U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy

CONGRESSIONAL REPORT ON THE FEASIBILITY OF ESTABLISHING A UNIFORM NATIONAL DATABASE ON ELDER ABUSE

March 2010

Office of the Assistant Secretary for Planning and Evaluation

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This report was prepared under a contract between HHS's ASPE/DALTCP and the RAND Corporation. For additional information about this subject, you can visit the DALTCP home page at http://aspe.hhs.gov/_/office_specific/daltcp.cfm or contact the ASPE Project Officers, Gavin Kennedy and Helen Lamont, at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C. 20201. Their e-mail addresses are: Gavin.Kennedy@hhs.gov and Helen.Lamont@hhs.gov.

Congressional Report on the Feasibility of Establishing a Uniform National Database on Elder Abuse

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LIST OF ACRONYMS

ACTS   ASPEN Complaints/Incidents Tracking System
AEM   ASPEN Enforcement Module
AFCARS   Adoption and Foster Care Analysis and Reporting System
AoA   HHS Administration on Aging
APS   Adult Protective Services
ASPE   HHS Office of the Assistant Secretary for Planning and Evaluation
ASPEN   Automated Survey Processing Environment

BJS   Bureau of Justice Statistics
BRFSS   Behavioral Risk Factor Surveillance System

CAPTA   Child Abuse Prevention and Treatment Act
CDC   HHS Centers for Disease Control and Prevention
CMS   HHS Centers for Medicare and Medicaid Services
CPS   Child Protective Services

DoJ   U.S. Department of Justice

FARS   Fatality Analysis Reporting System
FBI   Federal Bureau of Investigation

HHS   U.S. Department of Health and Human Services

ICD-9-CM   International Classification of Diseases, ninth edition
IPV   Intimate Partner Violence

LEIE   List of Excluded Individuals/Entities

MDS   Minimum Data Set
MFCU   Medicaid Fraud Control Unit

NAMCS	National Ambulatory Medical Care Survey
NCANDS	National Child Abuse and Neglect Data System
NCEA	National Center on Elder Abuse
NCVS	National Crime Victimization Survey
NEISS-AIP	National Electronic Injury Surveillance System-All Injury Program
NHAMCS	National Hospital Ambulatory Medical Care Survey
NHCS	National Health Care Survey
NHDS	National Hospital Discharge Survey
NHTSA	National Highway and Traffic Safety Administration
NIA	National Institute on Aging
NIBRS	National Incident-Based Reporting System
NIS	National Incidence Study of Child Abuse and Neglect
NNHS	National Nursing Home Survey
NORS	National Ombudsman Reporting System
NRC-CWDT	National Resource Center for Child Welfare Data and Technology
NVDRS	National Violent Death Reporting System
NVISS	National Violent Injury Statistics System
OIG	HHS Office of Inspector General
OSCAR	Online Survey, Certification, and Reporting System
RPS	Representative Payee System
SACWIS	Statewide Automated Child Welfare Information System
SSA	Social Security Administration
UCR	Uniform Crime Report
VAWA	Violence Against Women Act

INTRODUCTION

The limited research in the area of elder abuse suggests that the problem is widespread and largely unreported. In a 1988 study, 3.2 percent of older adults reported having experienced physical or verbal abuse or neglect.[1] An estimated 5 million older people may be victimized by financial exploitation each year.[2] There is evidence to suggest that the number of reported incidents has increased. Between 2000 and 2004, total reports of elder abuse and neglect to state Adult Protective Services (APS) agencies increased 19.7 percent,[3] but it is not clear whether the increase in number of reports is due to a greater underlying incidence of elder abuse or an increase in public awareness of elder abuse as an issue that should be reported to authorities, or both. These reports to APS likely represent only a small fraction of total cases, as most abuse is never reported.

Over the next several decades, the problem is elder abuse is expected to grow as the population of Americans age 65+ rapidly expands.[4]

Background

As early as 1992, the U.S. Department of Health and Human Services (HHS) Secretary's Task Force on Elder Abuse discussed elder abuse data collection as a vital first step that must be taken before effective policy solutions can be developed:

> *Despite increased media coverage and state and community concern, it is premature to try to develop a systematic legislative response to the problem of elder abuse and neglect because there is insufficient information and understanding about the nature and extent of the problem, how it is changing over time, and its causes.[5]*

Thus, the Task Force's first recommendation was to "develop and fund a national research and data collection strategy."[6] The Task Force report and more recent expert opinions note that a uniform national data system would benefit state and federal policymakers, as well as practitioners, researchers, and advocates, by providing the information needed to understand such basic issues as: the extent of elder abuse and neglect; characteristics of victims, perpetrators, and reporters; the nature of abuse; the causes of abuse; trends in the nature and magnitude of the problem over time; and outcomes of interventions.

Thus far, little progress has been made in collecting the information needed to understand the phenomenon of elder abuse on a national scale. Data continue to be collected by and housed in numerous state and local agencies. These agencies use their own definitions for data elements and gear their collection and analysis procedures to their individual needs.

In the absence of coordinated national data collection, independent investigators have undertaken a number of studies to shed light on the nature and extent of elder abuse.[7] However, the studies differ in research methods, sample sizes, and operational definitions, making it nearly impossible to compare their results. Research has also been significantly challenged by inconsistencies and gaps in data collection systems. Information about the number of elder abuse reports, the source of these reports, types of abuse, characteristics of perpetrators and victims, and outcomes of interventions are still lacking.[8]

In 2006, as part of the Tax Relief and Health Care Act of 2006, Congress directed the Secretary of HHS to conduct a study, in consultation with the Attorney General, assessing current elder abuse data collection systems and examining the feasibility of establishing a uniform national elder abuse database to improve the quality and accessibility of data (Public Law 109-432).[9] To develop the basis for its report to Congress, the HHS Office of the Assistant Secretary for Planning and Evaluation (ASPE) contracted with the Lewin Group to conduct research in support of this effort.

The elder abuse field lacks answers to basic questions such as: How many people are abused, neglected, and exploited? Who are the perpetrators, victims, and reporters of elder abuse? What are the victims' outcomes after the system responds? National data would help to answer questions about the characteristics of victims and perpetrators and system response.

There are two primary options for answering these questions, one of which may be more appropriate depending upon the purposes of a data collection effort. If the primary objective of data collection is to determine how many older adults are abused, neglected, or exploited then a national prevalence study would best serve this purpose. A national prevalence or incidence study (or a series of ongoing studies) could more accurately assess the total amount of elder abuse in the United States, including an estimate of the level of unreported abuse.

On the other hand, if the purpose is to examine the outcomes of services and other interventions after abuse is reported, then a nationally coordinated administrative dataset is more appropriate. A national dataset comprised of administrative data on elder abuse that is reported to local authorities and then centralized and analyzed in an ongoing, iterative manner, would provide information on reported cases of elder abuse and could be used to evaluate intervention efforts.

There was a general consensus among experts consulted for this research that both of these two complementary, but separate, data collection efforts are needed:

1. A national dataset comprised of **administrative data** on elder abuse that is *reported* to local authorities and then centralized and analyzed on an ongoing basis.

2. A national **prevalence study** (or a series of ongoing studies) to assess the *total* amount of elder abuse in the United States, including an estimate of the level of *unreported* abuse.

Both data collection efforts are critical and would complement each other to provide a comprehensive picture of the scope and nature of elder abuse and the system response to cases.

This Report to Congress examines the feasibility of a national data collection effort involving administrative data on elder abuse.

A national administrative data collection effort could serve a variety of purposes. A broad range of stakeholders, including policymakers, practitioners, researchers, advocates, and others would potentially benefit from the use of national elder abuse data. Such a data collection effort could be used to document the demographic characteristics of victims and perpetrators, risk factors, fatalities, services received by victims, the consequences of elder abuse, and the outcome of any criminal investigations. Analyses of these data over time could be used to help researchers and practitioners develop better risk assessment tools and identify high-risk cases. Ongoing data collection could be used to measure the impact of policies designed to stop or reduce elder abuse. A national elder abuse data collection effort could be designed to serve this broad range of potential purposes and with these different users in mind.

Sources of Administrative Data

Administrative data on elder abuse are currently collected by numerous state and local entities that play largely separate roles in investigating, reporting, and responding to cases. A range of entities that collect administrative data on elder abuse are relevant to any coordinated national elder abuse data collection effort (see *Table 1*).

In many cases of elder abuse the involved parties have contact with multiple entities such as law enforcement, medical personnel, and APS. Each of the many entry points of the system exist for a different purpose, and therefore each requires and collects different types of information. These entities may or may not view it as their responsibility to collaborate with other entities that operate under different mandates.

The quality and capabilities of systems, agencies, and individuals vary across states and local areas. Practices in one segment of the service system may affect the way a case is handled by other service systems, as well as collaboration between agencies. For example, police officers may fail to report suspected elder abuse to APS if they believe that such a report will not result in a positive outcome for a vulnerable elder. Similarly, APS workers may be frustrated when they perceive that referrals to law enforcement are not taken seriously and not acted on in an efficient and thorough manner. This impacts both the responses by service providers and law enforcement, as well as the types of data which are collected.

TABLE 1: Potential Sources of Administrative Data on Elder Abuse	
Entities Involved in Elder Abuse Data Collection and Reporting	**Related National Database**
Adult Protective Services (APS) agencies	*No national database*
Law enforcement	Uniform Crime Reports (UCR) National Incident Based Reporting System (NIBRS) National Crime Victimization Survey (NCVS)
Nursing facility survey and certification agencies	Online Survey, Certification, and Reporting (OSCAR) System Automated Survey Processing Environment (ASPEN) Minimum Data Set (MDS) and Quality Indicators
Medicaid Fraud Control Units (MFCUs)	HHS Office of Inspector General (OIG) quarterly and annual reports
Long-Term Care Ombudsman programs	National Ombudsman Reporting System (NORS)
Guardianship and representative payee programs	*No national database for guardianship* Social Security Administration (SSA) Representative Payee System (RPS)
Health indicator data	*No current national database*

Experts have identified a number of weaknesses and limitations in existing data systems that would need to be addressed in any effort to collect useful data on a national level, such as:

- The prevalence of, and reasons for, underreporting of abuse.

