

Report to Congress:
Feasibility of Uniform Data Collection on
“Shaken Baby Syndrome” or Abusive Head Trauma

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ADMINISTRATION FOR
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Table of Contents

Executive Summary	3
I. Introduction	7
II. Background	8
III. Existing Data on Abusive Head Trauma	9
A. Current Research Findings.....	9
B. Approaches to Monitoring Abusive Head Trauma	11
1. Administrative Data Surveillance	11
2. Active Surveillance	15
3. Mixed Approach	17
C. Sources of Data to Monitor Abusive Head Trauma.....	18
1. Hospital-based Data	18
2. Data Sources Beyond the Hospital	20
3. National Hospital-related Databases.....	22
4. Linked Data.....	23
IV. Feasibility of Collecting Uniform, Accurate Data from All States	25
A. Current ACF Data Collection Efforts on Child Maltreatment	25
1. National Child Abuse and Neglect Data System (NCANDS).....	25
2. National Incidence Study (NIS).....	28
B. Findings of a Related Study.....	29
V. Conclusions	30
Appendix: ICD Code Definitions for Fatal and Non-fatal AHT	33
Endnotes	38

Executive Summary

Abusive Head Trauma (AHT) is a leading cause of death from abuse in children under two years of age, with greatest risk to those aged 0 to 4 months. According to the Centers for Disease Control and Prevention (CDC), AHT can result not only in death, but in blindness, intellectual and developmental disability or developmental delays, cerebral palsy, severe motor dysfunction, spasticity, and seizures. It is a public health problem that results in significant mortality or lifelong morbidity to its victims and has a significant economic impact on society.ⁱ

AHT is also widely regarded as preventable. As such, there has been an interest in learning more about this type of maltreatment to inform prevention efforts. The Child Abuse Prevention and Treatment Act (CAPTA) Reauthorization Act of 2010 requires the Department of Health and Human Services (HHS) to conduct a study that: (1) identifies data collected on shaken baby syndrome; and (2) determines the feasibility of collecting uniform, accurate data from all states regarding incidence rates and characteristics of both victims and perpetrators.

This report represents the HHS response to the requirement to conduct a feasibility assessment of the mandated report on shaken baby syndrome, referenced herein primarily as AHT, the more inclusive term recommended by the American Academy of Pediatrics (AAP). The assessment included a literature review on incidence of AHT; identification of related federal activities, including activities authorized under CAPTA; stakeholder discussions; and broad consideration of benefits and costs involved.

Existing Data on Abusive Head Trauma

Determining the prevalence and incidence, including characteristics of both victims and perpetrators of AHT, is a challenging task, and may depend on the parameters used to classify these cases. Data on prevalence and incidence is more readily available than on characteristics of victims and perpetrators, as over the last 12 years, several studies have been completed to help define the incidence of AHT in the United States. These studies yield an incidence rate ranging from 17 to 38 per 100,000. The rate of AHT in the first year of life is significantly higher than the rate in the second and third years of life. It is estimated that in the United States about 30 children younger than one year of age per 100,000 are injured from AHT, resulting in at least 1,200 seriously injured infants and at least 80 deaths each year.^{ii iii} The reported numbers vary based on the surveillance techniques and criteria used to identify these cases.

An April 2012 report of the CDC, *Pediatric Abusive Head Trauma: Recommended Definitions for Public Health Surveillance and Research*, states that “abuse is the third leading cause of all head injuries, after falls and motor vehicle crashes.” According to the CDC report, the “case fatality rate for abusive head trauma has been estimated to exceed 20%, with significant disability for nearly two-thirds of the survivors.”^{iv}

Feasibility of Collecting Uniform, Accurate Data from All States

There are significant challenges to estimating the incidence of AHT, including characteristics of both victims and perpetrators, on a state and national level. Factors contributing to our current inability to accurately identify and count AHT include the application of universally used definitions across various professional fields and the complexity of diagnosing AHT for both living children and for children who have died. Severity of injury is also a factor, with both the most mild and most severe cases of AHT bypassing the medical system. Living victim children will likely come to the attention of the health care system where hospital admission is likely because of the seriousness of the injuries, but reliance on the national hospital-based databases is compromised by several limitations. These limitations include prospective coding errors, and missing data elements—most notably, perpetrator information and certain child victim characteristics. Child abuse data collection through state child welfare department data systems is neither detailed nor consistent enough to estimate AHT rates. Additionally, variations in state coroner and medical examiner systems, including the fact that some lack central policy and programmatic control over which children receive autopsies, also contribute to the challenges.

