a black eye, the stay most likely would be coded using the eye injury codes, not the abuse code. Frequently there is not enough information in the medical record to code as abuse. He explained that the National Hospital Discharge survey will be completely redesigned in the coming months to collect more in-depth clinical data. He will be the project officer

for a contract to redesign the survey system, and stated that elder abuse professionals and advocates could have input into this process by contacting him (R. Pokras, personal communication, August 2005).

        d. <u>National Nursing Home Survey.</u> This survey has been conducted several times, most recently in 2004. It uses a national sample of 1,500 nursing homes, their residents, and staff. Resident data includes demographic characteristics, health status, and services received (http://www.cdc.gov/nchs/about/major/nnhsd/nnhsdesc.htm). Administrators provide information on facility characteristics, and Census Bureau staff or contractors interview nursing home staff on a sample of current residents (12 residents per home in 2004). The survey will not be conducted again until 2009. Elder abuse professionals and advocates could request that an interview question be added on abuse (R. Remsburg, personal communication, August 2005). Added questions mean added federal cost, and could require additional budgetary requests by the agency. Also, nursing home staff would likely be conflicted about providing accurate information on abuse that occurs in the facility.

        e. <u>National Home and Hospice Survey</u>. This series of surveys is based on a probability sample of 1,500 home health agencies and hospice care agencies. It collects information from administrators and staff on diagnoses, visits, charges, health status, reason for discharge, and types of services provided (http://www.cdc.gov/nchs/about/major/nhhcsd/nhhcsdes.htm). As with the Nursing Homes Survey, Census Bureau staff or contractors interview agency staff, collecting information on six current patients and six discharges. The survey will next be conducted in 2007. Currently, a question is being added about agency staff training in recognizing elder abuse. Elder abuse professionals and advocates could request that a question be added on agency staff encounters with elder abuse. Again, cost is an issue, and the prospect of additional budget requests appears a significant barrier.

2. National Center for Health Statistics—Individual Health Care Surveys

        a. <u>National Health Interview Survey.</u> The National Health Interview Survey, conducted since 1957, is the principal source of information on the health of the U.S. civilian non-institutionalized population. Data are collected on a sample of households by Bureau of Census interviewers. National Health Interview Survey data are collected annually from approximately 43,000 households, including about 106,000 persons. Trained interviewers with computers visit households and record responses verbatim. The responses are sent to a contractor for ICD coding. Both the verbatim responses and the

ICD statistics are available to researchers. The survey does include one or more questions about injury, in which adult abuse could be included by the respondents.

As with other National Center for Health Statistics surveys, theoretically any individual verbatim responses and ICD coded statistics on family and caregiver violence could be correlated with age to yield some information on elder abuse. However, because there is no specific question on elder abuse, because respondents may be reluctant to bring up information on injuries due to family or caregiver violence, and because of the low usage of the ICD codes on adult abuse, it may not be likely that the survey would provide useful information (P. Barnes, personal communication, September 2005).

b. National Health Examination and Nutrition Survey. This survey provides national statistics on the health and nutritional status of the non-institutionalized civilian population through household interviews and standardized physical examinations in mobile examination centers. The present National Health Examination and Nutrition Survey, started in March 1999, will be a continuous survey of 5,000 persons per year from 15 randomly selected locations throughout the United States. The survey includes 18 components that measure the general health of the civilian non-institutionalized population and 74 laboratory analyses (http://www.cdc.gov/nchs/nhanes.htm). The survey does not include any question on or relating to elder abuse, and it was considered unlikely by one source that any would be added (C. Johnson, personal communication, September 2005).

3. CDC Injury Data Systems

A total of 39 different federal data systems provide injury-related data. The CDC National Center for Injury Prevention and Control's Office of Statistics and Programming made available a draft list of Web sites for these systems (L. Annest, personal communication, August 2005). Some are housed at CDC, including several databases described both above and below in this paper. Two other specific CDC injury data systems may have potential for shedding light on elder abuse, as described below:

a. National Violent Death Reporting System. The National Center for Injury Prevention and Control is developing a National Violent Death Reporting System to "inform decision-makers about the magnitude, trends, and characteristics of violent deaths" (http://www.cdc.gov/ncipc/profiles/nvdrs/facts.htm). The center funds state health departments to collect data on violent deaths from death certificates, medical examiners, police records, crime lab data, and news reports. The system started in 2003 with six states. Seven states were added in 2004 and 4 states were added in 2005, for a

current total of 17 states. In 2003, there were 7,500 incidents, 7,700 deaths, and 2,000 suspects. In 2004, there were 13,500 incidents, 14,000 deaths, and 3,000 suspects.

The National Violent Death Reporting System does include an element on age, and does include the "suspect" and the relationship between the suspect and victim when this information is available—but data is uneven. The system also includes variables on location of death, including "nursing home, long term care facility, and decedent's home," as well as information on the type of place at which the violent incident occurred (M. Steenkamp, personal communication, August 2005). The data is not available for public use now. However, soon the center will be releasing a public-use data set, which will include age and relationship with suspect for the universe of incidents recorded (M. Steenkamp, personal communication, July 2005). This information could be of use to elder abuse professionals and advocates in evaluating the number of deaths of elders due to violent acts by family/caregivers, at least in the participating states. Of additional interest is the fact that the center is piloting the collection of data from state child fatality review teams in four states (http://www.cdc.gov/ncipc/profiles/nvdrs/facts.htm).   With the development of elder fatality review teams in several states underway, this could be a significant contribution to the National Violent Death Reporting System.

b. National Electronic Injury Surveillance System, All Injury Program. The U.S. Consumer Product Safety Commission has a National Electronic Injury Surveillance System (NEISS) to collect data from hospital emergency rooms, with consumer product-based injuries in mind. The CDC National Center for Injury Prevention and Control has piggybacked onto this system, expanding it to an "All Injury Program." This expansion, called the NEISS-AIP, "is designed to provide national incidence estimates of all types and external causes of non-fatal injuries and poisonings treated in U.S. hospital emergency departments" (CDC National Center for Injury Prevention and Control, 2005). The system uses a sample of 66 hospital emergency departments nationally, from which about 500,000 medical records regularly are sampled. Coders go through the medical records and obtain data on age and other demographic characteristics of the patient, principal diagnosis, primary body part affected, disposition at discharge, locale of injury, and a narrative description of the circumstances. The coders use actual narrative verbatim from the medical records. They also code major categories of external causes of injury and intent of injury "in a manner consistent with the ICD coding rules" (CDC National Center for Injury Prevention and Control, 2005).

One of the categories of injury in the NEISS-AIP is assault, which can be correlated with age. The director of the National Center for Injury Prevention and Control's Office of Statistics and Programming observed that this "is about as high

quality surveillance data on assault as you can get"—and when correlated with age, offers "the best elder assault data available" (L. Annest, personal communication, August 2005). However, the victim-perpetrator relationship is hit or miss. If the perpetrator is noted in the medical record, it is coded, but frequently it is missing in the medical record. The director stated that they sometimes use the system to collect additional variables, but that such a special study on elder abuse would have to be requested specifically, probably by Congress.

The NEISS-AIP system on non-fatal injuries, together with information from the National Vital Statistics System on fatal injuries, makes up a Web-based Injury Statistics Query and Reporting System (WISQARS—see http://www.cdc.gov/ncipc/wisqars/).

4. CDC Chronic Disease Prevention and Health Promotion Survey

The CDC Division of Adult and Community Health, National Center for Chronic Disease Prevention and Health Promotion, administers a survey called the Behavioral Risk Factor Surveillance System. It is a state-based data collection system in which all states participate. The CDC has developed a standard core questionnaire for states to use to compare data across states. The survey examines personal health risk behaviors through telephone surveys at the state and local level. It does not include any element on elder abuse.

The CDC staff in the aging and health section of the chronic disease program indicated that they are proposing to include items on caregiver health, and to pilot such questions in North Carolina. Staff at first indicated the tentative addition of questions on the caregiver survey concerning elder abuse or the potential for elder abuse, but later confirmed that these questions had been eliminated (L. Anderson & J. Crews, personal communication, September 2005). It is not clear whether these questions would have targeted possible abuse by caregivers or caregiver observations of abuse by others. Elder abuse professionals and advocates could consider whether it is worthwhile to request reconsideration of the abuse questions, but it seems somewhat of a stretch to capture any real information about elder abuse through such a caregiver survey.