- Variations among states in the persons covered by elder abuse laws and reporting requirements.

- Inconsistencies in definitional interpretations across individuals, programs, and states.

- Inability of data systems to desegregate data by common data elements.[10]

- Inconsistent staff training across states on identifying, coding, and reporting abuse.

- Inconsistent levels of modernization and integration of paper and electronic records across states and agencies.

Because most elder abuse is not reported to *any* authority, administrative data alone cannot provide a complete understanding of the problem. Prevalence or incidence studies can provide additional insight into the issues by assessing the nature and extent of abuse overall. *Prevalence* refers to the total number of ongoing incidents, and *incidence* is the number of new incidents that occur during a specific time period, (e.g., a year). The few studies on the prevalence or incidence of elder abuse have used diverse methods, including surveys of potential victims, surveys of family members or

paid caregivers, reports from "sentinels," and analyses of administrative data. The studies tend to be based on small samples and vary in definitions and methods, making it difficult to compare their results.

Report Purpose and Organization

The Tax Relief and Health Care Act of 2006 directed the Secretary of HHS to conduct a study, in consultation with the Attorney General, assessing current elder abuse data collection systems and examining the feasibility of establishing a uniform national elder abuse database to improve the quality and accessibility of data (Public Law 109-432).[11] To develop the basis for its Report to Congress, ASPE contracted with the Lewin Group to conduct research in support of these efforts. This Report to Congress synthesizes the findings and discusses considerations and recommendations for a national elder abuse data collection effort.

Specifically, the report addresses:

- Current reporting systems for elder abuse at the federal and state levels.

- Elder abuse definition and laws.

- Examples of data collection efforts in similar fields.

- Considerations and recommendations for a national data collection effort.

CURRENT ADMINISTRATIVE DATA COLLECTION AND REPORTING SYSTEMS ON ELDER ABUSE

This section focuses on administrative data on elder abuse collected by federal, state, and local agencies that have a role in responding to elder abuse incidents. A summary of these systems, organized by governing structure, and a description of the information they collect is provided in *Appendix A*.

There are seven overarching sources of administrative data on elder abuse with varying degrees of relevance: (1) APS agencies; (2) law enforcement agencies; (3) nursing facility survey and certification agencies; (4) MFCUs; (5) long-term care ombudsman programs; (6) guardianship and representative payee programs; and (7) health indicator data. The strengths, weaknesses and commonalities of each corresponding data system are described below.

Adult Protective Services (APS) Data

All 50 states and the District of Columbia have enacted laws that authorize the provision of APS in cases of elder abuse. A large amount of information is gathered in the course of an investigation of alleged elder abuse and during the provision of services to the affected person or persons. As a result, APS administrative data systems are one of the most important archives of information on elder abuse that occurs in community settings. For a summary of APS procedures while pursuing a report, see *Appendix B*.

APS was established under title XX of the Social Security Act in 1975 as a federally-mandated program, but with little or no funding attached. Since that time, APS programs developed in each state in accordance with local needs, laws, and regulations.[12]

The lack of both federal funding and national coordination has resulted in marked differences in the way APS programs and services are structured and delivered across states. For example, some state APS laws only apply to vulnerable citizens who experience abuse in the community, while others go further to protect people who live in nursing homes and other long-term care facilities. Statutes governing APS differ from state to state in several ways, including:

- Age at or circumstances under which a victim is eligible to receive protective services.

- Definitions of abuse, neglect, and exploitation.

- Classification of the harmful act as criminal or civil.

- Mandatory versus voluntary reporting requirements.

- Investigation responsibility and procedures.

- Remedies or interventions for reported abuse.[13]

Just as eligibility and jurisdictional requirements differ, APS systems also vary in the particular elements of information collected about an incident while it is being handled by caseworkers. Two major research efforts that attempted to examine APS data across the states were hindered by this lack of standardization. In the 2004 Survey of State Adult Protective Services produced by the National Center on Elder Abuse, only 32 states were able to separate information on reports where the victim was at least 60 years old from all reports received about adults, and 23 states had no information on the number of reports of financial exploitation.[14] In addition, only 13 states were able to provide data on the race of victims, and only three states could compare Hispanic and non-Hispanic victims.[15]

Another factor that limits the current utility of aggregated APS data is that APS data collection efforts *within* states may not be well-coordinated. State law in Ohio, for example, gives the Department of Job and Family Services the authority for individual counties to designate their APS responsibilities to other entities. Counties designate local public and/or private agencies to perform the APS services of conducting investigations and providing protective services. With only one full-time employee responsible for oversight of APS at the state level, coordination across the state's 88 counties is minimal at this time. Because each county is, in effect, its own system, the comparability of data across counties is poor.[16]

States also vary in the sophistication of their APS data collection systems and the integration of electronic and paper records. Some states use fully electronic records while others use paper records exclusively. More commonly, certain program elements such as client intake are computerized to track basic information such as the name and address of the victim, the date of the report, the type of mistreatment alleged, the supposed perpetrator, and other basic fields.[17] Paper files are often maintained simultaneously to collect different types of information and/or evidence during ongoing investigation and service provision.[18] Efforts to modernize and streamline these program processes have encountered many obstacles including budget shortfalls, organizational resistance to change, union opposition, hardware or software failure, and so on. A few states, such as Texas, have implemented large-scale APS reform and modernization efforts in recent years.

Currently, the assessment and documentation of circumstances surrounding an allegation of elder abuse will leave any uncertainties up to the judgment of individual investigators. Because APS caseworkers may view situations differently based on their personal perspectives, coding and rates of substantiation are inconsistent. Some investigators may look for an inappropriately high burden of evidence before

substantiating a claim, leading to under-substantiation of cases,[19] while others might be more aggressive in pursuing case file information, such as pushing a bank to share information in a financial exploitation case.[20] There is general consensus in the elder abuse field that the utility of informational outputs are limited by the lack of standards for contact and documentation at the state and local levels.[21]

Law Enforcement Data

When an alleged case of elder abuse is reported as a crime, these entities collect information in fulfillment of their law enforcement duties. Police departments are generally involved in elder abuse investigations as-needed for a criminal investigation, most frequently in cases of serious crime such as sexual assault or financial exploitation involving large sums of money.

When the a local police department is involved in the investigation of elder abuse, they generally record the information collected in a police report of the incident, and the report is categorized by the type of crime involved, such as assault, fraud, or even homicide.[22] Most police jurisdictions do not, however, currently have a specific categorization for elder abuse.

Law enforcement agencies collect data on criminal offenses and report to the Federal Bureau of Investigation (FBI) through two voluntary reporting systems. First, the FBI operates the UCR system, which provides an aggregate total of crimes based on information provided to the FBI by limited number of local law enforcement agencies throughout the country.[23] The UCR system includes arrestee demographic characteristics and data on eight categories of crime: (1) criminal homicide; (2) forcible rape; (3) robbery; (4) aggravated assault; (5) burglary; (6) larceny theft; (7) motor vehicle theft; and (8) arson.[24]

The FBI also administers the NIBRS, which is related to the larger UCR system, but operates as an independent incident-based reporting system.[25] NIBRS includes more thorough data on offenses such as the nature and types of specific crimes, characteristics of the victim(s) and offender(s), types and value of property stolen and recovered, and characteristics of persons arrested are collected for each incident.[26] Data on the relationship between victim and offender, however, are sometimes missing.[27] The NIBRS requires 52 data elements to be reported for every crime, and states must meet certain reporting standards in order to participate.[28] As of 2007, 31 states were certified to report incident-based data to the FBI, although full participation in reporting by law enforcement agencies occurs in only ten states.[29] Many large police jurisdictions do not report to the NIBRS because of the FBI's strict reporting format and element requirements. In some states, law enforcement agencies are required to collect and report information in addition to what is collected by the FBI.

The utility of these systems for collecting elder abuse data is limited. The UCR system only reports an aggregated count and does not include incident-specific

information. There is no category or data element dedicated to elder abuse in the UCR or NIBRS databases. These systems cannot be used to identify rates of offenses against older adults because such crimes are dispersed across categories and elder abuse *per se* cannot be identified as its own phenomenon. Additionally, because information from NIBRS is organized by incident, the database may or may not include elements of interest to researchers, policymakers, and program administrators, such as detailed information on the victim and perpetrator of the offense.

Medicare/Medicaid Survey and Certification and State Licensure Data

Health care providers who receive reimbursement from the Medicare and/or Medicaid, including hospitals, nursing homes, home health agencies, and hospices, are charged with keeping older adults safe from harm. In order to ensure that charge is met, the HHS Centers for Medicare and Medicaid Services (CMS) uses a survey process to ensure compliance with health and safety standards. CMS contracts with state survey agencies in all 50 states, the District of Columbia, Puerto Rico, and two territories to document and enforce the safety and quality standards. Some states have additional health and safety licensure requirements, but monitoring and tracking of state law violations are at the discretion of the state and not reported to any national database.

Nursing facilities are required to be surveyed approximately on an annual basis. A complaint may also trigger an on-site survey to investigate a problem. The information collected during surveys includes provider characteristics, resident characteristics, and any deficiencies in compliance to health and safety standards that have been identified during the annual survey or complaint investigations. Deficiencies from surveys and other facility information are entered into the OSCAR system, making it the most comprehensive source of provider-level information on the operations, patient census, and regulatory compliance.

In addition, CMS developed quality measures from the patient assessment tool, the MDS, used in nursing homes. Quality measures can be used to identify facilities with problems with quality assurance. MDS data are collected on regular intervals for every resident in a Medicare or Medicaid certified nursing home.[30] Information is collected on the resident's health, physical functioning, mental status, and general well-being. These data are used by the nursing home to assess needs and develop a plan of care unique to each resident. State survey agencies use the MDS to develop quality indicators that help the agency focus on specific quality issues for the facility during the survey process.

