

**National Data Collection and Reporting on Elder Abuse:  
Lessons from the National Child Abuse and Neglect Data System**

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The intention of this paper is to summarize some of the key lessons that have been learned from the 20 plus year history of collecting national data on child abuse and neglect and to discuss how some of these lessons might be relevant to collecting national information on elder abuse.<sup>1</sup> This paper is meant to be used as background information for the Elder Justice Coordinating Council (EJCC). It does not presume to be a complete history of child abuse or elder abuse data collection. The objective of this paper is to provide some additional information to the EJCC for its deliberations on future directions.

Throughout this paper, I use the term elder abuse or elder mistreatment to include physical abuse, sexual abuse, psychological abuse, exploitation, neglect, and self neglect. I include as elders persons 60 years and older. I include in this concept all living arrangements of elders and all types of perpetrators, although the range of these attributes will influence national data collection and are discussed briefly in the paper.

I use the term national data collection system to refer to the goal of collecting data from all States and reporting annual on these data. I consider that this activity would be conducted under the auspices of the Federal Government and would be reported as State by State data, not solely aggregated data or national estimates. Such an effort could be supplemented by other activities that would provide additional information to the field.

When reviewing the field of child abuse compared to the field of elder abuse, one finds many similarities between both fields. These similarities include the following.

- The subjects of the data collection are vulnerable citizens who are considered to be of interest based upon their age and events that have occurred or alleged to have occurred.
- Both fields depend upon mandated reporters as well as other reporters for identification of persons at risk of mistreatment.
- In general the field as a whole is interested in both victims and perpetrators. There is also interest in services provided to these vulnerable persons as well as the outcomes of services.

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<sup>1</sup> The views and opinions expressed in this paper are those of the author's and do not represent those of the Children's Bureau or any other agency within HHS or other departments. Readers may wish to consult with others on the points discussed in this paper. Given that the author is not an expert on elder abuse, and that there were severe time constraints to developing this paper, I would appreciate receiving comments on oversights or inaccuracies and would be glad to make any modifications that would be useful.

- The objectives for collecting data are multiple including having an accurate count of victims of mistreatment, understanding the response to these conditions, and designing improved prevention strategies.
- In each State there is a one or more agencies responsible for conducting activities on behalf of these vulnerable persons (child protective services and adult protective services).
- Law enforcement also has a major role in terms of investigation and prosecuting child abuse and elder abuse.
- There is legislative authority for the Department of Health and Human Services (HHS) to collect data on both child abuse and elder abuse. The legislative authority gives HHS the ability to craft a response based on its interpretation of the legislation.
- Difficulties in data collection include issues related to the definitions of mistreatment, the living arrangements of the vulnerable persons, the agencies which respond to reports, and cooperation among agencies that have responsibility at the local and State levels.
- Both the fields of child abuse and elder abuse have undertaken and continue to undertake several different types of research and data collection activities to increase the knowledge pool about the characteristics and consequences of abuse.

Both fields are complex. Both have challenges in addressing the basic questions of the extent to which our citizens are being mistreated, the nature of our response to their needs, and the outcomes that result from interventions. However, the field of child abuse and neglect has a national system for collecting data and the field of elder abuse has periodic studies, but no national system.

This paper will provide information about the background of the national child abuse data collection effort and lessons learned. Some of the lessons are based on intentional decisions and others are based upon more serendipitous decisions. The implications for the field of elder abuse are also discussed. A list of reports consulted while writing this paper is provided at the end of this document.

## **BACKGROUND**

In 1988, amendments to the Child Abuse Prevention and Treatment Act required HHS to establish a national data collection and analysis program, which would make available child abuse and neglect data. Significantly the legislation required the Department to create a system but did not require States to participate. In rapid order a series of short term contracts were released by the National Center on Child Abuse and Neglect within the Administration on Children, Youth and Families (ACYF). These contracts were awarded to start the process of defining what the system could look like and what would be the strategy for developing a system. The proposed system was named the National Child Abuse and Neglect Data System (NCANDS) during these early contracts. After these short term contracts, longer 3-year contracts were competitively bid. Walter R. McDonald & Associates, Inc. has provided technical support to the government on NCANDS since its inception. (ACYF was reorganized in the mid 1990's. The responsibility for NCANDS was given to the Data Team within the Children's Bureau at that time. Currently the responsibility for NCANDS is shared between the Office on Child Abuse and Neglect in the

Children's Bureau and the Office of Data Analysis, Research and Evaluation, both within ACYF.) The current Federal Contract Officer Representatives for NCANDS are Melissa Brodowski and Kurt Heisler.