C. Health Care Data—Medicare Claims

Medicare claims information is available in a number of data files, called Standard Analytical Files (SAFs), which are 5 percent samples of the universe of claims information. As with the databases described above, the Medicare claims data uses ICD-9 codes and E-codes. The following data files may be relevant for correlating age and the

ICD-9 adult abuse codes (as the "diagnosis")
(http://www.resdac.umn.edu/Medicare/file_descriptions.asp). These files only have data
from Medicare fee for service claims, not managed care claims (B. Frank, personal
communication, August 2005):

- Inpatient SAF. Includes final action claims data submitted by in-patient hospital
  providers.

- Skilled Nursing Facility SAF. Includes final action claims data submitted by skilled
  nursing facility providers.

- Outpatient SAF. Includes final action claims data submitted by institutional
  outpatient providers, such as hospital outpatient departments, rural health clinics, and
  outpatient rehabilitation facilities.

- Home Health Agency SAF. Includes final action claims data submitted by home
  health agency providers.

- Hospice SAF. Includes final action claims data submitted by hospice providers.

- MedPAR File. Includes final action "stay records" from inpatient hospital and skilled
  nursing facilities—that is, if a beneficiary was in the hospital or a skilled nursing
  facility, the claims during that stay are rolled together.

To use these files, researchers must submit a "data request packet"
(http://www.resdac.umn.edu/Medicare/data_available.asp). Since the files are quite large
and complicated, the researchers should have the resources in terms of computer
technology and data expertise to handle them. There is a cost as well. According to the
CMS Research Data Assistance Center ("Resdac"), the cost of a physician claims data
file for one year would be about $6,400. She noted that nonprofit entities often contract
with universities to work with these files.

Since the files are based on ICD-9 codes and E-codes, they are subject to the same
risk of under-reporting abuse as outlined above. Nonetheless, it might prove useful for
elder abuse professionals and advocates to request selected files to correlate age with the
ICD-9 and E-code adult abuse entries. For such an inquiry, it would be important to
include all of the diagnoses codes, not just the primary diagnosis. The research expert
noted that another strategy for using the files would be to identify certain medical

conditions, such as various kinds of fractures, and to track individual beneficiary information for patterns that might reveal or imply elder abuse, as suggested above. However, this approach is based on a great deal of uncertainty, since currently there is little or no scientific research linking specific kinds of fractures or other conditions with elder abuse.

D. Additional Health Care Data

1. Agency for Healthcare Research and Quality—Healthcare Cost and Utilization Project

The Healthcare Cost and Utilization Project (HCUP) is a family of health care databases developed through a federal-state-industry partnership, sponsored by the U.S. Agency for Healthcare Research and Quality (AHRQ). "HCUP databases bring together the data collection efforts of state data organizations, hospital associations, private data organizations, and the federal government to create a national information resource of patient-level health care data." Of particular relevance for this report, HCUP includes a Nationwide Inpatient Sample from a national sample of over 1,000 hospitals; a State Inpatient Database, with the universe of inpatient discharge abstracts from participating states; and a State Emergency Department Database, with data from hospital-affiliated emergency visits that do not result in hospitalizations (http://www.hcup-us.ahrq.gov/overview.jsp).

Like other health care surveys described above, HCUP relies on ICD codes. Thus, an analysis could correlate data on age with the ICD-9 adult abuse codes to get a number showing how many elders discharged from community, non-federal hospitals (excluding outpatient and emergency room settings) were subject to abuse. The HCUP technical assistance support staff ran such a correlation on request, using 2003 data for individuals age 65 and older. The resulting numbers are very small—far too small to be useful. For example, the data show that in 2003 there were 154 community hospital discharges of individuals age 65-84 nationally, in which one of the diagnoses was "adult mistreatment," and 189 such discharges, in which one of the diagnoses listed was adult physical abuse. The HCUP data experts commented that "HCUP data may under-report this type of abuse—because it relies on patient report of abuse or suspicion of abuse by medical providers" and that "there is both under-reporting and under-coding going on here."(HCUP on-line data expert, August 2005; C. Steiner, personal communication, September 2005).

2. Medicaid Fraud Control Units

Federal legislation in 1977 authorized the establishment of, and federal funding for, the State Medicaid Fraud Control Units (MFCU). Currently, 49 states and the District of Columbia participate in the Medicaid fraud control program. North Dakota and Idaho do not have a unit. (National Association of Medicaid Fraud Control Units, 2005). Most of the units are located within state offices of the attorney general, but some are in various other state agencies. The mission of the MFCU is to investigate and prosecute Medicaid provider fraud and incidences of patient abuse and neglect (http://oig.hhs.gov/publications/mfcu.html).

The Department of Health and Human Services Office of Inspector General (OIG) compiles an annual report on the performance of the MFCU. In the FY 2003 report, the OIG states that during the year "the MFCU's opened 5,570 patient abuse and neglect cases" (U.S. Department of Health and Human Services [DHHS OIG], 2003). These are cases of abuse and neglect by Medicaid providers, as reported by each of the MFCUs to the OIG. Contacts with the CMS state MFCU oversight office and the OIG did not elicit any further information (S. Colby, personal communication, May 2005; S. Powell, personal communication, September 2005). Elder abuse professionals and advocates could seek to obtain the information as submitted directly by the MFCUs to determine whether this is broken down any further by type of provider or type of abuse, and whether the MFCU reports these cases to adult protective services, or receives reports from adult protective services.

3. State Quality Improvement Organizations

Under the direction of CMS, the Quality Improvement Organization (QIO) program includes a national network of 53 state and territorial QIOs that work to encourage high-quality health care delivery, and investigate beneficiary complaints about quality of care (http://www.cms.hhs.gov/qio/). It does not appear that QIOs maintain or aggregate any data on elder abuse (L. Geiger, personal communication, March 2005).

E. Long Term Care Data

1. Nursing Home Enforcement Data

The nation's 1.6 million nursing home residents in nearly 17,000 facilities are dependent on the federal and state governments to ensure quality of care. The federal government sets standards for homes that participate in the Medicare and Medicaid programs, and has authority to impose sanctions against those that fail to comply. The

federal Centers for Medicare and Medicaid Services (CMS) contracts with state agencies to survey participating facilities regularly and also in response to complaints. The results are recorded on CMS Form 2567, which is a statement of deficiencies. Deficiencies are categorized in a series of tag numbers known as "F-tags." The F-tags are listed in the CMS "Guidance to Surveyors," an appendix to the *State Operations Manual*: *Provider Certification* (Appendix PP).

The deficiencies identified by the state surveyors are reported in the Federal Online Survey, Certification, and Reporting System (OSCAR). Researchers with access to OSCAR can compile and analyze the data. Deficiencies for 1996–2002 and again for 1998–2004 were examined by Harrington, Carillo, & Mercado-Scott, (Harrington, Carillo, & Mercado-Scott, 2003, 2005).

The F-223 concerns violations of the resident's right to be free from verbal, sexual, physical, and mental abuse, corporal punishment, and involuntary seclusion, as provided in federal regulations (42 C.F.R. §483.13(b)), and F-224 concerns mistreatment, neglect, or misappropriation of resident property (42 C.F.R. §483(c)). Harrington reports the following data for F-223 and F-224, which shows the percent of nursing facilities in the United States, with one or more violations in F-223 and F-224 by year (Harrington et al., 2005):

Year	Percent of Facilities with F-223 Deficiency	Percent of Facilities with F-224 Deficiency
1996	1.5	1.9
1997	1.4	1.6
1998	1.8	2.1
1999	2.0	2.6
2000	1.6	2.9
2001	1.5	2.5
2002	1.4	1.9
2003	1.1	1.8
2004	1.0	1.7

While this OSCAR data is of interest, it has critical limitations:

- According to Harrington, the OSCAR data on F-223 is only a "yes or no" item entered by state survey agency staff based on the inspection reports (personal communication, April 2005). It does not indicate the kinds of abuse, the frequency, number of instances, or perpetrator. An expansion of OSCAR items, or, more

precisely, a clarification of the F-223 instructions to record at least the number of instances of abuse and the perpetrator would provide more useful information. The same could be said of F-224 on resident property.

- The inspection report on F-223 is based on surveyor interviews, observations, and record review (CMS, *State Operations Manual: Appendix PP*). Facilities may fail to document abuse; and surveyors may not be trained in abuse investigation and observation.

- Instances of abuse in facilities also may be reported to adult protective services, the long term care ombudsman program, a law enforcement agency, or the Medicaid Fraud Control Unit, and there is no way to account for this duplication.