One important difference between these survey data and other forms of elder abuse data is that the mandate of a state survey agency is narrowly confined to addressing deficiencies in care at the facility-level that qualify as violations of state and federal standards. While it may be important to monitor this information, the data collected in a survey is designed to ensure standards are met, not identifying whether a resident or patient might experience abuse or neglect. There is even less information

available on abuse and neglect in board and care homes, assisted living, and similar settings.[31] These providers are not regulated by federal standards and thus there is no national database containing information on deficiencies. Some small residential care settings may also fall outside the jurisdiction of state licensure, so no information would be collected by a state agency on potential elder abuse in that type of residence.

There are a number of additional limitations to using this survey data for assessing elder abuse. First, these databases only make it possible to identify cases of elder abuse at the facility level. A case might include one or more residents or perpetrators, so it is also not possible to accurately establish a number of victims or perpetrators. Substantiation is an issue. While a case of elder abuse may be claimed, there is variation across states and surveyors as to the resolution of the case. For example, in some states the facility is not cited if the situation is "resolved," which generally includes firing the accused perpetrator and educating the rest of the staff about abuse, while in other states, evidence that abuse occurred will lead to a citation. Finally, at any given time, under 5 percent of the population aged 65 and older is living in a nursing facility,[32] so the institutionalize population represents just a fraction of vulnerable elders.

Medicaid Fraud Control Unit Data

The enactment of the Medicare and Medicaid Anti-Fraud and Abuse Amendments of 1977 established and authorized federal funding for the state MFCUs.[33] The mission of the MFCUs is to investigate and prosecute Medicaid provider fraud and incidences of patient abuse and neglect. The MFCUs also pursue civil monetary repayment of Medicaid program funds when a Medicaid provider does not provide adequate services to recipients.[34] The majority of the MFCUs are located within the office of a state's Attorney General, though a small number of the MFCUs are located in various other state agencies.[35] The OIG provides oversight at the federal level.

To become involved in a case of elder abuse, a MFCU must first receive a referral about a potential criminal violation that has taken place within a licensed residential facility or board and care home. These referrals might come from a state's APS agency, a Long-Term Care Ombudsman, an elder's family, facility employees, local law enforcement, or any number of others who might report suspected elder abuse.[36] These referral channels vary by state depending upon jurisdiction, mandatory reporting laws, local relationships, and other factors, ultimately resulting in differences in the number of reports received by individual MFCUs. State MFCUs engage in a variety of other activities related to elder abuse, such as conducting public awareness campaigns that encourage reporting and monitoring Certified Nurse Assistant registries to detect patterns of potential mistreatment by facility employees.[37]

The MFCUs are required to submit quarterly and annual reports to the OIG on the status of their activities. These reports include information on the number of resident abuse cases currently open and closed, but they do not make distinctions with regard to many case details, such as the type of abuse alleged. The OIG reports on aggregated

data from state MFCUs on an annual basis. The OIG also maintains a list of excluded individuals/entities that have been barred from receiving payment from any federal health care program. Placement on this list can quickly drive a residential care facility out of business. Bases for exclusion include convictions for program-related fraud, patient abuse, and licensing board actions.[38]

Long-Term Care Ombudsman Data

State Long-Term Care Ombudsmen are charged with protecting the rights of residents of long-term care facilities. Ombudsmen advocate for residents' rights and quality care, educate consumers and providers, and resolve residents' complaints. Under the federal Older Americans Act, every state is required to have an ombudsman program that addresses complaints and advocates for improvements in the long-term care system.

The HHS Administration on Aging's NORS data summarizes the work of state long-term care ombudsman offices. All state ombudsman programs are required to report to this national database. NORS data includes the number of facilities visited by ombudsman representatives and the types of complaints filed and handled by the program. Seventeen categories of complaints are collected in the NORS system, including six subcategories pertaining to abuse, gross neglect and exploitation. Information on ombudsman activities has been collected at the state level and reported nationally since 1996, providing a profile of the extent of ombudsman activities nationwide.[39]

In each NORS report relating to abuse, neglect, or exploitation, the complaint is grouped as (i) physical abuse including corporal punishment, (ii) sexual abuse, (iii) verbal or psychological abuse including punishment and exclusion, (iv) financial exploitation, (v) gross neglect, or (vi) resident-to-resident physical or sexual abuse. Ombudsman data are focused on the type and outcomes of complaints, and NORS does not capture demographic information about the victim or perpetrator, such as gender, age, activities of daily living, impairments, or other characteristics.[40]

The quality and uniformity of data collected and reported by ombudsmen may be limited by low staffing levels and different levels of training about reporting for staff and volunteers across states. In 1995, the Institute of Medicine published an evaluation of long-term care ombudsman programs that recommended one full-time ombudsman for every 2,000 nursing facility beds in the state.[41] Most states rely heavily on volunteers to operate their ombudsman programs in addition to paid staff. Ombudsman representatives are trained to be advocates, not protective services caseworkers or forensic investigators, and may not report all complaints to the NORS system or to a state's survey agency or nurse aide registry.[42]

In general, confidentiality laws are not thought to hinder the collection of data on elder abuse by ombudsman representatives, but they do interfere with sharing that

information across enforcement and service systems. Ombudsmen are prohibited from sharing information about cases with law enforcement unless they have the specific consent of the resident or his or her guardian. Residents may be reluctant to allow the ombudsman to report to law enforcement or the state's licensing agency for fear of retaliation by the perpetrator(s).[43] Some ombudsman representatives reportedly find this to be a significant and frustrating barrier.

Guardianship and Representative Payee Data

Additional sources of information about potential elder abuse are courts' guardianship data and SSA's representative payee information.

Guardianship

When the effects of Alzheimer's disease, stroke damage, and other conditions leave some older adults unable to care for themselves, or to make and articulate decisions, family members may assume those responsibilities on their behalf. In cases where an older adult does not have a family member to take over, has not provided a living will or advance health care directives, and has not appointed someone to assume durable power of attorney, the government can intervene with several measures to protect a person after they become incapacitated.

A guardianship is a relationship created by state law in which a court gives a designated individual (the guardian) the duty and power to make decisions on behalf of another person who has been judged to lack that capacity for himself or herself (the ward). Guardians may be appointed to oversee a ward's personal welfare (termed "guardian of the person"), financial well-being (termed "guardian of the estate"), or both. A person under guardianship is not able to vote, sign contracts, buy or sell real estate, or make medical decisions, creating the inherent opportunity for abuse and exploitation of the relationship. Although most guardians serve selflessly, others act in their own interests rather than those of the people they are designated to protect. The incidence of elder abuse and financial exploitation at the hands of a guardian or representative payee is unknown, but some cases have received significant public attention.[44]

Each state has its own process for initiating and evaluating petitions for guardianship appointment, and there is variation in the amount of power customarily granted to guardians across states. Likewise, states differ in the extent to which they collect information on guardianships and monitor them for possible abuse or exploitation. At a minimum, most states' laws require guardians to submit a periodic report to the court regarding the well-being of the ward. Recent reports have called for strengthening the oversight of guardianships, but progress has been confined to a handful of jurisdictions thus far.[45] In 2004, a report by the GAO on guardianship found a general lack of information related to guardianship:

With few exceptions, courts and federal agencies don't systematically notify other courts or agencies when they identify someone who is incapacitated, nor do they notify them if they discover that a guardian or a representative payee is abusing the person. This lack of coordination may leave incapacitated people without the protection of responsible guardians and representative payees or, worse, with an identified abuser in charge of their benefit payments.[46]

Neither the states nor the Federal Government collect data on the number of people who have been assigned a guardian or representative payee. A 2006 study by Wood surveyed state court administrators regarding the information they collect and found that:[47]

- Only 24 percent of responding state court administrative offices receives information from trial courts on filings and dispositions for adult guardianship of the person and/or property.

- Only five states collect data on elder abuse as a distinct case type.

- Nearly 45 percent of respondents indicated that they are interested in compiling information on guardianship, conservatorship, and elder abuse, but named substantial barriers.

Information on elder abuse within the guardianship system is scarce. Experts have noted that additional funding and supervision would be required to produce data robust enough for effective management and monitoring of guardianship, conservatorship, and representative payee relationships by the courts. Wood commented separately that there is a need for a single commonly-utilized tool that courts could use to identify and track potential and actual elder abuse in adult guardianship.[48]

Representative Payees

SSA does not recognize durable powers of attorney for managing federal benefits, so SSA assigns representative payees for incapacitated persons to receive these funds. Generally, when an older adult is under a guardianship (or other arrangement) SSA and other federal agencies that manage benefit programs will appoint that guardian as the representative payee. More than 7 million recipients of Social Security benefits have a representative payee.[49]

States do not monitor or collect information on representative payees. In fact, representative payees are entirely independent of court supervision unless they also serve as a court-appointed guardian to the beneficiary in question. Instead, representative payees are supervised by the federal agencies that appointed them, although each agency has different monitoring procedures. The SSA uses the RPS database for this purpose,[50] but this database is thought to be flawed. For example, the 2007 National Research Council study, *Improving the Social Security Representative Payee Program: Serving Beneficiaries and Minimizing Misuse*,

recommended many improvements to the RPS system including "Recommendation 6.15" which suggests including all payees in the system and creating data elements for violations by payees.[51] Redesign of the RPS would create a potential opportunity to craft data elements to collect information about abuse or exploitation of beneficiaries and to make these elements consistent with elder abuse data elements collected elsewhere.[52]

Health Indicator Data

The HHS Centers for Disease Control and Prevention (CDC) is the nation's foremost public health agency and the most trusted source for information about health indicators in the United States. There are efforts already underway at the CDC to plan for elder abuse surveillance that have consisted of a series of meetings with the purposes of: (1) addressing a recommendation that CDC attempt to coordinate activities regarding the use of APS and criminal justice data on elder abuse; and (2) developing a system to measure the prevalence and incidence of abuse, and a definition and set of data elements for surveillance purposes. Researchers with CDC's Violence Prevention Program are developing a definition of elder abuse and potential data elements that could be used by other entities in future associated prevalence or incidence study.