Initially several key decisions were made by the National Center on Child Abuse and Neglect. These decisions have held the effort in good stead for many years.

- a) A Federal-State partnership would be built and maintained to sustain the effort. To that end, States participated in the design of the system, in the piloting of all parts of the system, and in the design of the initial reports. The Federal Government invested in annual technical assistance meetings and onsite technical assistance to build capacity of States to participate. A State Advisory Group was formed.
- b) Given that participation would be voluntary, the data collection would need to be cleared and approved by the Office of Management and Budget (OMB), but would not require rulemaking or regulation.
- c) Data would be collected annually on a calendar year basis, as that was most familiar with the States. This was later changed to the Federal fiscal year to maximize comparability to other data collection efforts of the Children's Bureau.
- d) Data would be reported by States in a common record format, and States would crosswalk data elements from their own information systems to the common record format. These crosswalks would be reviewed by the technical assistance team to reduce inappropriate cross walks and maximize data comparability, wherever possible. States would be responsible for their own data extracts and submitting the data. Data would be resubmitted if the validation of the data resulted in a recommended corrections to the data file.
- e) Data were collected on all reports for which investigations were completed during the reporting period. Thus both data on reports that resulted in unsubstantiated findings, as well as those that resulted in substantiated findings, were collected. States were given 3 months after the close of the data reporting period to submit their data. These decisions resulted in more complete data on each record.
- f) Data would be validated and approved before compiling the annual report. Over the years the validation routines have become more comprehensive as more has been learned about the procedures and policies of child protective services agencies.
- g) The system was designed as a two-tiered phased-in system. At first States would only be asked to provide aggregated data. Then States that had the capacity to do so were encouraged to provide child-level data. For several years both types of data were collected. By the reporting year of 2000, child-level data had become the dominant method of submitting data and the primary source of reporting and estimating national statistics. By 2012, 51 jurisdictions were providing child-level data.
- h) The child-level data record was designed to establish an entity of report and child (a report-child pair) to enable data to be analyzed by reports made to the agency or by child.

Some further explanation of the last point above may be useful. When NCANDS was first started, many State systems were collecting data on reports, not persons. This is analogous to current reporting by APS

data systems. Even though child identifiers were in their infancy, it was decided that in order to participate in the child-level reporting, States would need to use child identifiers in addition to a report identifier. A report could include more than one child and a child could occur in more than one report. This retained the work-related unit of analysis, namely reports that were investigated, and encouraged the development of the person unit of analysis. It has taken several years for the child identifiers to become consistent and to have a high level of reliability of being unique within a State. This goal has been achieved by almost all States, and continues to be a focus of attention.

Today NCANDS is a large system, receiving data from all 50 States, the District of Columbia and Puerto Rico, with 51 jurisdictions providing child-level data. More than 3.5 million child-level records a year are collected from the States in a common format. While not all States complete all data elements for each record, the record layout includes data on the characteristics and risk factors of the child, the characteristics of perpetrator, the types of maltreatment that were alleged and that were supported, and services provided to the child and the family. Each year, States continue to work on improving the comprehensiveness and accuracy of the data that they submit. Child-level data are maintained in a data warehouse environment allowing for the rapid deployment of many key analyses. Additional analyses are conducted using SQL (Structured Query Language) and IBM SPSS (originally Statistical Package for the Social Sciences). The 2011 annual report will be the 22<sup>nd</sup> annual report issued by HHS. It is scheduled for release in December 2012.

#### **LESSONS FROM THE DESIGN AND IMPLEMENTATION PROCESS**

Several lessons were learned during the design and early implementation stages of NCANDS.

- **Utilize Legislative Authority:** Under the CAPTA amendments of 1998, the authority for pursuing a national data collection system was given to HHS. The legislation was interpreted as giving the department the authority to establish a voluntary data collection system. Subsequent amendments to CAPTA established additional data reporting requirements, to the extent practicable, and several of these were incorporated into NCANDS in subsequent years.