2. Long Term Care/Health Care Complaint Data

In 2004, CMS initiated the use of a complaint database system and all states have agreed to use it. The ASPEN Complaints/Incidents Tracking System (ACTS) is a program "designed to track, process, and report on complaints and incidents reported against health care providers and suppliers regulated by CMS. It is designed to manage all operations associated with complaint/incident processing, from initial intake and investigation through the final disposition" (CMS, *State Operations Manual*: 5060, and at http://new.cms.hhs.gov/manuals/downloads/som107c05.pdf. State survey agencies and CMS regional offices are required to enter complaint information into ACTS. The ACTS is used for allegations concerning "skilled nursing facilities, nursing facilities, home health agencies, end stage renal disease facilities, hospitals, suppliers of portable x-ray services, providers of outpatient physical therapy or speech pathology services, rural health clinics, and comprehensive outpatient rehabilitation facilities" (CMS *State Operations Manual*).

The ACTS traces a complaint from beginning to end, including each milestone, such as an onsite survey. The allegations are categorized, and according to CMS staff, abuse is one of the complaint categories (E. Lew, personal communication, October 2005). Therefore, it offers elder abuse professionals and advocates an opportunity to identify information on the incidence and prevalence of elder abuse, with the following limitations:

- ACTS includes *allegations* that might not necessarily be substantiated.

- Currently, ACTS is available only to CMS and to state survey agencies. If elder abuse professionals or advocates are interested in ACTS information, they would need to file a Freedom of Information Act request.

3. National Ombudsman Reporting System

The Older Americans Act (42 U.S.C. § 12101 *et seq.*) requires states to collect long term care complaint data and requires the state ombudsman to report the aggregate data to the AoA. In FY 1995, the AoA implemented the National Ombudsman Reporting System (NORS), which consists of 128 complaint categories for nursing homes and similar types of long-term care facilities.

Under NORS "Residents Rights," Complaint Category A includes "Abuse, Gross Neglect, Exploitation," and this is divided into seven subcategories of abuse (physical abuse, sexual abuse, verbal/psychological abuse, financial exploitation, gross neglect, resident-to-resident physical or sexual abuse, and other). These groupings apply to "willful mistreatment of residents by facility staff, management, other residents, or unknown or outside individuals who have gained access to the resident through negligence or lax security on the part of the facility or for neglect which is so severe that it constitutes abuse." The NORS coding instructions define each type of abuse (Office of Management and Budget [OMB], 2005). In addition, categories P.117 and P.121 are for complaints of abuse, neglect, and exploitation by family members, friends, and others "whose actions the facility could not reasonably be expected to oversee or regulate" (OMB, 2005).

A DHHS OIG report on state long term care ombudsman data concerning nursing home complaints shows the number of abuse complaints as follows (DHHS OIG, 2003).

Year	Total Reported Nursing Home Abuse Complaints
1996	13,469
1997	14,025
1998	15,501
1999	14,871
2000	15,010

The report also states that complaints of physical abuse were included in the "Top Ombudsman Complaint Categories, 1996–2000." In 1996, physical abuse complaints

numbered 4.321 and ranked seventh; and in 2000 such complaints numbered 4,350 and ranked 11th (DHHS OIG, 2003).

In addition, the AoA has analyzed NORS complaints through 2003, including not only the "A" category of abuse by or related to facility staff, but also the "P" category of abuse by family members (S. Wheaton, personal communication, March 2005; also see (http://www.aoa.gov/prof/aoaprog/elder_rights/LTCombudsman/National_and_State_Data/national_and_state_data.asp for data updated to 2004). This analysis shows the percent of each type of abuse, as well as the percent of total nursing home complaints that are abuse complaints (holding fairly steady at 9 percent to 11 percent in the years 1996 through 2003). It also includes the same information for "board and care facilities." This analysis is attached as Appendix A.

The NORS abuse complaint information is useful and should be further explored. However, it has the following limitations:

- The DHHS OIG report noted that variations in state laws and policies may affect the number of abuse complaints, and that "ombudsmen do not always use the same NORS categories to classify complaints, and they sometimes report a single complaint in several different categories" (DHHS OIG, 2003).

- The NORS focuses on ombudsman "complaints" and "cases." However, ombudsman also may receive informal calls or questions concerning abuse of facility residents that don't rise to the level of being classified as "complaints" or "cases," and thus may not be included in the number tallied. The NORS Part III.F is meant to capture these contacts, and should be examined for the number of instances of abuse.

- The same cases that are referred to the ombudsman programs also may be reported to adult protective services, and there is no way to account for this duplication.

4. Additional Sources of Long Term Care Data

a. Nurse Aid Registry. Federal regulations require each state to establish and maintain a registry of all individuals certified to work as nurse aides in long term care facilities, as well as all individuals who have been prohibited to work as nurse aides because of substantiated findings of abuse, neglect, or misappropriation of property (42 C.F.R. § 483.156). The purpose of the registry is to ensure that long term care facilities employ only certified aides who do not have substantiated findings. A DHHS OIG report

on nurse aide registries found that as of September 2003, state registries included 2.6 million certified nurse aides; and that out of these, 33,768 were aides listed with substantiated findings and/or had their certifications revoked (DHHS OIG, 2005).

As a tool for estimating the incidence and prevalence of abuse in long term care, the nurse aide registries are limited in that they report only the number of aides who engaged in abuse, not the number of abusive incidents. In addition, the OIG report found that some states failed to update the registries with substantiated adverse findings, some filed to remove records of inactive aides from the registries, and some individuals with substantiated adverse findings in one state were certified in other states (DHHS OIG, 2005). Also, some incidents of elder abuse may not be substantiated for various reasons. The proposed Elder Justice Act as introduced in 2005 includes provisions for a study on establishing a national nurse aide registry, and for the establishment of such a national registry. While this would provide for more uniform data across the country, it would still focus only on the number of abusive aides instead of the number of incidents of abuse.

b. Nursing Home Minimum Data Set. According to federal law, nursing facilities must complete a full assessment of each resident's condition upon admission, at least once every 12 months thereafter and if a significant change occurs. The assessment must include certain information specified by CMS—referred to as the Minimum Data Set (MDS). The assessment must be recorded on a Resident Assessment Instrument developed by or meeting the criteria of CMS (CMS, *State Operations Manual* § 4145.4, Rev. 2004). Nursing facilities must electronically transmit MDS data to the state, which in turn sends it to CMS. The system currently includes 24 quality indicators in 11 "domains" (Carlson, 2004).

The only direct mention of abuse in the MDS refers to abusive behavior *by* the resident—under "behavioral symptoms" at E4 and "changes in behavioral symptoms at E5 (CMS, RAI *User's Manual*, Rev. 2005). While researchers could scan the MDS data searching for certain medical patterns that might commonly indicate abuse (as certain patterns of bruises), sorting out abuse from accidents or other causes for changes in the resident's condition would appear extremely problematic in light of the lack of scientific research linking specific conditions with elder abuse.

c. Data from State Health and Long Term Care Agencies. Inquiries concerning state health and long term care agencies did not yield any information (aside from federal requirements as described above) aggregated in a national database that would be useful in examining the incidence and prevalence of elder abuse. Individual state health and

long term care agencies may or may not have helpful information, and it may be worth exploration.

d. <u>National Aging Program Information System</u>. The AoA requires states to report on client characteristics and services provided with funds under Title III of the Older Americans Act on home- and community-based care. The AoA operates a data collection system called the National Aging Program Information System (NAPIS) that includes the NORS system outlined above, plus the "State Program Report" system (SPR). Through the SPR, AoA receives statistics from state units on aging on the total unduplicated number of persons served. It also receives counts in several "client descriptor" areas, such as the number served in poverty, minority, in rural areas, and with impairments in activities or daily living or instrumental activities of daily living. In addition, AoA receives statistics on the number of service units provided for selected services under Title III, such as home-maker services, chore services, adult day care, case management, congregate meals and more; as well the number of services providers (http://www.aoa.gov/prof/agingnet/NAPIS/napis.asp).

The AoA does not receive any specific statistics under NAPIS on clients who were abused. Elder abuse professionals and advocates could explore with AoA the possibility of adding abuse as a client "descriptor." Definition of abuse and cost could be significant barriers.