Efforts are currently underway by some researchers to overcome these limitations by combining the use of administrative data with active follow-up using more limited samples of children who experience AHT. However, the inclusion of the active surveillance component poses its own challenges, such as cost, logistics, and legal and ethical issues.

Existing ACF Data Collection Efforts

The Administration for Children and Families (ACF) currently gathers information on child maltreatment in the United States through the National Child Abuse and Neglect Data System (NCANDS) and the National Incidence Study (NIS).

NCANDS is a data collection system that gathers information annually from all 50 states, the District of Columbia, and Puerto Rico about reports of child abuse and neglect made to state Child Protective Service (CPS) agencies. Participation is voluntary. It is also important to note that NCANDS does not specifically differentiate AHT from other causes of serious physical abuse.

If NCANDS were to address the issue of AHT as a cause of death, it would also need to consider other causes of death, invest in developing a typology, and support enhancing the capacity of states to report all causes of death to NCANDS. Additional study would be needed to assess the feasibility of future enhancements to statewide data collection systems, given the myriad issues involved. CPS agencies might need to work with hospitals and child death review teams to obtain more detailed information. It would be beneficial if a common typology for the classification of causes of death were established prior to data collection. Another possibility would be to cross-walk each agency's classifications to a common typology.

Additionally, it is important to note that an undertaking of this kind would require considerable effort and cost on the part of states. States participate in NCANDS voluntarily and cover the majority of the financial burden associated with the data collection effort. States would need technical assistance and funding to support such initiatives.

The NIS is a congressionally mandated, periodic effort by HHS to estimate the number of abused and neglected children in the United States. The NIS offers an expansive perspective on the scope of the problem of child maltreatment because it includes data on children who were not reported to CPS, and who were screened out by CPS without investigation, in addition to children who were investigated by CPS agencies. These additional children were those recognized as maltreated by community professionals. Thus, NIS estimates include both abused and neglected children who are included in official CPS statistics and those who are not.

In the NIS classifications, abuse includes physical abuse, sexual abuse, and emotional abuse. Neglect includes physical neglect, emotional neglect, and educational neglect. The NIS does not specifically address AHT as a subset of physical abuse. It is important to note that the NIS collects data on maltreatment acts or omissions that are perpetrated by a parent or caregiver. AHT, as defined within this report and elsewhere, is largely a clinical diagnosis consisting of certain clinical medical markers. Because of the methodology employed by the NIS, it is not designed to capture a clinical diagnosis such as AHT, and therefore it would not be feasible to use this study to capture ongoing AHT surveillance. Information about the incidents of physical abuse that include the actions to “shake, throw or purposefully drop,” and the perpetrators and the victims, could be obtained from the NIS, but it would be unknown if the clinical diagnosis of AHT would be applied to each of these incidents. Furthermore, while NIS represents a valuable source of information, costs have limited the NIS to roughly one snapshot per decade. This is likely insufficient for the purposes of determining the incidence rates of AHT and perpetrator and victim

characteristics, much less for determining whether interventions or policy changes may be associated with decreased rates of AHT.

Conclusion

With a fatality rate in excess of 20 percent, and significant disability for nearly two-thirds of the survivors,^v there is no question that AHT is a devastating form of abuse—especially since it is widely regarded as preventable. However, this feasibility assessment has determined that there are very substantial challenges involved in moving to collect uniform, accurate data from the states on the incidence rates of AHT, along with characteristics of perpetrators and victims. It may be possible to overcome some of these challenges, but doing so may involve substantial costs and could be burdensome to state and local systems. In the end, it is unclear whether or by how much AHT identification and prevention would be improved through a national data collection effort. Future feasibility study activities and pilot programs could assess further the implications of such an effort and explore ways of addressing a number of the challenges identified to date.

I. Introduction

Section 104 of the Child Abuse Prevention and Treatment Act (CAPTA) as amended by Pub. L. 111-320, the CAPTA Reauthorization Act of 2010, requires the Department of Health and Human Services (HHS) to “conduct a study that –

- A. identifies data collected on shaken baby syndrome;
- B. determines the feasibility of collecting uniform, accurate data from all States regarding—
 - i. incidence rates of shaken baby syndrome;
 - ii. characteristics of perpetrators of shaken baby syndrome, including age, gender, relation to victim, access to prevention materials and resources, and history of substance abuse, domestic violence, and mental illness; and
 - iii. characteristics of victims of shaken baby syndrome, including gender, date of birth, date of injury, date of death (if applicable), and short- and long-term injuries sustained.”