More generally, the CDC regularly conducts large-scale surveys to monitor critical health indicators nationwide. One such effort is the National Health Care Survey (NHCS) performed by the HHS National Center for Health Statistics, a division of the CDC. The NHCS, as well as most of the CDC's health surveillance efforts, relies on the International Classification of Diseases (ICD-9) to code and classify information on morbidity and mortality. The ICD-9 classification includes five codes for types of adult "maltreatment" that might be used to determine the incidence or prevalence of abuse or neglect. However, these diagnostic codes for abuse of adults are not age-specific, so any elder abuse analysis would require cross-checking by date of birth in order to rule out the victimization of younger adults.

Research has demonstrated that the ICD-9 codes for abuse are rarely used in practice. Elder abuse is often secondary to other conditions that are more likely to be coded and reported. Health care providers often lack the training to recognize elder abuse and therefore are unlikely to code for it.[53] Physicians lack training on how to identify possible elder abuse and neglect and need more consistent guidelines on how to determine whether malnutrition and weight loss, bruises, and fractures result from deliberate harm or from medical conditions.[54]

ELDER ABUSE DEFINITIONS AND LAWS

The general term "elder abuse" encompasses a range of harmful actions and inactions that affect older adults, including (but not limited to) seven generally recognized categories: physical, sexual, emotional, verbal, and psychological abuse; financial exploitation; neglect; and in some cases, self-neglect. Researchers have also used the terms "elder mistreatment" or "elder maltreatment" with similar intention. Other definitions in use may exclude self-neglect as a form of elder abuse and/or require that abuse, neglect, or exploitation be at the hand of a caregiver or other person in a position of trust.[55]

At the federal level, the terms *elder justice*,[56] *exploitation*,[57] *neglect*,[58] and *self-neglect*[59] are all defined in the 2006 amendments to the Older Americans Act (Public Law 109-365), but these definitions and others have not been uniformly adopted across federal agencies, states, or state agencies.

In the absence of firm national guidelines, a variety of autonomous agencies and private organizations have defined elder abuse in the context most useful for fulfilling their own specific mandates, roles, and responsibilities. For example, many states' definitions of elder abuse are found in laws authorizing APS agencies to respond to reports of endangered and vulnerable elders, but parameters for what constitutes abuse and the groups eligible to receive services from this program are different in each state.

A uniform definition of elder abuse could be used to address the following questions:

- *Who are the victims of elder abuse?* Although elder abuse is usually characterized as mistreatment of a "vulnerable elder," others might argue that mistreatment of anyone over the age of 65 should counted as a form of elder abuse.

- *Who are the perpetrators of elder abuse?* Most definitions define elder abuse as harm perpetrated by "a person in a position of trust," although clear guidelines for what is meant by "a position of trust" are lacking. In addition, some experts have argued that abusive acts committed by strangers should also be included. Financial exploitation by strangers is a growing form of crime experienced by older adults.[60]

- *What types of actions constitute abuse?* It is fairly clear that a deliberate action taken against a vulnerable elder should be considered abuse, but there is some disagreement as to whether an inaction that harms an elder should also be included. Additionally, some definitions count only intentional acts that result in harm to a person as abuse, while others include unintended harm as well.

Legal Framework for Reporting Elder Abuse

Federal law related to abuse, neglect, and exploitation of older adults is found in Title II, *Elder Abuse Prevention and Services* and Title VII, *Vulnerable Elder Rights Protection,* of the Older Americans Act. Title VII provides funding to support efforts to prevent and address abuse, neglect, and exploitation. Title VII also includes provisions for states' long-term care ombudsman programs and state legal assistance development. The 2006 amendments to the Older Americans Act contained additional language that encouraged multi-disciplinary and collaborative programs for elder abuse in the community.[61]

In addition, the Federal Government, through CMS, is charged with ensuring that nursing homes and other health care facilities meet standards of care. As stated in federal regulations, residents have the right to be free from verbal, sexual, physical, and mental abuse, corporal punishment, involuntary seclusion, mistreatment, neglect, and misappropriation of their personal property.[62] CMS contracts with agencies in every state to enforce minimum standards of quality in facilities that participate in the Medicare and Medicaid programs. These state agencies perform ongoing site inspections and respond to complaints. Any violations or deficiencies noted by the state surveyors are reported to a national database maintained by CMS.

State laws addressing elder abuse designate various agencies to receive and investigate reports of elder abuse, neglect, and exploitation. The types of agencies most frequently designated to receive reports are state or local APS human service agencies and law enforcement agencies.[63]

Laws requiring the reporting of suspected elder abuse exist in all states but differ significantly. Mandatory reporting laws require certain people to report known and suspected incidents of abuse, neglect, and exploitation to the proper authorities, usually APS. The list of who is mandated to report by law varies greatly from state to state, and can range from every citizen to a small number of professional groups, such as physicians and social workers. Under voluntary reporting laws, no one is absolutely required to report, but any person may report incidents of elder abuse to officials. As of 2006, 45 states and the District of Columbia had mandatory reporting laws of some kind. Five states (Colorado, New Jersey, New York, North Dakota, and South Dakota) had voluntary reporting laws.[64] All states' reporting laws provide immunity from civil liability for those who report in good faith, and most also offer protection from criminal liability.[65]

Abuse, neglect, or exploitation that takes place in a home or community setting may be reported by the abused elder, a family member, friend or neighbor, physician, postal worker, or any number of concerned persons. The initial report is likely to be handled directly by APS via a telephone hotline. In other cases, reports of elder abuse will first go to the local police department. In many states, law enforcement is mandated to report cases of suspected of elder abuse that they receive to APS. Experts have indicated that these required reports are not always made, but that police officers are

likely to involve the APS system if they fear the elder is in imminent danger and are reasonably confident that APS will be able to provide sufficient services to protect the victim.[66]

Elder abuse that takes place in a nursing home setting may also be reported by the abused elder, a family member, friend or neighbor, facility employee, or other party. That report is likely to be handled first by the facility's own staff, especially if the allegation involves abuse at the hand of another resident or a facility employee. The facility is required by federal regulations to report the allegation immediately to the state survey agency. In other cases, especially where a resident might benefit from an outside advocate, a concerned person might report suspected abuse or neglect to the state long-term care ombudsman, who is tasked with ameliorating the complaint. If a case is considered to involve a crime, local law enforcement might also receive a report, directly or as a referral from another agency. Complaints and reports of incidents of abuse may also reach a state's MFCU.

The setting in which the elder resides, the type of alleged abuse, the relationship between the victim and the perpetrator, public awareness, and many other factors all contribute to the likelihood that a report of elder abuse will reach any of the entities mentioned above.

EXAMPLES FROM OTHER FIELDS

While elder abuse is different from child abuse and intimate partner violence (IPV), there are many common issues around vulnerability, stigma, violence, and exploitation. Historically, child abuse and IPV issues have received more attention, research, and funding than elder abuse, which is much less developed. A 1998 review of interventions in child abuse, elder abuse, and domestic violence identified 144 controlled evaluations, yet only two addressed the topic of elder abuse.[67] In 2007, the Federal Government spent approximately $153 million on programs addressing elder abuse,[68] compared to $6.7 billion on child abuse and $520 million for the Violence Against Women Act (VAWA).

The government has also made substantial investments in data collection systems for the field of child abuse, creating data systems that are used to track trends in abuse on a regular basis, and can be used to examine risk factors for abuse and track the impact of policies and interventions on abuse rates. Two additional national data reporting systems are that are of interest for their data gathering and quality control procedures are described below.

Child Abuse

The current Child Abuse Prevention and Treatment Act (CAPTA), as amended by the *Keeping Children and Families Safe Act of 2003*, defines child abuse and neglect as, at a minimum, "any recent act or failure to act on the part of a parent or caretaker which results in death, serious physical or emotional harm, sexual abuse or exploitation, or an act or failure to act that presents an imminent risk of serious harm."[69] Within the broad minimum standards set by federal law, each state provides its own definitions of child abuse and neglect.[70] Most states recognize four major types of child maltreatment: neglect, physical abuse, sexual abuse, and emotional maltreatment. Some states define other categories of abuse or neglect, such as medical neglect or truancy. Efforts to standardize state statutory definitions of child abuse have been limited.[71] In the field, "structured decision-making" models have been developed to help caseworkers assess the risk of abuse, but definitions of abuse, standards for substantiation, and interventions differ from state to state.

National Child Abuse and Neglect Data System (NCANDS)

Despite differences in definitions across states, data from state Child Protective Services (CPS) agencies are the primary source of statistics on child abuse and neglect. These data have been compiled into a national database for nearly 20 years. The 1988 CAPTA (42 U.S.C.A. §5106g) directed HHS to establish a national data collection and analysis program that would make available state child abuse and neglect reporting information.[72] HHS, through the National Center on Child Abuse and Neglect, responded by developing the NCANDS as a voluntary and collaborative effort

with the states to collect and analyze annual child abuse and neglect data from state CPS agencies. NCANDS data were first reported in 1990. The Children's Bureau, within HHS, manages the collection and analysis of the data.[73]

CPS are also funded primarily by the states, which influenced the decision to make reporting into NCANDS voluntary.[74] Experts remarked that voluntary reporting requirements have been a beneficial aspect of the program because it allowed a federal-state partnership to be cultivated through ongoing discussions with states.[75]

States have participated in the development of NCANDS through two forums.

1. A **State Advisory Group**, comprised of individual states' CPS program administrators and information systems managers, helped to identify initial data elements and definitions to include in the national database.[76] The state representatives subsequently assisted in pilot testing and implementing NCANDS. Experts remarked that holding the early design meetings with the states and using a consensus-building approach to developing the system worked well.[77] The State Advisory Group continues to suggest strategies for improving the quality of data submitted by the states and reviews proposed modifications to NCANDS.[78] The Children's Bureau convenes the State Advisory Group annually; it currently consists of representatives from 18 states.

2. A **national technical assistance meeting** for all states is convened annually. The technical assistance meeting provides an opportunity for states to receive guidance for their annual data submissions, and discuss data utilization and training needs.

The Children's Bureau funds travel for state CPS administrators to attend both types of meetings, and also provides technical assistance to states through the National Resource Center for Child Welfare Data and Technology (NRC-CWDT) (http://www.nrccwdt.org).