F. Criminal Justice Data

In the National Research Council report, Acierno states in the background paper *Elder Mistreatment: Epidemiological Assessment Methodology* that one way of obtaining data on elder mistreatment is through "translation of criminal justice statistics using age and perpetrator data fields" (Acierno, 2003). There are several possible sources of such data. Crime statistics generally—and more specifically crime statistics on family violence—can be conceptualized as a series of statistical snapshots at different stages in the justice system, as shown below (reproduced from Bureau of Justice Statistics, *Family Violence*, 2005).
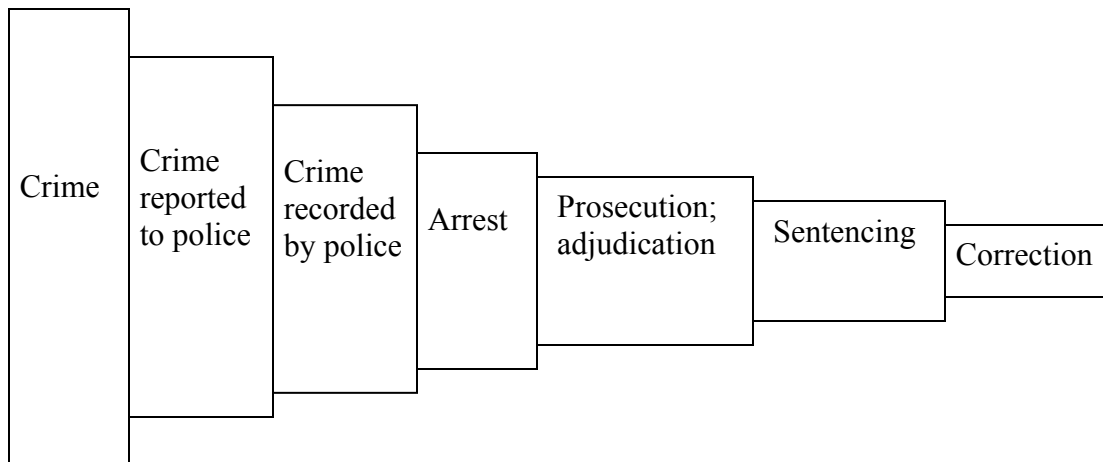
At all of these stages, older adults make up only a very small proportion of victims. For example, as reported in a national survey of crime victimization, adults age 55 or older—as compared with other age groups—were the least likely to be family violence victims between 1998 and 2002, comprising only 6 percent of the victims (Bureau of Justice Statistics, 2005). As to family violence recorded by police, adults 55 or older made up the smallest percentage of victims, comprising less than 5 percent of family violence victims (and less than 3 percent of non-family violence victims) (Bureau of Justice Statistics, 2005). It is useful to examine the various sources of data along the crime statistics spectrum to determine whether and to what extent any may document the incidence and prevalence of elder abuse.

1. Bureau of Justice Statistics--National Crime Victimization Survey
(Boxes 1-3 in figure above)

The Bureau of Justice Statistics conducts an annual National Crime Victimization Survey (NCVS) of some 76,000 respondents from a nationally representative sample of about 42,000 households. The survey asks about the frequency, characteristics, and consequences of criminal victimization. The survey asks individuals about both reported and unreported victimization (thus documenting the first three boxes in the figure above). The NCVS

> enables [the Bureau of Justice Statistics] to estimate the likelihood of
> victimization by rape, sexual assault, robbery, assault, theft, household

burglary, and motor vehicle theft for the population as a whole, as well as for segments of the population, such as women, the elderly, members of various racial groups, city dwellers, or other groups. The NCVS provides the largest national forum for victims to describe the impact of crime and characteristics of violent offenders (http://www.ojp.usdoj.gov/bjs/cvict.htm#ncvs).

The Bureau of Justice Statistics has analyzed data concerning elders from the NCVS and other sources in two publications on *Crimes Against Persons Age 65 or Older—*one for 1992 through 1997, and another from 1993 through 2002 (Klaus, 2000, 2005; Bureau of Justice Statistics, 2005). These publications include extensive statistics on crimes against older persons, including a table on the "Relationship of victim and offender for murder and non-lethal violence, by age of victim," but nothing specific to elder abuse. The earlier publication includes a special note explaining that the NCVS cannot accurately measure elder abuse, which involves victims who are "injured, neglected, or exploited because of vulnerabilities associated with age, such as impaired physical or mental capacities" (Klaus, 2000). The report cites several limitations on securing elder abuse data:

- Victims may not be able to report the abuse because of cognitive impairment, may be afraid to report it, or may not see it as a crime;

- A victim of financial exploitation may not be a aware of it;

- The survey does not include crimes occurring in institutional settings (Klaus, 2000); and

- The survey would not capture the vulnerability of the individual or the trust relationship with the caregiver or family member.

2. FBI Uniform Crime Reports
(Box 3 in figure above)

The FBI system of Uniform Crime Reports (UCR) is a voluntary city, county, state, and federal law enforcement effort based on the submission of crime data by law enforcement agencies throughout the country (http://www.fbi.gov/ucr/ucr.htm#cius). UCR Part A collects offense information from police on murder, non-negligent manslaughter, forcible rape, robbery, aggravated assault, burglary, larceny-theft, motor vehicle theft, and arson; and Part B includes more minor crimes. The UCR is not very useful for collecting information on elder abuse because:

- Although elder abuse *per se* is defined as a crime by some jurisdictions (National Center on Elder Abuse, http://www.elderabusecenter.org/default.cfm?p=backgrounder.cfm), it is not a data element in the UCR. At least one jurisdiction, South Carolina, sought to add an item on elder abuse, to be coded separately by police, but officers frequently did not fill out the additional coding form (R. Thomas, personal communication, April 2005). Adding elder abuse as an integral part of the survey might be more workable, yet problematic as elder abuse is not a crime in all jurisdictions.

- While elder abuse *per se* may not be a crime in some jurisdictions and in the UCR, the acts that make up elder abuse may be crimes. However, the UCR requires police officers to record only one crime against an individual, and only the most aggravated crime (the "hierarchy rule"). Moreover, it collects information only on those crimes reported to police. Thus, since many crimes are not reported to police, and since individuals may be victims of more than one crime, results may be skewed (Acierno, 2003).

- The UCR is dependent on accurate entries by police, who may not recognize elder abuse or may not uniformly report it.

- The serious crimes reported in the UCR could be cross-correlated with age of the victim (where this is provided), but this would simply result in data on crimes against elders, and would not include information on the relationship of the victim to the perpetrator or the vulnerability of the victim.

3. **FBI National Incident-Based Reporting System**
   (Box 3 in figure above)

   To collect more comprehensive information about crimes, the FBI launched the National Incident-Based Reporting System (NIBRS), which goes beyond the UCR to collect data on more categories of crime, weapons, injury, location of the crime, property loss, and characteristics of victims, offenders, and arrestees In NIBRS, each incident, rather than only the most aggravated incident, is recorded. Also, NIBRS includes information on the perpetrator's relationship to the victim.

   Nonetheless, NIBRS still only includes crimes reported to the police—and elder abuse frequently is not reported. Moreover, police may not recognize or record a crime as elder abuse. Indeed, both UCR and NIBRS "are affected by subjective interpretations by police officers of (1) whether an event actually occurred, and (2) classification of the

event by police departments across the country" (Acierno, 2003). Finally, NIBRS is not yet operational in all states. As of 2001, more than 3,700 agencies across 21 states were submitting NIBRS data (http://www.ojp.usdoj.gov/bjs/ibrs.htm). Thus, adding elder abuse as an item in NIBRS might have some utility, but it would still be hampered by the very limitations that make elder abuse so difficult to define and measure. For all of these reasons, Bureau of Justice Statistics data represents "preliminary, as opposed to comprehensive, epidemiological data regarding elder mistreatment" (Acierno, 2003; R. Thomas, personal communication, April 2005).

4. Bureau of Justice Statistics—National Survey of Prosecutors
   (Box 5 in figure above)

In 2001, the Bureau of Justice Statistics surveyed all U.S. prosecutors' offices that handled felony cases in state courts of general jurisdiction, including over 2,300 offices. The survey found that during the previous year nearly 42 percent of the offices had prosecuted elder abuse cases, with the larger offices more likely to prosecute such cases (97.1 percent) than the small (42.3 percent) or part-time (20.5 percent) offices (Bureau of Justice Statistics, *Prosecutors*, 2002). Thus, the survey asked "Did you prosecute elder abuse?" rather than "How many cases?" providing a very rough measure of prevalence, but shedding no light on the incidence of elder abuse. Elder abuse professionals and advocates could inquire into opportunities for revising the survey to include the number of elder abuse cases.