There were two additional pieces of legislation that were highly influential on the evolution of NCANDS. One was legislation that provided enhanced funding for statewide automated child welfare systems (SACWIS) passed in 1993. The second was the requirement under the Promoting Safe and Stable Families Act of 2001 which modified the Social Security Act (Section 1123A) to establish Child and Family Services Reviews (CFSR) to monitor State child welfare performance. The development of indicators and standards under the CFSR gave additional impetus to States to increase their capacity to collect and report data to NCANDS, which became one of several key information sources for the CFSR.

- **Start from Existing Strengths but Strive for Aspirational Goals:**  
The basic starting points in implementing a national data system are to determine which agency or agencies has the most relevant and accessible information in an automated format to support an ongoing effort to collect data. In today's environment, automated information systems, as

known as producing administrative databases, are critical for any ongoing national system, which will not be solely occasional.

The original design of NCANDS decided to focus on child protective services agencies, rather than other agencies such as law enforcement, hospitals, schools, day care centers, etc. The reasoning behind this decision was that the Federal Government had an ongoing relationship with State child welfare agencies and that furthermore child welfare agencies are charged through Federal and State legislation to investigate reports alleging child abuse and neglect. Both State-administered and State-supervised county-administered agencies agreed to participate.

Prior to the NCANDS initiative, various non-profit groups had had their own programs to develop national data, but these, whether supported by the Federal Government or not, were short term and eventually unsustainable. Indeed part of the emphasis behind the development of NCANDS was some lack of satisfaction with the previous efforts conducted by advocacy groups.

Working with State child welfare agencies as partners has had the result that some types of maltreatment are under reported. In many States institutional abuse is handled by other agencies. In the most recent report, 16 States did not report on abuse by facility and group home staff to NCANDS. Furthermore NCANDS only includes those cases that have been reported to child welfare, and thus the data do not contain information not known to the child welfare agency. NCANDS does however make special efforts to collect some data that are not maintained by the child welfare agency. These notable exceptions include information on child fatalities, information on funding streams, and a few other topics.

In addition, although very few States could report on services, and many still have problems, the NCANDS record contains aspirational data elements related to risk factors and services.

- **Build Peer Leadership among the Reporting Entities:** The Federal Government has provided technical assistance to the States each year in order to encourage and improve participation in NCANDS. However, the initiative has also depended upon peer leadership among the States themselves. From the very beginning, the States were active in the design of the system. There continues to be a State Advisory Group, which essentially is a forum for discussing complex issues in depth before presenting the issues to the wider group for discussion and making suggestions to the Federal Government. Each cycle of OMB approval involves intensive discussion with the States about their capacity to report on new data elements.
- **Involve Information Technologists as well as Policy and Practice Experts:** From the beginning NCANDS largely depended upon automated information systems. At the original design sessions, data processing department staffs were active participants in the design of the common record layout. This resulted in the core design concept of NCANDS, which is a record

for each child in each report. Twenty years ago, many systems were primarily report-oriented rather than child-oriented. Therefore a record layout which included both reports and children associated with a report, allowed more States to participate, while still focusing attention on then need to develop and retain unique child identifiers.

The IT specialists were useful because they knew the details of their systems' capacities and could accurately discuss what was possible and what was not. The importance of recognizing the need to strengthen the infrastructure of data collection at the State and local levels was also emphasized when Federal enhanced funding was provided for the development of SACWIS systems in States.

Even today, nearly half of the State representatives to the national meetings are business analysts, information technologists, and reporting specialists. Many are responsible for State information systems, which encompass far more than child protective services. The remaining attendees are primarily program managers and administrators, as well as quality assurance specialists.

#### **LESSONS ON THE RETURN ON INVESTMENT**

In order to be successful, an investment needs to have returns that are useful to supporters and advocates. Some general lessons have been learned from the NCANDS experience.