NCANDS was developed incrementally, and has grown and evolved considerably over time based on the available data and the needs of the field.[79] When the system was first developed, 11 states participated.[80] As the data began to be used for more high profile reports, other states began to recognize the utility of the NCANDS data, as well as the pressure to participate from reporters and elected officials who wanted to see how their state compared. Now, all states report at least some data and the majority report most data elements.[81] In 2006, 51 states (including the District of Columbia and Puerto Rico) reported case-level data, and one state provided aggregate data.[82] Clearance from the U.S. Office of Management and Budget is required to make changes to the elements or methods of reporting data to NCANDS, but this has not been a barrier to changes.[83] The Children's Bureau requests input from state CPS offices every three years, and states vote on proposed changes.

One important change that has taken place since NCANDS was first developed is that the system has evolved from collecting aggregate to case-level data. In the early years, states were not able to provide case-level data, but were able to report aggregated data as the first stage of contributing to the national database. In 1993, a few states began to voluntarily submit case-level data. For a number of years, states provided both datasets, but beginning in the year 2000, the case-level dataset became the primary source of data for the annual report. The aggregated data file is phasing out as more states are able to provide case-level data.

Currently, NCANDS collects case-level data on all children who received an investigation or assessment by a CPS agency.[84] These quantitative data include demographics and important indicators of child abuse and neglect: information about the characteristics of a referral, the child or children referred, the type or types of maltreatment that are alleged, the findings of the investigations, the risk factors of the child and the caregivers, the services that are provided, and the perpetrators. The case-level data in NCANDS are completely de-identified, so that confidentiality provisions can be met.[85] NCANDS data fields represent only a small subset of all CPS data collected by the states. For example, most states have 20-30 discrete classifications of child maltreatment; NCANDS collapses them into about six categories. States also tend to have more assessment data, such as risk factors, and more information on the household than are reported nationally.

Some variations in the specific data fields collected and reported across states persist, but the overall quality and consistency of the reported data have reportedly improved over time.[86] This is partially a result of the effort of federal staff and the technical assistance resource center that have worked directly with states for long periods of time to improve the integrity of their information.

NCANDS data have many constituent users. Federal agencies are some of the most important users of the information.[87] They include the Administration for Children and Families, CDC, other HHS agencies, the Department of Justice (DoJ), and the Government Accountability Office. Other primary audiences include states, advocates, researchers, providers, and the media.

NCANDS data are disseminated primarily through three regular reports:[88]

1. **Child and Family Services Reviews** report on a system of performance-based measures to monitor state welfare programs, ensuring conformity with state plan requirements in titles IV-B and IV-E of the Social Security Act.[89] The reviews assess states' performance on a number of national indicators, two of which are based on NCANDS data.

2. The annual report *Child Maltreatment* (http://www.acf.hhs.gov/programs/cb/stats_research/index.htm#can). This report summarizes the data in the NCANDS and is sent to state governors' offices and congressional committees, which creates a constituency for the data.[90] States

may be embarrassed if there are blank spaces indicating unreported data from their state, and this is a major incentive for states to report.

3. ***Child Welfare Outcomes*** annual reports to Congress also include data from NCANDS and the Adoption and Foster Care Analysis and Reporting System (AFCARS) (http://www.acf.hhs.gov/programs/cb/pubs/cwo03/index.htm).

In addition, researchers and others may obtain NCANDS data to perform their own analyses from the National Data Archive on Child Abuse and Neglect, maintained by Cornell University, at http://www.ndacan.cornell.edu.[91] Federal agencies may also make a request for data analysis to the Children's Bureau.[92]

There are a few noteworthy limitations of NCANDS data. The data system was designed to support casework and surveillance, not research, so it is not as user friendly as other dataset.[93] While the collected data are fairly comprehensive, information on services received is often missing or in text form rather than categorized. Another gap is that NCANDS lacks information on the severity of abuse or neglect.[94] In addition, states have had to make decisions about how to report abuse investigations versus more general assessments, because the latter are not necessarily indicative of a report of abuse.

Finally, the total operating cost of NCANDS includes the costs of collecting, validating, and analyzing the data and producing profiles and reports.[95] The federal costs for the initial design were approximately $1 million over two years. The cost of the current annual contract to operate NCANDS is $1,385,000.[96] States bear the costs of collecting, formatting, and sending data to the system.

Other Child Welfare Data Collection Systems

Data about children placed for adoption and foster care are reported in AFCARS, which does not include abuse and neglect data, but is another example of a similar data collection effort. In contrast to NCANDS, state participation in AFCARS is mandatory.[97] Unlike CPS, AFCARS is largely funded by the Federal Government. Federal matching funds for foster care were increased to support development of the database. States that receive federal funding for Statewide Automated Child Welfare Information Systems (SACWIS) are required to link AFCARS data with NCANDS.[98] Currently, most states and the District of Columbia are at some stage of SACWIS planning, development, implementation, or operations.[99] Total approved SACWIS developmental project costs currently exceed $2 billion. This amount continually increases, because several states are still planning, developing, or implementing their SACWIS projects.

Another source of child welfare data are the state child abuse registries, which contain information on cases of child abuse that have been substantiated by CPS. A current HHS study is examining possible approaches to developing a national registry, merging state registries. The national registry would include identifying information and be used for investigation and enforcement purposes. In that way, a registry user could

check the national system to obtain information from other states on whether a family or individual had previously been investigated by CPS elsewhere. The study was mandated by the 2006 Adam Walsh Child Protection and Safety Act (Public Law 109-248).[100] An expert commented that confidentiality laws are a significant issue with respect to building a national registry that includes identifying information.[101] Another challenge is that current state child abuse registries vary, reflecting different definitions of abuse and neglect and different standards for substantiation. At this early point in the study it is not clear what relationship, if any, there will be between NCANDS and the national registry.

Studies of the Incidence and Prevalence of Child Abuse

The National Incidence Study of Child Abuse and Neglect (NIS) is a congressionally mandated, periodic research effort to assess the incidence of child abuse and neglect in the United States.[102] The NIS is conducted approximately every ten years. The first NIS (NIS-1) was mandated under Public Law 93-247 of 1974, conducted in 1979 and 1980 and published in 1981.[103] Subsequent studies have assessed not only the current national incidence of child abuse and neglect, but also how the severity, frequency, and character of child maltreatment had changed since earlier NIS studies. Work on the NIS-4 began in 2004 was transmitted to Congress on January 25, 2010.[104] The Office of Planning, Research, and Evaluation, in the Administration for Children and Families within HHS, manages the research.

The NIS provides information about the nature and severity of the maltreatment, the characteristics of the children, perpetrators, and families, and the extent of change in the incidence or distribution of child maltreatment over time.[105] One expert commented that the NIS provides the child abuse field with important insights about the incidence and distribution of child abuse and neglect, and about changes in incidence since previous studies.[106] The NIS includes data on cases investigated by CPS and on children seen by community professionals who were not reported to CPS or were screened out by CPS without investigation. The study is based on a nationally representative sample.

In 2008, CDC released child maltreatment uniform definitions and recommended data elements.[107] The uniform definitions draw upon definitions that are currently in use in the literature, as well as input from a panel of experts on child maltreatment and public health surveillance. An expert explained that CDC-recommended definitions are intended for research and surveillance purposes, not for investigation and enforcement by the states.[108]

Intimate Partner Violence Data

Laws and Definitions of Intimate Partner Violence

The Office on Violence Against Women, within DoJ, defines domestic violence (also called intimate partner violence or IPV) as "a pattern of abusive behavior in any relationship that is used by one partner to gain or maintain power and control over another intimate partner."[109] This includes behaviors that intimidate, manipulate, humiliate, isolate, frighten, terrorize, coerce, threaten, blame, hurt, injure, or wound the victim. Types of IPV include physical, sexual, emotional, economic, or psychological actions or threats of actions.

As with the analogous terms *elder abuse* and *elder mistreatment,* the terms *violence against women*, *domestic violence*, and *intimate partner violence* have been used to describe a wide range of acts. These inconsistencies have led to varied conclusions about the extent of violence against women just as researchers are unsure about the extent of elder abuse. The lack of consistent data on IPV has reportedly impeded efforts to plan effective interventions and to monitor changes over time. All states have enacted legislation that defines domestic or IPV, but statutory definitions vary from state to state.[110] In most states, the definition includes couples who have ever had some kind of romantic relationship, regardless of gender and cohabitation status. However, several states limit the definition to couples who have lived together or who share a child.

CDC published uniform definitions and recommended data elements for IPV surveillance in 1999 and revised them in 2002.[111] Developing CDC uniform definitions and recommended data elements took several years and involved a literature review, collecting written feedback from reviewers, and discussions at several meetings and workshops with state representatives and other experts. The definition and data element recommendations are intended for voluntary use by individuals and organizations interested in gathering data on IPV.[112] As a next step, CDC funded pilot tests of the data elements in three states and encouraged other jurisdictions to conduct limited pilot tests. Once the testing is complete, the data elements and definitions will then be revised to incorporate comments and lessons learned from the pilot.

Administrative Data on Intimate Partner Violence

There is currently no comprehensive source of national data on IPV.[113] Instead, most data on IPV exist primarily in state criminal justice systems. These data are reported to the FBI through the UCR system and the NIBRS, described previously in this report.[114] NIBRS includes offense, victim, offender, property, and arrestee information are provided for each incident, but data on the relationship between victim and offender, however, are sometimes missing.[115]

Because law enforcement data represent only incidents that are known to the police, it is widely believed that many offenses are underrepresented.[116] As with people

who are harmed by elder abuse, victims of domestic violence may not report the abuse for fear of reprisal, embarrassment, or other reasons. Other sources of domestic and sexual violence data include victimization surveys, service providers, victim compensation offices, and health/medical entities. The quantity and quality of the information differs from state to state.

There are several additional gaps and limitations of domestic violence that are similar to weaknesses seen in law enforcement information about cases of elder abuse:[117]

- Because police reports focus on discrete incidents, the data are out of context of the dynamics and history of the relationship. An incident that, in of itself, may appear to be relatively minor may actually be a sign that the victim is in serious danger when viewed in context of the ongoing pattern abuse in the relationship.

- Abusers tend to minimize their abusive actions in self-reports.