5. Additional Criminal Justice and Related Information Sources

a. <u>Suspicious Activity Reports.</u> National banks are required to report known or suspected criminal offenses involving transactions over $5,000 that they suspect may involve money laundering or violate the Bank Secrecy Act. Banks make this report by filing a Suspicious Activity Report (SAR) form with the Financial Crimes Enforcement Network of the U.S. Department of the Treasury (http://www.occ.treas.gov/sar.htm). The SAR form has categories of suspicious activity, including embezzlement/theft, check fraud, false or conflicting IDs, use of multiple credit or deposit accounts, and more. However, there is *no indication of age* of any victims on the SAR form. A victim specialist for the FBI who is familiar with SAR reports stated that trying to add information about age would be "too simplistic" as "the whole SAR operation is not geared to things like elder exploitation. That's too small and falls under the radar for SAR," which is really targeted toward uncovering large scale drug trafficking and money laundering (D. Deem, personal communication, April 2005).

b. <u>State Offices of the Attorney General.</u> Inquires to the National Association of Attorneys General did not reveal any aggregated statistics on elder abuse. The NAAG maintains projects on end-of-life, consumer protection, and violence against women, but none of these issue areas have data on elder abuse (S. Reznik, personal communication, May 2005). Some state attorney general offices have a special focus on aging, and it is possible that one of more of these could have elder abuse data that might prove useful.

c. <u>AARP Member Surveys</u>. From time to time AARP conducts "Member Opinion Surveys." While elder abuse has not yet been a topic on a member survey, it may be possible to add such a question (N. Karp, personal communication, October 2005; S. Hurme, personal communication, October 2005). The question would have to be carefully structured to obtain useful information, as members would not be likely to report that they had committed elder abuse, and may well not be willing to admit to being a victim.

d. <u>National Domestic Violence Hotline.</u> The National Domestic Violence Hotline was created through the 1995 Violence Against Women Act, and has received more than one million calls since its opening in February 1996. Hotline workers field up to 500 calls a day (http://www.ndvh.org). The hotline does collect information on age of the caller, although some callers do not give their age. In 2005, out of a total of 201,064 calls, some 7,172, or 3.5 percent of callers, were age 55+ (Shawn, personal communication, January 2006).

Callers may be victims, family or friends of victims, interested parties or just individuals seeking information about domestic violence. The hotline does maintain data on the type of caller, and could identify the number of callers in each category by age. The hotline does not collect data on the type of incident involved. Thus, it appears possible to determine the number of older callers who were calling about a violent incident of some kind concerning themselves or others. However, since (1) the number and percent of older callers is very small; (2) there is no solid information about the violent incident; and (3) there is no way to determine whether these callers also reported to APS, the hotline does not seem to offer an effective means for gauging the incidence or prevalence of elder abuse.

G. Fiduciary Data

An additional perspective on the incidence and prevalence of elder abuse is abuse by financial fiduciaries—such as representative payees, primarily those appointed by the

Social Security Administration (SSA) and the Department of Veterans Affairs, and guardians appointed by state courts.

1. Social Security Representative Payee System

In 1939, Congress passed legislation granting the Social Security Administration (SSA) power to appoint "representative payees" (42 U.S.C. §§ 405(j) & 1383(a)). A representative payee is an individual or organization that receives Social Security and/or Supplemental Security Income (SSI) payments for someone who cannot manage his or her money. As of December 2003, there were more than 6.8 million individuals who had representative payees—approximately 60 percent children and 40 percent adults. Currently there are about 5.4 million representative payees, managing almost $4 billion in monthly benefit payments (B. Pautler, memo, 2005). This includes both individual and organizational payees. The SSA monitoring program requires all representative payees to file a report annually. In addition, certain payees (including individual payees serving 15 or more beneficiaries, organizational payees serving 50 or more beneficiaries and others) are subject to triennial site reviews through a face-to-face meeting.

Misuse of funds by SSA representative payees occurs when a representative payee fails to use the funds in the best interests of the beneficiary—for instance, using the funds in a way that would leave the beneficiary without necessities, putting the funds on another person's account, keeping the funds, or charging the beneficiary for services (http://www.ssa.gov/oig/hotline/repayee.htm). News articles and studies over the past decade have uncovered concerns about such misuse of funds. Press reports in the latter 1990s cited incidents of mismanagement of benefits and fraud by "high volume" representative payees in Los Angeles, northern Michigan, Detroit, Phoenix, Denver, Washington, and West Virginia (American Bar Association, 2001). In 1996, a Representative Payment Advisory Committee to the Commissioner of the Social Security Administration recommended enhanced monitoring measures (Representative Payment Advisory Committee, 2001). The OIG for SSA has made a number of reports on misuse of funds by representative payees and the need for enhanced oversight (Huse Statement, House Committee on Ways and Means, 2003). In 2004, the U.S. Government Accountability Office (GAO) found a lack of coordination among the SSA representative payment program, the Department of Veterans Affairs fiduciary program, and state courts handling guardianship (see below) (U.S. Government Accountability Office [GAO] 2004).

The Social Security Protection Act of 2004 (P.L. 108-203, §107) required that SSA conduct an assessment of the representative payee program including a major survey

of individuals serving from one to 14 beneficiaries and non-fee-for-service organizations serving less than 50 beneficiaries. The survey will "assess the extent to which representative payees are not performing their duties as payees in accordance with SSA standards of payee conduct" (B. Pautler, memo, 2005, referencing *Congressional Record,* Dec. 9, 2003). The Division of Behavioral and Social Sciences and Education of the National Academies has contracted with SSA to implement the survey, and has established a committee of 11 experts to assist.

The study director, Bud Pautler, indicated that SSA maintains data on representative payees in a database called the RPS (Representative Payee System), which was started in the early 1990s in response to negative publicity about the payee program. He observed that it is somewhat of a hodgepodge, including all information SSA has on all representative payees since the beginning of the database, including current, terminated, and pending payees, and all associated beneficiaries for each. Every field office has access to the RPS. While it notes whether the payee misused funds, "many of the entries are text and cryptic." It is "not good for statistical analysis" and has errors and inconsistencies (B. Pautler, personal communication, July 2005). For example, it might note that "better payee found," but this does not tell why the next payee was better or whether the first payee abused his or her fiduciary duty.

For the legislatively required study, the National Academies has pulled a 5 percent sample research file, which also includes all misusers, which Mr. Pautler indicated is about 0.1 percent of all payees in the system. The sample file includes about 730,000 payees. There are about 1,000 misusers a year. The study director has some tables on this information, but they are not publicly available now. Upon questioning, he indicated that payees of minors and adults could likely be separated, and that instances of misuse theoretically could be correlated with age of the beneficiary. (However, Mr. Pautler believes there are very few instances of payee misuse of funds with elders because the family generally handles the funds informally and does not apply to be payee.) The study includes only individual payees and smaller organizational payees, and thus information about larger organizational payees would need to be requested directly from SSA—and SSA may be cautious about releasing it (B. Pautler, personal communication, 2005).

2. U.S Department of Veterans Affairs Fiduciary Program

The Department of Veterans Affairs (VA) allows for the appointment of a fiduciary for a beneficiary who is not able to manage his or her own affairs. The beneficiary may be adjudicated incapacitated by a state court and VA benefits paid to the

court-appointed guardian or conservator. In addition, when it appears that the interest of a beneficiary would be served by appointment of a fiduciary, the VA may make payments to the spouse of a beneficiary, the chief of staff of a non-VA institution where a beneficiary is receiving care, or to some other entity overseeing the care or estate of a beneficiary (38 U.S.C. § 5502(a)). Currently there are approximately 100,000 fiduciaries managing funds valued at approximately $2.8 billion for 65,000 disabled veterans; 32,000 widows or adult disabled children; and 3,000 minors. Some 224 field examiners and 127 legal instruments examiners in 57 VA regional offices are charged with the monitoring of the needs of Fiduciary Program beneficiaries (Henke Statement, U.S. House Committee on Veterans' Affairs, July 2003).

The OIG for the VA has commented over the years about needed changes in the fiduciary program. A 1997 OIG report found that the VA could provide more effective supervision of fiduciaries (VA OIG, 1997, *Audit*). Another report the same year found that the VA's fiduciary system did not include records for all beneficiaries with fiduciaries, and recommended that "establishment of appropriate Fiduciary Beneficiary System records would help fiduciary program personnel monitor the financial affairs of incompetent beneficiaries and reduce the risk of theft or misuse of the beneficiaries' funds" (VA OIG, 1997, *Completeness of Data*). The OIG hotline receives allegations of fiduciary and field examination irregularities. From 2000 to 2003, the hotline received 79 allegations concerning fiduciary and field examination activity, and of these, the OIG found that 20 were substantiated and 13 were still under inquiry (Griffin Statement, U.S. House Committee on Veterans' Affairs, July 2003). In addition, the 2004 GAO report found insufficient coordination between the VA fiduciary program, the SSA representative payee program and state courts that handle guardianships (GAO, 2004).