- **Recognize and Emphasize the Utility of the Data:** Voluntary participation in large initiatives, such as NCANDS, need to have incentives. One incentive has been that the data are used and reported by the Federal Government. An annual report has been published each year. This report has grown in its sophistication and breadth but certain key components have remained constant. One is that the core tables report data at the State level. National estimates are developed where useful. Data are aggregated across States for very specific multivariable analyses. Second, a large section of the report enables States to describe and comment on the context of their reporting, including policy, practices, definitions, and new initiatives. This is a rich source of information that is helpful in understanding the data. Third, the NCANDS data have been used by the government in major initiatives such as the CFSRs and an annual Report to Congress on Child Welfare Outcomes.

The data are used by several other governmental initiatives, researchers, and the general public. The data are included in several national reports on the status of children. A version of the data set is archived annually at the National Data Archive on Child Abuse and Neglect at Cornell University. This is the public usage version of the data prepared for researchers. In addition, on average more than 600,000 persons a month access NCANDS reports on the Children's Bureau website.

- **Data Improve Due to Reporting:** The NCANDS and other data collection initiatives have shown that data improve as data become more available and accessible for analysis and review. As agencies find that other agencies, researchers, and policymakers are using their data, continuous quality improvement becomes an ongoing feature of service delivery, with regards to data, as well as service delivery.
- **Do Not Put all the Eggs in One Basket:** In addition to NCANDS, the government supports a periodic national incidence study of child abuse and neglect that utilizes sentinels in a sample of counties. In addition, two major research efforts, LONGSCAN and the National Study of Child and Adolescent Wellbeing, have provided rich detailed information on samples of children, most of which have had some contact with child welfare services. Furthermore the Children’s Bureau has incorporated key measures of child maltreatment as reporting elements in several grant programs. The Children’s Bureau has further supported collaborative efforts among courts, service providers, and child welfare agencies in service provision, outcome monitoring, and data reporting.
- **Return on the Investment Quickly:** Most students of successful systems change urge early return on investments. In other words, people need to see the value of the effort, even if it is not yet totally complete. NCANDS started in 1988 with the initial design effort. By 1991, OMB approval had been received on a reporting strategy that had been achieved through consensus building among all key stakeholders, including the reporting agencies and other key players in the field of child abuse. Data collection was launched that same year. By 1992, data were published in an annual report on 1990 data. Thus in a span of less than 5 years, from the start of the initiative, national data were published. This momentum retained the interest and commitment of all participants, and today, annual data are reported within 9 months of collection, responding to the ever increasing demand for current data.

#### **APPLICATION OF LESSONS LEARNED TO ELDER ABUSE**

This section discusses briefly the possible implications of these lessons for the national collection of elder abuse data.

##### **Legislative Authority and Home of the Initiative**

It appears that both the Older Americans Act amendments of 2006 and the Elder Justice Act give HHS authority to collect national data on elder abuse. Furthermore it would appear that the most appropriate home for a national data collection system, if it were based upon Adult Protective Services data, would be the Administration on Aging within the Administration on Community Living. Depending upon the operationalization of the organizational chart of ACL, another branch of ACL might be a logical candidate, such as the Center for Disability and Aging Policy or the Center for Management and Budget. As stipulated in the legislation, cooperation with the Department of Justice would be beneficial.

Whichever unit was selected, it is likely that additional specialists in data collection, reporting and analysis would need to be hired or assigned in order to undertake and maintain such a complex endeavor. Providing technical support, and perhaps financial incentives to reporting agencies, could be important components of a strategy. Input from partner agencies would be critical during the design phase and very useful once the system was implemented. If the national data system were based upon other data, such as law enforcement data, the logical home would be a different agency, such as the DOJ.

### **Type of Vehicle for National Collection**

Recent data collection efforts regarding elder abuse have been conducted under grant funding to the partners of the National Center on Elder Abuse and to independent researchers. The many and varying partners of the National Center on Elder Abuse have played lead roles in many of these efforts. In addition the Bureau of Justice Statistics has currently a project under a voluntary cooperative agreement with the Urban Institute to assess administrative data on elder abuse, mistreatment, and neglect. This study will largely focus on the capacity of APS agencies. The GAO has also surveyed APS agencies as part of their recent report.

When deciding how to move forward in establishing a national data system, different types of funding vehicles, such as grants, contracts, and cooperative agreements, will need to be reviewed to determine the pros and cons for different approaches within AOA or another agency. One thing appears clear. Regardless of the vehicle that is used, the Federal Government would need to undertake to support the program. It is highly unlikely at this time, that a national data collection effort could be sustained without Federal funding.