- It is sometimes not possible to determine the seriousness of the injury or whether or not the violence was in self-defense.

- When there is no recidivism, it is unclear whether this is a sign of an intervention's success or because the victim opted not to call the authorities after a repeated incident because they were not helpful the first time.

- Physical violence is easier to capture than emotional abuse.

The VAWA called for a study to assess how the states could centralize data collection on sexual and domestic violence offenses and to examine federal data collection on domestic violence-related criminal complaints. In response to the legislation, the National Institute of Justice and the Bureau of Justice Statistics jointly published a report in 1996, titled ***Domestic and Sexual Violence Data Collection***.[118] The study found that the Federal Government and the majority of states were collecting some statistics annually on these crimes.[119] However, states varied widely in how they defined these offenses, determine what is counted, and measure or report incidents. States also varied in the types of victims included in reports. This variability reflected differences in state domestic or family violence laws and reporting systems. The study also identified the need to include data from other parts of the criminal justice system. It emphasized the need for collaborative data collection within law enforcement and with outside sources such as health care providers, employers, and schools, in order to develop a more detailed picture of domestic and sexual violence. Nearly identical challenges have emerged in this research effort with respect to elder abuse data collection.

Studies on the Prevalence and Incidence of Intimate Partner Violence

In the absence of a national database on IPV, several national studies have made estimates of the prevalence of the problem, of which these are a subset:[120]

- CDC's Behavioral Risk Factor Surveillance System, conducted in the United States yearly since 1984, offers a seven-question optional module on IPV.

- In 1996, the National Institute of Justice and CDC jointly sponsored the National Violence Against Women Survey.[121]

- The NCVS, the primary source of information on criminal victimization in the United States, includes data on victimization rates for various types of crimes for the population as a whole and for various segments, including women and older persons.

Similar to attempted analyses of elder abuse data, researchers seeking information on domestic violence have had to rely on multiple data systems (e.g., police and hospital records), which were designed for purposes other than monitoring the scope of abuse. Data collection is complicated by the fact that multiple records may reflect repeated incidents involving the same victim.

Other National Databases on Violence

National Violent Death Reporting System

In 1999, the Harvard Injury Control Research Center launched the National Violent Injury Statistics System (NVISS) with funding from six private foundations to pilot a model injury reporting system and to advocate for its implementation at the national level by the Federal Government. While the project initially focused on firearm injuries, in its second year it expanded to incorporate all homicides and suicides. Based on that work, in 2003 the CDC later launched the National Violent Death Reporting System (NVDRS) with the participation of seven states.[122] An additional six states joined in 2004 (Colorado, Georgia, North Carolina, Oklahoma, Rhode Island, Wisconsin) and four in 2005 (California, Kentucky, New Mexico, Utah) for a total of 17 participating states to date.[123]

The NVDRS aims to provide communities with facts to inform a clearer understanding of violent deaths so they can be prevented. NVDRS informs decision-makers and program planners about the magnitude, trends, and characteristics of violent deaths so appropriate prevention efforts can be put into place; and state-based prevention programs and strategies can be evaluated.[124]

The system consolidates data from many sources since individual systems do not always provide all of the information needed to accurately assess the factors associated

with a violent death. For example, death certificates provide data on the victim but do not provide information on the perpetrator; this information is more commonly found in police reports. Together, these sources and others offer a more comprehensive picture of the circumstances surrounding a violent death.[125] An entry into the NVDRS system consists of information documented by coroners and medical examiners, vital records registries, law enforcement, and crime laboratories which is gathered at the local level, linked in a standardized database, stripped of individual identifiers, and forwarded to the national database.

The NVDRS uses specific quality control measures that may inform potential future data collection of elder abuse information from disparate sources.

- **Data are entered into source-specific computerized data entry screens.** For example, police report data are entered into police report screens and death certificate data into death certificate screens. In addition to allowing independent entry for each source, this approach permits later review of what each source contributed and identification of missing sources.

- **Automatic electronic importation of specific data sources** is possible. This requires no manual entry of information, minimizing the additional opportunity for human error.[126]

- **Hierarchical rules for each variable are assigned to minimize inconsistency across sources.** For each variable in the analysis set of the NVDRS, a primacy rule is established on the basis of a hierarchy of assumed reliability of all the possible sources for a given variable. For example, the primacy rule for sex is expressed as death certificate then medical examiner record then police report.[127]

- **Coding training is held annually for all participating states**.

Fatality Analysis Reporting System (FARS): Motor Vehicle Deaths

A final national database that links multiple sources of information across states is the Fatality Analysis Reporting System (FARS) which monitors motor vehicle deaths in the United States and is operated by the National Highway and Traffic Safety Administration (NHTSA). This system was established in 1975 to provide an overall measure of highway safety and offer an objective basis on which to evaluate the effectiveness of motor vehicle safety standards and highway safety programs.[128]

NHTSA has a cooperative agreement with an agency in each state government to provide information on fatal crashes that occur in the state. FARS analysts are state employees who extract the information and put it in a standardized format. Data are collected, coded, and submitted into a computer data system at the state before being transmitted to the national database. Each FARS analyst attends a formal training program, and also receives on-the-job training.[129]

Each case has more than 100 coded data elements that characterize the crash, the vehicles, and the people involved.   Documents consulted for entry into FARS include: Police Accident Reports, state vehicle registration files, state driver licensing files, state highway department data, vital statistics, death certificates, coroner/medical examiner records, and emergency medical service reports. More than 40,000 deaths from motor vehicle incidents are reported each year.[130] Quarterly files are produced for analytical purposes to study trends and evaluate the effectiveness of highway safety programs.

CONSIDERATIONS AND RECOMMENDATIONS

Purpose of National Data Collection Effort

The design of the data collection effort needs to be lead by the goals and purposes of such an effort. For example, the goal may be to track trends in elder abuse. Alternatively, the focus may be how and what data elements to collect it order to help research, policymakers, and practitioners prevent and reduce the risk for and consequences of elder abuse. Measuring the impact of the interventions through administrative data may be another goal for these data. The considerations and recommendations below will each need to be adjusted to meet these goals, so it is important to set these goals before taking additional steps.

Technical Considerations

There are a number of technical considerations for establishing any national elder abuse data collection effort. These include creating a uniform national or benchmark definition, whether reporting should be mandatory or voluntary, what data elements and populations to include, how to ensure confidentiality, and data systems issues. Some considerations for each of these issues are outlined below.

National Benchmark Definition

Studies and expert committees dating back more than 15 years have recommended a uniform definition of elder abuse to enable more consistent data collection.[131] A consensus or benchmark definition of elder abuse could serve the following purposes:

- Provide a "gold standard" for use in research and practice.

- Contribute to a more comprehensive and consistent framework for understanding and responding to elder abuse.

- Improve quality and comparability of elder abuse data in academic research and social services.

- Enhance systems' ability to track trends in elder abuse over time.

- Demonstrate a need for more social services resources for victims of elder abuse.

However, it has been consistently challenging to establish a definition that is broad enough to incorporate the variation of forms of elder abuse, and yet narrow enough to be meaningful. Some experts have argued that a "one-size-fits-all" approach to defining elder abuse is impractical, if not impossible. Different levels and concepts must be used depending on the context and goal of the definition. For example, elder abuse could be loosely and broadly defined for purposes of prevention and intervention from a public health perspective. At the opposite end of the spectrum, criminal statutes would need to set forth a much more specific description of the characteristics of an elder abuse victim, alleged perpetrator, and nature of the crime itself in order to lead to successful, consistent, and just prosecution of abusers.

Whether a federal definition is created in the short or long-term, most informants consulted for this research agreed that such a definition is absolutely necessary for a national data collection effort to coalesce in this field, although a national definition is not used for child abuse. Experts also stressed the importance of operationalizing all of the individual terms within the larger definition of elder abuse so that interpretations of what is meant by the terms "vulnerable" or "position of trust" are as consistent as possible.[132]

Mandatory or Voluntary Reporting

Within the other data collection systems discussed previously in this report (e.g., NCANDS, NVDRS), state participation is mandatory only when federal funds are received for the program or the development of the data system. For example, long-term care ombudsman programs are supported, in part, by federal funding from the Older Americans Act, so reporting to the NORS is mandatory. In contrast, state-funded programs are generally a part of voluntary national data systems. CPS programs are primarily state-funded; therefore states voluntarily submit data to NCANDS. However, federal funding has been made available for SACWIS, and states that receive this funding are required to submit data to NCANDS. These patterns suggest that a national database of APS data would likely be developed as voluntary with stakeholder input since APS programs are not federally-funded, but like SACWIS, could also include incentives that assist states in developing statewide information systems with the condition that states accepting the incentive would link to a national APS reporting system. While it is inherently more difficult to ensure cooperation with a voluntary effort, experts in child abuse data noted that the voluntary and collaborative approach to designing and implementing a national database of CPS data has been effective.[133]

Data Elements

A significant level of effort will be required to **develop the correct data elements** for the national database and to communicate the qualities of those data elements properly to state and local programs. In reference to child abuse, the Children's Bureau convened an advisory group of state CPS representatives and other stakeholders to help shape the data elements and definitions to be included in NCANDS and experts

have reported that this process worked very well. Stakeholders consulted for this research similarly suggested convening an advisory group of state APS representatives and other stakeholders to determine what definitions and data elements to initially include in a national database. A state's participation in a voluntary national data collection effort may be more likely if the data requested are already being collected by the state.[134] Thus, the design of any elder abuse data system should consider what data elements are already commonly collected by states and in what form.

The number of data fields should be kept to a minimum. The following data elements may be particularly useful to collect:

1. Victim Characteristics (e.g., age, gender, race).

2. Type of Incident (Physical Abuse, Neglect, Financial Exploitation, etc.).

3. Reporter of Incident.

4. Perpetrator Characteristics (e.g., age, gender, race).

5. Relationship of Perpetrator to Victim (e.g., guardian, spouse, adult child).

6. Setting (e.g., community, facility) and Living Arrangement.

7. Cognitive Status/Capacity of the Victim.

8. General Health of the Victim.

9. Whether the Abuse was Substantiated, Indicated, or Inconclusive.

10. APS System Response/Disposition.

Some of these data elements and the number of states (including the District of Columbia and the United States territories) that were able to report them are shown in *Table 2*.