The Veterans Benefits Improvement Act of 2004 (P.L. 108-454) requires the VA to include in annual reports information on the fiduciary program, including the number of beneficiaries, the types of benefits paid, the number of cases in which the fiduciary was changed because of a finding that benefits had been misused, and other actions taken in cases of misuse. Contacts with the VA fiduciary program revealed that currently data on misuse of fiduciary funds is not aggregated. However, in response to P.L. 108-454, the data system of the fiduciary benefits program will soon allow the collection of data on reported instances of misuse. Implementing instructions were issued in June 2005 and the office has not yet received any misuse determinations (P. Knapp & B. Grimes, August 2005). Thus, elder abuse professionals and advocates should check with the VA fiduciary program to track the data on misuse. Limitations include that: (1) not all of the veteran beneficiaries are elderly, so the results would have to be correlated with age, and (2) instances of fiduciary abuse may of course not be uncovered or reported.

3. Guardianship and Conservatorship Data

Guardianship is a relationship created by state law, in which a court gives one person (the guardian) the duty and power to make personal and/or property decisions for another (the ward). The appointment of a guardian occurs when a judge decides the ward lacks capacity to make decisions. Adult guardianship data can contribute to an assessment of the incidence and prevalence of elder abuse in two ways: (1) providing information about the number and proportion of guardianship petitions brought to protect an individual from ongoing elder abuse, and (2) providing information about guardian or conservator abuse of the ward and/or misuse of the ward's funds. Very little hard statistics are available on either.

a. <u>Lack of Guardianship Data</u>. The adult guardianship system has been maligned in a number of press accounts since the mid-1980s. In 1987, the Associated Press (AP) report, *Guardians of the Elderly: An Ailing System*, alleged that "the nation's guardianship system, a crucial last line of protection for the ailing elderly, is failing many of those it is designed to protect." More recent press accounts (*Detroit Free Press*, 2000; *Phoenix New Times*, 2000; *Rocky Mountain News, 2001*; t*he Washington Post*, 2002; *AARP Magazine,* 2003; *The Washington Post,* 2003; *Detroit News,* 2004; *The New York Times,* 2004; *Los Angles Times,* 2005) mirror the AP claims, despite continuing reform efforts.

Whether these accounts reflect isolated examples of abuse in an otherwise well-functioning process or come closer to the norm is unknown, as data on the adult guardianship system is scant or nonexistent (Hannaford & Hafemeister, 1994; Frolik 1998). Courts have widely varying guardianship statistics. In many states guardianship is lodged in probate courts, but in others it is heard in general jurisdiction courts where it may easily get lost in the wide variety of cases. In some instances, case information on adult guardianship may not be separated from guardianship for minors. Some courts lump guardianship data in with more general probate or decedents' estates data. State differences in terminology can present a real barrier—"guardian" may refer to guardian of the person, guardian of the property, or both, and some states use the term "conservator" as well, with varying meanings. There is no uniform method for data collection or uniform data fields. Moreover, courts and court administrative offices have differing computer capabilities and technical systems (E. Wood, unpublished memo, 2004). In recent years, there have been a few attempts to collect basic data:

- The AP report provided the country's first guardianship statistics in 1987—numbers that remain today among the very few such national-level counts. It concluded that there were approximately 300,000 to 400,000 adults under guardianship in the country. The reporters reviewed over 2,200 case files, but did not include hard numbers on abuse either as the reason for filing or at the hands of guardians. The report did find that accountings were missing in 48 percent of the files and that some 13 percent of the files were empty except for the opening of the guardianship. (Recently the *Los Angeles Times* reporters reviewed 2,400 cases involving professional conservators, including every one handled in Southern California between 1997 and 2003. It found many instances of abuse, but did not provide statistics on the instances of abuse.)

- The National Probate Court Standards Project compiled statistical information about the number of guardianship cases filed in 36 jurisdictions from 1990 through 1992 (Hannaford & Hafemeister, 1994), but included no information on abuse by guardians.

- A national study by The Center for Social Gerontology in 1994 examined the guardianship process intensively in ten states, and made 14 findings on the guardianship process, but did not include any finding on abuses by guardians. (Lisi, Burns, & Lussenden, 1994).

- Individual states or localities have undertaken varying efforts to collect guardianship information. For example, the Vermont Bar Association Elder Law Committee is completing a statewide survey of all (approximately 2,500) adult guardianship court files. The San Francisco Probate Court completed a retrospective review and questionnaire concerning "conservatorship" (guardianship) files dating back to 2000. The study reviewed 168 cases and found that in 29, one of the reasons listed for seeking the conservatorship was "abuse." The study also reviewed 21 applications for elder and dependent adult restraining orders filed by people over age 65, and found that in 15 of these (71 percent) "physical abuse" was checked as a reason for seeking the protection. Financial abuse was checked on three petitions (Quinn & Nerenberg, 2005).

The compelling need for statistics on adult guardianship was addressed in 2001 by a National Guardianship Conference ("Wingspan Conference") sponsored by several national collaborating groups, which recommended that:

A uniform system of data collection within all areas of the guardianship process [should] be developed and funded. Comment: Although significant legislative revisions have been adopted, little data exists on the effectiveness of guardianship within each state or across the states, and less information is available about how the system actually affects the individuals involved (*Stetson Law Review,* 2002, Rec. #4).

b. GAO Report. In 2004, following hearings by the U.S. Senate Special Committee on Aging, the Government Accountability Office (GAO) conducted an investigation on adult guardianship. It found that "most courts surveyed do not track the number of active guardianships," that a lack of systematic coordination between state courts, the SSA representative payment program, and the VA fiduciary program "weakens oversight of incapacitated people," and that "certain data, such as the number of active guardianships and incidence of abuse, could help courts and agencies determine the effectiveness of efforts to protect incapacitated people but are not currently available."

The GAO recommended that "the Department of Health and Human Services provide support to states and national organizations involved in guardianship programs in efforts to compile national data on the incidence of abuse with and without the assignment of a guardian or representative payee" (GAO, 2004).

c. NCEA/ABA Data Study. Following the GAO report, the NCEA, through its support from the AoA, contracted with the ABA Commission on Law and Aging to survey state court administrators concerning what data they maintain on adult guardianship, adult conservatorship, and elder abuse. The survey found that not all state court administrative offices receive information on guardianship from trial courts, and in those states that do receive such information, it indicates only the number and sometimes the disposition of guardianship cases, but not information on whether cases involved elder abuse.

The survey also asked whether elder abuse is a "distinct case type" reported by trial courts to the state court administrative office. Only two states responded positively—Vermont, with 61 filings, and Wisconsin, with 20 filings and 23 dispositions in the most recent year. In addition, Kansas indicated that trial courts began reporting elder abuse as a distinct case type in 2005 (ABA Commission, *State-Level Adult Guardianship Data*, manuscript in preparation, see http://www.elderabusecenter.org for survey results).

In addition, the AARP Public Policy Institute contracted with the ABA Commission to assist in a national survey on adult guardianship monitoring. The survey includes a question on data maintained by the court, including "whether the case involved elder abuse" as well as "reasons the case was initiated." The results of this survey (currently underway) also will be of interest. (Contact the AARP Public Policy Institute for more information.)

d. <u>Guardian Certification Programs</u>. Finally, a possible additional source of data on elder abuse by guardians may be actions taken under the certification process. The National Guardianship Foundation has had a national certification program since 1997. Currently there are over 700 Registered Guardians (basic proficiency) and 35 Master Guardians. Upon receipt of complaints, the National Guardianship Foundation (NGF) chair appoints a professional review board to review the actions of a Registered Guardian or Master Guardian. There is no permanent board. A new board is composed for each complaint. Thus far, at least six boards have been formed and two are currently active. The deliberations of the boards are confidential. The process is set out by the NGF Rules (S. Hurme, personal communication, August 2005).

Additionally, some states maintain registries of professional guardians, and several have or are developing certification programs. The concept of guardian certification is still too new to yield much data on elder abuse, but as it gains momentum it may have significant potential. Elder abuse professionals and advocates should track the trend and ensure that as programs are established they are set up to maintain statistics that would be most useful, and that these statistics can be accessible.