To the degree possible, a strategic plan should be developed that would allow for minimally two phases of the effort to be achieved. The first phase would include the design and piloting of a system. The second phase would include obtaining OMB approval, initiating the data collection, and issuing the first report. Subsequently, the government could determine if the ongoing maintenance of the system would be conducted under grant, contract, or by the government itself.

### **Primary Source of Data**

Given the many efforts that have already been conducted to collect data from APS agencies, and the currently ongoing effort to assess the capacity of these agencies, it would seem that APS would be a key source of national data and indeed perhaps the obvious starting point. Several reports have already discussed the limitations of such data, and more work would have to be done to establish priorities in collecting data that are the most reliable at the present, with the additional goal of collecting data that have the best chance of becoming available.

Given that there will always be differences in policies, priorities, and definitions among APS agencies, a critical part of the design of the system would be to create definitions for the national system against which the States would crosswalk their own data elements, mapping to the national specifications. This process would require technical assistance and some degree of oversight. Moreover the mapping to

national specifications should be updated periodically by each State as it develops its own capacities. These mapping documents could be made available to those who would be interested in interpreting the data further.

Based on the experience of NCANDS and other national projects, a common record layout is highly recommended. A common record layout would encourage States to take responsibility for their data submissions and the interpretation of their data.

An alternate approach would be to obtain the data in various formats and structures from the 52 States and analyze these different submissions. This approach was used for a period of time prior to the development of NCANDS. The problem with such an approach is that it results in overhead costs needed to keep up to date on all 52 systems. Such an approach also removes the primary responsibility for keeping data submissions up to date from the submitting agency. Moreover agencies may perceive that their participation is minimal and not undertake to improve State and local capacity. As new capacities for such data mining become available, this may be more viable in the future, but such techniques for cross-jurisdictional data are still in their infancy and the costs unknown.

#### **Annual Data Collection from all States**

To date the reports of national estimates of elder abuse have been periodic. Indeed one report made the recommendation that data be collected every 4 years. NCANDS and the other two major data collection efforts of ACYF are annual programs. The advantages of annual data collection efforts include that data are more up to date for use by multiple stakeholders and that capacity building becomes an ongoing priority rather than receiving only periodic attention.

#### **Core Data Elements and Aspirational Goals**

The last APS survey was conducted in FY 2003. A list of suggested key elements that would be part of a national data collection system is provided below for further discussion. These elements all refer to persons aged 60 and older, although a national system might collect data on the larger population coming to the attention of State and local APS agencies.<sup>2</sup> The issues pertaining to collecting data on elders who are abused while in nursing homes, other residential care, hospitals, or prisons, need further discussion. An initial list of data elements includes the following.

- Reports with completed investigations in the reporting year
- Report sources for these reports
- Reports substantiated or founded in the reporting year
- Number of persons associated with the substantiated reports (duplicated count)
- Age distribution of these persons
- Race distribution of these persons
- Sex distribution of these persons

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<sup>2</sup> In discussion with some APS leaders the opinion was expressed that data collection based upon APS systems include all reports and cases, rather than just those of persons who were aged 60 years or older.

- Functional capacity of these persons
- Living arrangement of these persons
- Founded maltreatments of these persons
- Number of these persons who received ongoing services by APS
- Number of persons who needed to be placed under guardianship due to mistreatment
- Number of persons who needed to change their living arrangement due to mistreatment
- Relationship of perpetrator(s) to these persons (duplicated count)
- Number of perpetrators referred to law enforcement (duplicated count)
- Number of uniquely counted persons associated with the substantiated reports
- Number of uniquely counted persons who had received prior services from APS
- Number of uniquely counted perpetrators associated with these persons

A number of the above elements may be aspirational at this point and might need to be included in a person-level data collection system, if such a system were to be implemented. States would also be asked to include their policies and definitions as related to the above data elements. If a person-level system were implemented, it is highly likely that additional data elements would be considered.