It is equally important to clearly **define all of the individual terms** so that interpretations of what is meant by the terms "vulnerable" or "position of trust" are as consistent as possible when the national data collection effort is implemented in the field.[135]

TABLE 2: APS Data Elements, by Number of States Reporting	
Data Element	**States Reporting**
Information on reports where the victim was at least 60 years old separated from reports involving younger adults	32
Information on reports where the victim was at least 60 years old separated from reports involving younger adults	32
Investigation information for adults aged 60+	29
Substantiations by age group	24
Self-neglect reports by age group	21
Self-neglect substantiations by age group	20
Sources of reports on elder abuse	11
Information related to specific categories of abuse reports and substantiations for adults age 60+	19
Sex of victims	15
Age of victims	20
Race of victims	13
Information on whether abuse occurred in domestic or long-term care settings	13
Sex of perpetrators	11
Age of perpetrators	7
Relationship of victims to alleged perpetrators	11
Reasons why cases of elder abuse are closed	8
Outcomes of APS involvement, in terms of whether client risks were reduced, stayed the same, or increased for substantiated cases	4 states and the territory of Guam

Populations Included

Another technical consideration is **what service population to include** in the database. In contrast to CPS, in which the service population is clearly defined as children under the age of 18, APS service populations vary across states. Most states offer APS services to younger, vulnerable adults in addition to elders. An estimated one-third of APS clients are younger adults with a disability.[136] Experts commented that there may be resistance to providing funding for elder abuse data collection from the APS system that would partition resources for serving elders from the rest of the service population.[137] An alternative to this arrangement would be to include information about the abuse and exploitation of younger adults with disabilities in the national data collection effort and any associated funding.

Use of Aggregated or Case-Level Data

Another decision will be whether the database will contain **aggregated or case-level data**. Duplication of records is an issue for any database comprised of multiple sources. A single incident sometimes exists in the files of multiple entities under slightly different guises, or an individual may experience multiple incidents of abuse or neglect. Linking data at the individual level would allow for calculating unduplicated numbers of incidents and individuals involved. This methodology could also greatly enhance the field's understanding about the risk factors for abuse and patterns of abuse. In the field

of child abuse, NCANDS began with a small number of states reported aggregated data, because these data were more readily available. As data collection evolved, states gradually began to report case-level data, which provides richer information. Today, nearly all states report case-level data.

Ensuring Confidentiality

An additional consideration for any national data collection effort is **the need to ensure confidentiality** and comply with applicable confidentiality laws when working with case-level data. Many entities are prohibited from sharing information about cases with others unless they have the specific consent of the affected older adult or his or her guardian. Experts agreed that rigorous procedures to ensure confidentiality would need to be included. Techniques to protect privacy include restricting access to the database, creating numeric identifiers, and encrypting names.[138]

The level of personally identifiable information included in a national database will be governed by the ultimate purpose that the database is expected to serve. In general, databases designed for policy and planning purposes do not require identifying information. For example, the case-level data in NCANDS are completely de-identified, so that confidentiality provisions can be met.[139] Data in NVDRS are also stripped of individual identifiers. In contrast, HHS is currently exploring the possibility of developing a national child abuse registry that would contain individual identifying information.

Data Systems and Coding

Methods for entering and coding the data will also need to be developed. The NVDRS suggests quality control measures for combining data from multiple sources. For example, data may be entered into source-specific data entry screens, data can be automatically imported, and hierarchical rules are assigned to each variable to minimize inconsistency across sources. Similarly, the FARS incorporates a series of checks to ensure data consistency, timeliness, completeness, and accuracy.

Data Ownership is another consideration: **which entity or entities will "own" the data** that are to be collected and who will have authority to access the data. This is especially relevant in situations in which data management in states or programs might be contracted out to private vendors. For example, the Children's Bureau contracts with William R. McDonald and Associates to maintain and analyze NCANDS data and with Cornell University to operate the National Data Archive on Child Abuse and Neglect, which makes NCANDS data available to researchers to conduct their own analyses.

Given the inconsistencies in current data systems and the additional burden of reporting to the national level, ensuring consistency and completeness is another concern. States may be limited initially in the amount and quality of data they are able to report. After the national database is established, efforts should be made to continue to

work collaboratively with states and other stakeholders to continually improve the consistency and completeness of the reported data. This was the approach used in developing NCANDS, which initially contained aggregated data from 11 states and eventually grew to collect case-level data from 51 states and territories. Experts noted that state APS agencies have perpetually constrained operating budgets and suggested that financial incentives to enable states to enhance their data collection practices would be advisable.

Cost and Funding Considerations

An important consideration for determining feasibility of and potential approaches for implementing a national elder abuse data collection effort is potential costs.

A national data collection effort is a highly complex undertaking that will not occur without the investment of human and financial resources. Political will and the ability to address these costs can ultimately make or break the feasibility of any proposed data collection strategy. A national elder abuse data collection effort would likely require some level of federal funding but the amount will greatly depend on the extent to which states and localities can leverage other older adult systems change efforts and continue to invest in Information Technology and/or Management Information Systems improvements.

Cost Components

Based on the cost components of related national data collection efforts, a national elder abuse data collection effort would likely involve the following:

1. **Federal infrastructure**: A comprehensive national database would likely require a specific federal entity to manage and oversee the data collection effort. Such an entity would provide structure to the project, allocate funding, and work to leverage resources and leadership in support of the endeavor. The organization responsible for oversight of elder abuse data collection would also play the important role of distributing any findings from the national data collection effort to other federal agencies and the public.

2. **Development and pilot testing**: Development of the new system will entail costs to hold meetings to work with states and other stakeholders to identify initial data elements and develop data collection methods and the database design. The initial cost to design NCANDS was approximately $1 million over two years.

3. **Collecting, validating, and analyzing the data nationwide and producing profiles and reports**: The cost of the contract to operate NCANDS is $1,385,000 for the current year. As of September 2003, Congress has appropriated $3 million to CDC for the NVDRS, and CDC has augmented that

with internal monies to fund 13 states to implement the system; additional states will be added to the system as funds become available.[140]

4. **Federal-state collaboration for ongoing improvements and modifications**: The database will evolve over time as states' data systems improve and as stakeholders' data needs change. In the child abuse field, the Children's Bureau convenes a State Advisory Group annually to develop strategies for improving the quality of the data and review proposed modifications to NCANDS.

5. **Technical assistance and staff training**: The consistency and quality of data are both affected by the extent to which professionals are trained on how to identify and code abuse, and how to refer cases to other agencies if necessary. Legal definitions are often unclear and may be subject to inconsistent interpretations by caseworkers in the field. Additional training of staff will be necessary to ensure that workers understand modified operational definitions and are coding appropriately. For example, the Children's Bureau funds states to attend an annual technical assistance meeting on NCANDS and also provides technical assistance to states through the NRC-CWDT. For NVDRS, ongoing coding support is provided through an email help desk, monthly conference calls with all states, and regular conference calls with individual states. A coding manual is also provided.

6. **Federal funding for service improvements**: In our review of the literature and discussions with experts, it was generally agreed that efforts to address elder abuse are under-funded in general. Federal dollars fund services and shelters for victims of child abuse and domestic violence at the state and local level, but no comparable, dedicated, federal funding stream for elder abuse services exists, though elders do have access to services such as batter women's shelters. APS is not a federal program. The Older Americans Act provides funding for elder abuse awareness, prevention, identification, response, and coordination activities. States have discretion on how to use those funds, including for supporting APS programs, emergency beds, or elder shelters. However, there is great variability in elder abuse programming across the states, and few states use their OAA funds for those purposes. Experts reported that it is especially difficult to house male victims of elder abuse because many shelters refuse to serve them.[141]   Experts in Wisconsin's Department of Health and Family Services reported that abuse is more likely to be consistently reported when funding is available to provide services to victims.[142]

7. Federal funding for services might also be used as an **incentive for states** to provide certain data elements. For example, in national child abuse data collection, federal financial incentives have affected the data elements collected and reported by states. In 1996, the CAPTA was amended to require all states that receive funds from the Basic State Grant program to provide specific data, to the extent practicable, about children who had been maltreated. These required

data elements were incorporated into the NCANDS, the national dataset of information from state CPS agencies.

8. **Hiring new staff to consolidate data**: The NVDRS and FARS databases have employees fully dedicated to collecting and reviewing individual sources of reported data and consolidating them into unduplicated entries for input into the national databases.

9. **Funding to support APS data collaboration with other entities**: Our findings suggest that states would likely need incentives to integrate any national database of APS data with other sources of data on elder abuse, similar to the arrangement with SACWIS for child abuse data. Total approved SACWIS developmental project costs currently exceed $2 billion. This amount continually increases, because several states are still planning, developing, or implementing their SACWIS projects.

Recommendations

Based on these considerations, we next examine the feasibility of several options to address the current lack of national data on elder abuse, organized by a continuum of increasing complexity. Three primary approaches to national administrative data collection emerged:

1. Strengthen existing data collection systems but do not move forward with combining the data at the national level.

2. Create a national database of administrative data on elder abuse, drawing from data sources on an incremental basis.

3. Create a national database of administrative data on elder abuse, drawing from many data sources from the outset.

Again, the goals and purpose of this data collection effort should lead the decision on the most appropriate approach. The third option -- to build an all-inclusive national database that draws from multiple sources via uniform reporting forms -- was the approach proposed in the Elder Justice Act introduced in the 109th Congress, but has been dropped in subsequent versions of the bill.[143] The experts consulted for this research unanimously agreed that such an ambitious undertaking, while a worthy long-term goal, might be difficult at this time due to the limitations, gaps, and inconsistencies in existing data collection systems.[144] Federal partners added that this approach would be very costly, potentially over-burden many Federal and state staff, and still not provide good data due to poor quality of current data collection systems.[145]

Rather, Congress might consider a multi-step approach to developing a national database of administrative data on elder abuse. Initially, the effort could focus on

developing a national database of states' APS data. While there are several important limitations of using and aggregating APS data as outlined earlier in this report, APS data are the most directly relevant to this topic as well as the most readily accessible. Subsequent efforts would contribute to the longer-term goal of creating a comprehensive and cross-disciplinary database of elder abuse data.