H. Legal Services Data

Data maintained by legal programs serving older clients offers another possible avenue for information on the incidence and prevalence of elder abuse, including caseload statistics kept by legal services offices and statewide legal hotlines for the elderly.

1. Legal Services Programs

The Legal Services Corporation (LSC) is a private, non-profit corporation established by Congress in 1974 to seek to ensure equal access to justice under the law by providing civil legal assistance to those who otherwise would be unable to afford it. The LSC is funded through congressional appropriation. It funds 143 legal aid programs around the nation to provide legal help for poor people.

The LSC maintains a reporting system on all LSC-supported cases to measure program service and report to Congress and the public. The LSC *Case Service Reporting Handbook* sets out legal problem categories and codes. There are codes for "juvenile neglected/abused/dependent" and "spouse abuse," but no code specifically for elder abuse. This year the LSC Office of Information Management broadened Case Code 37 for "Spouse Abuse" to "Domestic Abuse," effective in March 2006. Theoretically, this could include elder abuse, and could be cross-referenced with age to get the number of elder abuse cases handled by LSC grantees. After the code change has been in effect for a year, elder abuse professionals and advocates could contact the LSC Office of Information Management to request that Code 37 on Domestic Abuse be correlated with client age. They also could request another code change to create a separate code on elder abuse, but this approach seems unlikely to succeed since the change to "domestic abuse" was just made (C. Nolan, personal communication, September 2005).

Additionally, as with the medical ICD coding, even if there was a specific code for elder abuse, law cases may be more likely to be coded under other topics. For example, an attorney in a Maryland legal aid office noted that "If a client's adult child 'misuses' the client's funds and the client is facing foreclosure or other debt-related issues, the case would usually be characterized as either bankruptcy or debt collection" (L. Sarro, personal communication, April 2005). Moreover, if a legal aid attorney happens to encounter elder abuse in the course of representing a client on another matter, this would not be reported in LSC data collection, although the attorney may report the matter to APS.

Individual legal services programs may maintain sub-codes further refining the LSC categories, but it is not known to what extent, if any, these programs have any additional codes that might relate to elder abuse. Some local programs may have a general code for "domestic abuse" or "domestic violence" (broader than just spouse abuse) that could be correlated with age of clients. For example Pine Tree Legal Assistance in Maine includes several categories for domestic violence (see Pine Tree Web site at: http://www.ptla.org/ptlasite/manual/casecode.htm). The Legal Services Corporation of Virginia does not require its local legal aid programs to report separately on elder abuse, and upon a query to the local programs, found that none of them do so. However, the director stated that he is in the process of revising the reporting system and would be willing to add a category entitled "Obtained Protection from Domestic Violence for Client Aged 60 or Over" (or to collect the data on domestic violence and ensure that it can be crossed with age) (M. Braley, personal communication, July 2005). Note,

however, that such a category would not include abuse related to staff in a nursing home or assisted living, nor would it include other elder abuse that is not domestic violence.

In some communities, local LSC programs also receive funds from Area Agencies on Aging under Title III of the Older Americans Act to provide free legal assistance to older persons. These programs may maintain data collection categories beyond the LSC codes that are more attuned to problems common to older clients. It is not known to what extent programs or states collect data on cases involving elder abuse. However, at least one state, Georgia, does so. The Georgia Elderly Legal Assistance Program *Standards* includes a case coding sheet with categories for financial exploitation, neglect, self-neglect, sexual abuse, and physical abuse (Georgia Elderly Legal Assistance Program, 2005). The Georgia Legal Services Developer reported the following recent statewide statistics for two quarters of 2004 (but did not indicate the total number of cases reporting) (N. Thomas, personal communication, May 2005):

Cases Type	July-Sept 2004	Oct-Dec 2004
Adult Neglect/Exploitation	1	3
Family Violence (Physical)	2	2
Self-Neglect	1	0
Financial Exploitation	3	1
TOTAL Cases for 2 Quarters		13

These low numbers probably reflect the tendency noted above to code cases involving elder abuse under other substantive law categories. It does not appear that there is any secondary case type coding equivalent to a medical "secondary diagnosis." Even if local programs collect such data, it is not reported to the AoA (see section on NAPIS above).

2. Statewide Legal Hotlines for the Elderly

During the past decade, AoA has funded some 20 statewide Senior Legal Hotlines—nonprofit programs that provide telephone legal advice at the initial call for service or soon thereafter. Some hotlines also provide brief services, such as review of documents or drafting of letters. Many offer referrals for more extended services. Most of the hotlines are funded through Older Americans Act funds, although a few have some LSC or state dollars. The AARP Foundation operates a program of Technical Support for Legal Hotlines. The director of this technical support program agreed to query the

statewide hotlines on whether they collect any data on elder abuse. Five programs responded, as follows (S. Ehrlich, personal communication, July 2005):

- Kentucky–Keeps data in the standard LSC format. "Elder abuse may be reported under guardianship, power of attorney, property, torts, domestic violence, or contracts. There is not a way to pull 'elder abuse.'"

- Iowa–Does have specific case type codes for physical abuse, emotional abuse, and financial abuse.

- Idaho–Hotline uses state legal services coding system, which does have specific codes for adult abuse and adult neglect/exploitation, but there is ambiguity on how to record these cases.

- Ohio–Does track physical or financial abuse if it is the primary legal problem presented.

- California–Does not track elder abuse in enough detail to be useful.

The director of the hotline technical support center indicated that she is going to redesign the hotline data collection system in the fall of 2005, and that "it may be possible to get them to report elder abuse in a particular code" (S. Ehrlich, personal communication, July 2005). Thus, elder abuse professionals and advocates could work with the hotline technical support center, the AoA, and LSC to identify ways to encourage the reporting of elder abuse. As with medical data, the barriers are significant.

III. Conclusions and Recommendations

This study has examined possible sources of data on elder abuse in the health care, long term care, criminal justice, fiduciary, and legal services arenas, beyond adult protective services data. Such data are required as a basis for informed and enlightened social policy on the prevention and treatment of elder abuse.

Databases that might yield information on elder abuse fall into two categories. The first is data that are regularly coded for either claims or regulatory purposes—for example, ICD data coded by physicians, hospitals, and other health care providers; or nursing home deficiency data coded by state surveyors. The second is data collected continually, episodically, or periodically (often annually) for research, evaluation, and

policymaking purposes—such as data available through the National Health Care Surveys, the National Violent Death Reporting System, or the National Crime Victimization Survey. In both categories, not surprisingly, elder abuse data are extremely difficult to identify, and generally fall below the radar screen because:

- Providers and professionals coding the information lack the training to recognize a fact pattern or medical condition as involving elder abuse. There is no paradigm or "frame" that makes elder abuse indicators evident;

- Elder abuse often is secondary to other conditions or case types that are more likely to be coded;

- There are no incentives for coding or reporting information on elder abuse, and there may be conflicts or disincentives; and

- The largest single driver of data on which elder abuse information might be based is the massive and long-standing ICD coding system widely used throughout the health care and health financing systems. It is the foundation for multiple CDC surveys, for Medicare claims information, and for ARHQ databases. While it does include codes for adult maltreatment, these must be correlated with age to yield information on elder abuse, and even then information on the victim-perpetrator relationship may be missing. Moreover, the existence of coding line items or categories certainly does not guarantee they will be used. It appears that the adult maltreatment codes are used exceedingly rarely for all of the reasons given above. While the development of the next ICD iteration—ICD-10—may offer an opportunity for some change, the barriers are enormous.

This report offers a detailed snapshot of existing sources across multiple agencies and organizations—an alphabet soup array. For each source, the report examines the gaps and limitations, and possible use by AoA, other federal agencies, and elder abuse professionals and advocates, to bolster the statistical basis for elder abuse policy. Indeed AoA is in a key position to partner with the other federal agencies that collect the data described, to strengthen information on the incidence and prevalence of elder abuse. Exploration of approaches could be initiated in collaboration with the Federal Interagency Forum on Aging-Related Statistics, as well as through the Federal Interagency Working Group on Elder Justice, in which AoA already has a leadership role.