#### **Peer Leadership and Partnership Support**

The success of a national system will depend upon the agreement of State agencies to participate and the recognition that certain States would be leaders in the efforts, due to their relatively advanced information systems or experience with collecting comprehensive and reliable data. Without the participation of these States as leaders and partners the effort is likely to be less successful or more slowly successful. The government could also consider if financial support were to be provided to leading States in order to assist other States and/or to those States who have specific plans to improve their participation in a system. Technical assistance in general will also need to be provided.

Partnership support might also be defined as the collaborative support of other governmental agencies in supporting States to develop their data system in conjunction with their improvements to other data systems, such as health and justice systems. As HHS encourages the development of comprehensive cross-sector systems, such enterprise systems might also benefit the national collection of data on elder abuse. Various funding vehicles could be considered and assessed as to their utility in encouraging such collaboration and exchange of data.

#### **Information Technologists**

As a plan is developed to design and implement a system, the role of information technologists in the Federal Government, as well as in the States, will need to be considered. The standards of data exchange established by HHS and other government agencies may apply. Local capacity and resources to participate may be under the control of the state or local data processing units. Thus, the stakeholders in such an effort should include not only policy specialists, programmatic specialists, and advocates, but also information technologists and planners. The State offices of information technology might be a group with which to discuss plans for a national system.

## **Return on Investment**

A clear concept of return on investment will be needed. Not all lessons learned from NCANDS may be appropriate or other returns may be more appropriate. Some to consider are listed below.

- **Emphasize Utility:** A strategic plan could include a discussion of the utility and purpose of the data. It is likely that the various stakeholders would need to be considered so that such an effort could meet as many needs as possible.
- **Improve Data Quality:** The argument might be made that it is through making data more available to a wide audience that the complexities of the data, the environments in which data are collected and reported, and the need for continual attention to improving both the breadth and depth of data becomes a reality and is integrated into ongoing agency performance. This would suggest that the development and implementation of a national strategy is of utmost urgency.
- **Institute Multiple Approaches:** One national data collection program could not collect all useful and necessary data. While investing in a national data system, other means of gathering information on elder abuse could and should be conducted in parallel. Research needs to be supported on the characteristics and risk factors associated with elder abuse; prevention programs need to be developed, evaluated, and replicated; and experiments of integrating existing data sets to gain a cross-agency perspective could also be conducted. The roles of intensive local prevalence studies and a national incidence study could also be considered. These efforts would serve to complement and enhance the understanding of national data, which could not be successful in addressing all topics of interest.
- **Make Quick Returns:** Each type of initiative needs to be able to gain and maintain momentum. Momentum is lost when there is not a clear focus or a clear purpose of an initiative.

## **SUMMARY**

In outlining the steps that would be important in developing a national system, the complete critical path is not yet clear. One of the most important steps will be for AOA to determine how it wishes to utilize its legislative authority. It will also be important to determine how the federal requirements that certain classes of professionals are mandated reporters of elder abuse could support such a system.

While considering future options, additional strategies such as listed below should be considered in terms of their relationship to the analysis of data from a national system.

- a) Continue to fund rigorous studies of prevalence of elder mistreatment conducted through surveys of individual. Establish a plan to repeat a number of these studies, including those funded by the Department of Justice, within another 3-5 years.
- b) Continue to work with the National Center on Aging and its partners to support periodic surveys of the APS workforce and policies of APS agencies.
- c) Consider repeating the national incidence study conducted in 1998.
- d) Develop parallel efforts to collect information from hospitals, nursing homes, other facilities and law enforcement to supplement data collected by APS. Consider adding data elements to other ongoing data collection efforts supported by the Federal Government.
- e) Coordinate grant, cooperative agreements, and contracts within AOA to maximize various initiatives to compile additional statistics on elder abuse. Invest in data integration projects to develop analyses and products based on the multiple sources.
- f) Provide grants to States to develop interagency data sets which they can use to analyze data on elder abuse. Disseminate widely the results from these analyses to encourage other States to also conduct such efforts.

In short, elder abuse is a comprehensive issue that could widely benefit from national statistics on a core set of data from all jurisdictions in the nation on an annual basis. The route to achieve this goal chosen by those responsible for meeting the needs of our vulnerable elders will be shaped by the history, interests, leadership, commitment of many individuals and agencies, and resources of the field. However it is hoped that lessons from other fields, such as child abuse and neglect, may be helpful in making timely progress towards achieving national data on this most important issue.

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