Step 1: Address systemic weaknesses in existing elder abuse data collection systems. There are a number of limitations in current data systems that would need to be addressed before the disparate systems potentially involved in national data collection would be able to contribute meaningfully consistent information. There are a number of pertinent examples of innovative state efforts that improve elder abuse data collection systems, such as web-based systems and cross-disciplinary teams, which can be found in Georgia, Wisconsin, Texas, and Minnesota, among others, which could be applied elsewhere.

Step 2: Compile a national database of state APS data. States' APS agencies are primarily responsible for responding to reported cases of elder abuse that occur outside of long-term care facilities. Therefore, APS data are the primary source of information on elder abuse that occurs in domestic settings. A national APS database could be developed that is similar to the NCANDS database for CPS. Building a data system capable of reconciling states' vastly different APS systems will be a complex challenge, but collecting this information annually and compiling it nationally would likely be a relatively lower cost, more feasible, and more useful option than combining data from different types of sources nationally from the outset.

Any national data collection effort, even one that begins solely in the APS system, should first be piloted in a number of states before being implemented full-scale. If the experiences of the early participants provide evidence of success, the pilot could serve as a basis for other states to begin participating in national data collection, incorporating comments and lessons learned from the pilot. States may be limited initially in the amount and quality of data they are able to report, but their reporting ability would be expected to improve over time, given the experience of the NCANDS development in the child abuse arena.

Step 3: Plan to build a comprehensive cross-disciplinary national database of administrative data on elder abuse by combining sources incrementally. Any initial database planning efforts should continue to explore and preserve the potential for combining or linking data from multiple systems, even if the first phase involves much more limited data collection from a single system, namely APS. The results of National Institute on Aging-funded research underway in the state of Rhode Island that is seeking to link multiple elder abuse administrative data sources will be particularly informative to discussions of the overall feasibility, advantages, and disadvantages of linking many sources of elder abuse data on a national scale.[146] Potential data sources beyond APS would include law enforcement, nursing facility survey agencies, MFCUs, long-term

care ombudsman programs, courts' guardianship records, SSA's representative payee data, and medical records. Other sources of information not listed here may also be available.

CONCLUSION

HHS was charged with examining the technical considerations for implementing a uniform national data collection effort on elder abuse. This report provides context and background of the national elder abuse data collection effort. There currently are a number of different programs and systems that collect data on cases of elder abuse at federal, state, and local levels. The nature, scope, details, and level of information collected on cases of elder abuse differs greatly across systems and is driven in large measure, by the mission of the system collecting the data. This is further complicated by the variation in definitions and laws between states and local jurisdictions.

Even with similar challenges, data collection efforts in other fields have successfully be implemented nationally. In particular, lessons may be learned from the experience in the development of the NCANDS, which collects data from state CPS agencies despite varying definitions, and was developed incrementally with significant input from state CPS agencies. Many of the data collection issues in the field of IPV are the same as the challenges for elder abuse, making it possible to leverage solutions applied in one field to the other.

Despite the many challenges and considerations, an investment in a national data collection effort could build upon the existing systems. The primary recommendations for action steps are first to establish the goals and purposes of a national database of administrative data on elder abuse. Once these have been established, decisions can be made about the best data sources and ways to draw these data. One option may be drawing primarily from APS data, in a few states and incrementally expand the types of measures include and states participating. This process could build upon the lessons learned in the area of child abuse, maximize existing systems and resources, and build stakeholder support for a national data collection effort.

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APPENDIX A. SOURCES OF ADMINISTRATIVE DATA ON ELDER ABUSE, BY ORGANIZING STRUCTURE

Federal Agency	Setting	Organization	Database	Purpose	Basis
Department of Health and Human Services (HHS)	Institutional Setting	Centers for Medicare and Medicaid Services (CMS)	Online Survey, Certification, and Reporting System (OSCAR) Minimum Data Set (MDS) and Quality Indicators	Includes the nursing home characteristics and health deficiencies issued during the three most recent state inspections and recent complaint investigations. MDS contains information on resident health, functioning, mental status, and general well-being. Quality Indicator data come from the MDS.	Results from the standard facility surveys are evaluated to determine whether a nursing facility is providing care according to the requirements, which the Federal Government deems representative of quality care, and whether the care and services provided by the facility meet the assessed needs of each resident.
			Automated Survey Processing Environment (ASPEN) Complaints/ Incidents Tracking System (ACTS) ASPEN Enforcement Module (AEM)	ACTS used by state surveyors to track, process, and report on complaints and incidents. AEM used to track, process, and report on case enforcement information. Both databases are concerning skilled nursing facilities, hospitals, home health agencies, and other CMS-certified health services providers.	
		Office of Inspector General (OIG)	Report on State Medicaid Fraud Control Units (MFCUs)	OIG reports on state MFCUs aggregates of number of cases opened on patient abuse and neglect by Medicaid providers.	The mission of OIG, as mandated by Public Law 95-452 is to protect the integrity of the HHS programs, as well as the health and welfare of beneficiaries served by those programs. This statutory mission is carried out through a nationwide network of audits, investigations, and inspections.

Federal Agency	Setting	Organization	Database	Purpose	Basis
Department of Health and Human Services (HHS)	Institutional Setting	Office of Inspector General (OIG) *continued*	List of Excluded Individuals/ Entities (LEIE)	Bases for exclusion include convictions for program-related fraud and patient abuse and licensing board actions. Entities on the list are prohibited from receiving payment from any federal health care program.	Social Security Act, Sections 1128 and 1156.
		Administration on Aging (AoA) National Long-Term Care Ombudsman Program	National Ombudsman Reporting System (NORS)	Collects complaints reported to state Long-Term Care Ombudsmen, including 119 complaint codes that take place in nursing facility settings, divided into six abuse, neglect and exploitation groups.	Congress established the State Long Term Care Ombudsman Program in the Older Americans Act Amendments of 1978. NORS was implemented by AoA in 1995.
	Community Setting	National Center on Elder Abuse (NCEA)	No database is maintained by NCEA	NCEA has collected and analyzed state adult protective services (APS) data in 2000 and 2004.	Title XX of Social Security Act APS is **not** a federal program.
		Centers for Disease Control and Prevention (CDC)	NHAMCS, NAMCS, NHDS, NNHS, NHHS, NHIS, NVDRS, NEISS-AIP, BRFSS	Multiple surveys of different universes of health statistics, largely relying on International Classification of Diseases (ninth edition) coding, in order to perform ongoing surveillance of health and well-being.	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
		National Institute on Aging (NIA)	No database is maintained by NIA.	NIA conducts finite research efforts related to elder abuse.	As a part of the National Institutes of Health, NIA's mission is to lay the scientific research groundwork for topics related to aging.

Federal Agency	Setting	Organization	Database	Purpose	Basis
Department of Justice (DoJ)	Community Setting	Federal Bureau of Investigation (FBI)	Uniform Crime Reports (UCRs) National Incident-Based Reporting System (NIBRS)	UCR collects information reported by local law enforcement via police reports. Data collection is ongoing by year. NIBRS collects data found in UCRs, plus information on alleged perpetrator(s).	Part of the mission of the FBI is to "protect and defend the United States … and to enforce the criminal laws of the United States."
		Bureau of Justice Statistics (BJS)	National Crime Victimization Survey (NCVS)	Large-scale annual household survey collects information about criminal victimization. Currently contains no questions about elder abuse or neglect.	The BJS mission is to collect, analyze, publish, and disseminate information on crime, criminal offenders, victims of crime, and the operation of justice systems at all levels of government. The BJS was first established in 1979 under the Justice Systems Improvement Act of 1979, Public Law 96-157.
		Individual District or Circuit Courts	Only about a quarter of state administrative offices receive information about guardianship.	Most states require guardians to submit annual reports regarding the well-being of the ward as a basic accountability measure of guardianships.	In cases where an older adult has become incapacitated but not provided a living will, advance health care directive, or appointed someone to assume durable power of attorney, the courts may appoint a guardian on his or her behalf.
Social Security Administration (SSA)		SSA and others for different federal benefits	Representative Payee System (RPS) and others for different federal benefits.	Representative Payees are monitored by the federal agencies that appoint them. The RPS used by SSA has been found to be flawed by the National Research Council.	SSA does not recognize durable powers of attorney for managing federal benefits, so a representative payee is assigned to an incapacitated person to receive their allotments.

APPENDIX B. ADULT PROTECTIVE SERVICES (APS) STANDARD PROCESS FOR CASE INVOLVEMENT[a]

1. Report is Made
    - Someone suspects elder or vulnerable adult abuse, exploitation, or neglect.
    - Person calls an abuse hotline or state or local APS office to report suspicion.
    - If emergency, APS immediately forwards report to police or emergency medical staff.
    - If the report does not meet the APS target population as defined by state law, the caller will be given information and/or referral to an appropriate agency.
    - Report is assigned a priority response time based on the level of victim risk.
    - Report is assigned to APS staff for investigation.

2. Investigation
    - APS staff makes contact with victim within state-regulated timeframe, depending on the reported urgency of the situation.
    - Caseworker assesses current victim risk factors.
    - Caseworker assesses victim's capacity to understand current risk and to give informed consent for further investigation and service provision.

3. Support
    - With the consent of the victim, APS caseworker develops service plan.
    - Services may be provided directly by caseworkers, through arrangements with other community resources, or purchased by APS on a short-term, emergency basis.
    - Victims of abuse, neglect, or exploitation may receive short-term services such as emergency shelter, home repair, meals, transportation, help with financial management, home health services, and medical and mental health services.
    - APS caseworker may continue to monitor service provision to assure that victim risk is reduced or eliminated.

4. If Victim Refuses Service
    - Victims who have the capacity to understand their circumstances have the right to refuse services, regardless of the level of risk.
    - In some states, competent adults have the right to refuse an APS investigation.
    - APS caseworker may refer victim to other resources.
    - Case is closed.

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