It is difficult to gauge which, if any, of these recommended actions are most viable and cost-effective. Some are clearly long term and ongoing—for instance, the need to educate physicians and other health care providers about elder abuse and the importance of coding it. Others may not be realistic in view of the barriers—for instance, seeking to have the ICD-10 coding system separate out elder abuse. All should remain on the list for initial consideration. However, several actions seem more timely and doable than others:

✓ National Hospital Ambulatory Medical Care Survey and the National Ambulatory Medical Care Survey Age-Abuse Correlation. The National Center for Health Statistics should be requested to do a correlation of age data and ICD-9 codes on abuse from the National Hospital Ambulatory Medical Care Survey and the National Ambulatory Medical Care Survey. Because the ICD coding of abuse is so problematic, the resulting data might show abuse at unrealistically low levels and be of little use, yet it may be a starting point of investigation, and might be undertaken without much additional burden.

✓ National Hospital Discharge Survey Redesign Input. Since the National Hospital Discharge Survey is about to undergo a redesign, and since the project officer for the redesign invited input on elder abuse, it seems a reasonable opportunity to pursue.

✓ National Violent Death Reporting System—Violent Death Data. The emergent CDC National Violent Death Reporting System may offer a valuable new source of elder abuse data. The possible addition to the system of information from the nascent state and local adult fatality review teams should be explored.

✓ Medicare Claims Data File. A "data request packet" to CMS could be submitted asking for use of a 5 percent Standard Analytical File of Medicare claims data to correlate age and the ICD adult abuse codes. The file would be large enough to yield interesting information, at only a small cost. Again, because the ICD coding of abuse is problematic, the data might not be an accurate barometer of the incidence and prevalence of elder abuse, but it might be a worthwhile exercise as a basis for additional investigation.

✓ Aspen Complaints/Incidents Tracking System—Database on Complaints. The exact nature of abuse information under the new Aspen Complaints/Incidents Tracking System database on complaints could be explored with CMS staff; and a

determination made as to the usefulness of filing a Freedom of Information Act request to obtain data on abuse complaints.

✓ National Ombudsman Reporting System Abuse Categories. The National Ombudsman Reporting System is one of the few national systems that does routinely collect information on elder abuse. However, there are substantial problems with the system. It appears that the complaint definitions and categories are not used consistently and that there may be duplication with APS reports. These problems should be examined to determine if improvements can be made.

✓ National Crime Victimization Survey and National Incident-Based Reporting System Criminal Justice Categories. While it may seem a large leap to request that elder abuse be added as a question on the National Crime Victimization Survey and be added as a reporting category for law enforcement under the National Incident-Based Reporting System, it is an avenue to explore. Admittedly, there are problems with both—victims filling out the survey may be reluctant to indicate any elder abuse; and law enforcement officers may unlikely to record it. However, it is a place to start and may help to bring visibility to the issue and "reframe" the way abusive actions against elders are seen.

✓ Social Security Representative Payee Study & Redesign. The current study underway concerning Social Security representative payee data should be tracked, and the study director contacted concerning approaches to clearly identify data on misuser payees of adults.

✓ VA Fiduciary Data. The new VA fiduciary data system should be tracked, and the results concerning data on fiduciary misuse analyzed.

✓ Legal Services Corporation. The LSC Office of Information Management should be contacted after March 2007, when the new code for "domestic abuse" has been in place for a year, concerning the possibility of having data from this code correlated with age of clients. The yield might be small, but could be informative.

✓ Legal Hotline Data Collection. While a long term goal might be to include elder abuse in the Legal Services Corporation case reporting system and in the AoA program information system, a more immediate and doable objective might be to include elder abuse in the redesign of the data collection system for the state legal hotlines for the elderly. The technical assistance support coordinator for the

hotlines stated the redesign will come up this fall, and invited input on elder abuse.

In addition, an overarching barrier that cuts across many of the data systems is the lack of capacity by professionals—physicians, nurses, hospital staff, coding experts, state health department surveyors, law enforcement officers and legal services attorneys—to recognize a fact pattern as elder abuse and to so code it. Enhanced training and education would help these professionals on the front line to "reframe" the situation so as to more accurately reflect the incidence and prevalence of elder abuse.

While each of the above actions offers some potential to fill in the blanks in the national picture of elder abuse, taken together they are nonetheless insufficient and piecemeal. Indeed the examination of data sources for this white paper supports the need for: (1) the development of scientific research on elder abuse under proposed projects supported by the National Institute on Aging, and (2) a national incidence and prevalence study and other collection of data as recommended by the National Research Council (National Research Council, 2003).

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Appendix A

National Ombudsman Reporting System Data on Elder Abuse
U.S. Administration on Aging

Abuse, Neglect, and Exploitation (A/N/E) Complaints Made By or on Behalf of Long Term Care Facility Residents to Long Term Care Ombudsmen

Code	Type of Abuse	U.S. Federal Fiscal Year: Oct. 1 – Sept. 30							
		1996	1997	1998	1999	2000	2001	2002	2003
A1	Physical	4,321	4,080	5,426	4,591	4,350	4,842	4,777	5,163
		27%	25%	30%	27%	25%	25%	24%	23%
A2	Sexual	548	535	666	707	662	787	749	962
		3%	3%	4%	4%	4%	4%	4%	4%
A3	Verbal/Mental	2,431	2,676	2,598	2,601	2,787	3,171	3,256	3,618
		15%	16%	14%	15%	16%	16%	16%	16%
A4	Financial Expl.	640	691	841	855	840	966	1,485	,1048
		4%	4%	5%	5%	5%	5%	7%	5%
A5	Gross Neglect	2,123	2,648	2,551	2,331	2,372	2,591	2,610	2,775
		13%	16%	14%	14%	14%	13%	13%	12%
A6	Resident to Res.	2,532	2,565	2,577	2,851	3,034	3,569	3,746	5,010
		16%	16%	14%	17%	17%	18%	19%	22%
A7	Other Abuse	874	830	842	935	965	928	663	1,084
		6%	5%	5%	6%	6%	5%	3%	5%
P117	Abuse/Abandoned by Family	825	781	804	648	703	878	959	902
		5%	5%	4%	4%	4%	4%	5%	4%
P121	Family Financial Exploitation	1,558	1,587	1,627	1,468	1,640	1,874	1,740	1,936
		10%	10%	9%	9%	9%	10%	9%	9%
	Total: 100% of Abuse, Neglect, and Exploitation Complaints*	15,852	16,393	17,932	16,987	17,353	19,606	19,985	22,498
	Total NH Comp* Percent A/N/E	144,680	157,380	163,540	172,661	186,234	209,663	208,762	226,376
		11%	10%	11%	10%	9%	9%	10%	10%

* Abuse, neglect, and exploitation complaints represent only a percentage of the total number of complaints made to ombudsman programs each year.

Abuse, Neglect, and Exploitation (A/N/E) Complaints Made By or on Behalf of Long Term Care Facility Residents to Long Term Care Ombudsmen

Board & Care-Type Facilities

Code	Type of A/N/E	U.S. Federal Fiscal Year: Oct. 1 – Sept. 30 1996	1997	1998	1999	2000	2001	2002	2003
A1	Physical	1,291 30%	938 25%	1,044 25%	901 23%	847 19%	979 20%	1,076 19%	1,189 19%
A2	Sexual	220 5%	183 5%	180 4%	170 4%	201 5%	232 5%	225 4%	340 5%
A3	Verbal/Mental	822 19%	652 18%	797 19%	843 22%	802 18%	895 18%	1025 19%	1023 16%
A4	Financial Expl.	349 8%	340 9%	385 9%	403 10%	509 12%	563 11%	756 14%	707 11%
A5	Gross Neglect	500 12%	705 19%	562 14%	614 16%	649 15%	798 16%	771 14%	868 14%
A6	Resident to Res.	411 10%	348 9%	424 10%	329 8%	505 11%	529 11%	695 13%	997 16%
A7	Other Abuse	108 3%	85 2%	156 4%	146 4%	171 4%	183 4%	118 2%	284 4%
P117	Abuse/Abandoned by Family	119 3%	106 3%	146 4%	135 3%	184 4%	210 4%	259 5%	270 4%
P121	Family Financial Exploitation	444 10%	338 9%	403 10%	379 10%	526 12%	567 11%	608 11%	734 11%
	Total: 100% of Abuse, Neglect, and Exploitation Complaints*	4,264	3,695	4,097	3,920	4,394	4,956	5,533	6,412
	Total B&C Comp*	31,680	30,783	34,696	37,953	41,397	50,152	49,463	56,470
	Percent A/N/E	13%	12%	11%	10%	11%	10%	11%	11%

* Abuse, neglect, and exploitation complaints represent only a percentage of the total number of complaints made to ombudsman programs each year.