This report represents the HHS response to the requirement to conduct a feasibility assessment of the mandated report on shaken baby syndrome, referenced herein primarily by the more inclusive term recommended by the American Academy of Pediatrics (AAP), abusive head trauma (AHT). The assessment included a literature review on incidence of AHT; identification of related federal activities, including activities authorized under the Child Abuse Prevention and Treatment Act; stakeholder discussions; and broad consideration of benefits and costs involved.

In the following pages, HHS presents: (1) background on the field of AHT (2) current data collected on AHT; and (3) a discussion of the feasibility of collecting uniform data from the states on AHT incidence rates and characteristics of perpetrators and victims to fulfill the mandate of the CAPTA Reauthorization Act of 2010.

II. Background

According to the Centers for Disease Control and Prevention (CDC), “Shaken Baby Syndrome (SBS) is a preventable, severe form of physical child abuse resulting from violently shaking an infant by the shoulders, arms, or legs. SBS may result from both shaking alone or from shaking with impact.” The CDC further states that, “SBS resulting in head injury is a leading cause of child abuse death in the United States. Nearly all victims of SBS suffer serious health consequences and at least one of every four babies who are violently shaken dies from this form of child maltreatment.”^{vi}

In 2009, the AAP recommended the use of the term abusive head trauma (AHT) to replace SBS, stating, “Although shaking an infant has the potential to cause neurologic injury, blunt impact or a combination of shaking and blunt impact cause injury as well. Spinal cord injury and secondary hypoxic ischemic injury can contribute to poor outcomes of victims. The use of broad medical terminology that is inclusive of all mechanisms of injury, including shaking, is required.”^{vii}

The CDC also states that “serious traumatic brain injury in young children is largely the result of abuse.”^{viii} According to the AAP, “Most experts believe that AHT is largely preventable. The most common incident leading to abusive head injury is infant crying. Exhausted parents and other caregivers may become frustrated and angry and ‘lose it’ when infants in their care cry inconsolably.”^{ix}

In an effort to prevent AHT, programs and targeted public awareness campaigns designed to educate and support parents and caregivers have been implemented in many states. These include home visiting and other efforts designed to remind new parents of techniques to quiet their infants, reduce their own stress, and avoid hurting their infants. Such programs are being studied to see how helpful they are in preventing AHT and other forms of child maltreatment.

According to the CDC—

In more severe cases of SBS [AHT], babies may exhibit:

- Unresponsiveness
- Loss of consciousness
- Breathing problems
- No pulse

Babies suffering lesser damage from [AHT] may exhibit:

- Change in sleeping pattern or inability to be awakened
- Vomiting
- Convulsions or seizures
- Irritability
- Uncontrollable crying
- Inability to be consoled
- Inability to nurse or eat

[AHT] can potentially result in:

- Death
- Blindness
- Intellectual and developmental disability or developmental delays
- Cerebral palsy
- Severe motor dysfunction
- Spasticity
- Seizures

III. Existing Data on Abusive Head Trauma

Determining the prevalence and incidence of AHT, along with characteristics of both victims and perpetrators, is a challenging task, and may depend on the parameters used to classify these cases. Overall, studies suggest that AHT is under-diagnosed in medical settings and that many children subsequently diagnosed with AHT are seen on earlier occasions without being correctly diagnosed.

The Brain Trauma Foundation's 2012 *Guidelines for the Acute Medical Management of Severe Traumatic Brain Injury in Infants, Children, and Adolescents-Second Edition* notes that the medical field of pediatric traumatic brain injury is still evolving, and that there is a "lack of a systematic approach to data collection and reporting [which] created important problems."^x The Guidelines observe that the lack of a template for uniform data collection and reporting of pediatric AHT poses significant challenges to researchers. The failure to develop such a template may be due to the fact that individual hospitals see pediatric patients with AHT so rarely. As an example, the Children's National Health System, which has a major pediatric neurology center, lists mild traumatic brain injuries (concussions), but not severe traumatic brain injury, among the conditions they treat.

Over the last 12 years, several studies have been completed to help define the incidence of AHT in the United States. The reported numbers vary based on the surveillance methodology and criteria used to identify these cases. Additional limitations also exist and are discussed below.

A. Current Research Findings

In 2003, Keenan et al., reported a study of all resident children under two years of age in North Carolina who were either admitted to pediatric intensive care unit (PICU) with traumatic brain injuries (or AHT) or identified by the state's medical examiner system as having died with AHT during a two-year period.^{xi} The study included surveillance in surrounding states for hospitalized North Carolina resident children. Keenan et al reported an annual incidence of inflicted AHT in the first two years of life at 17.0 per 100,000 children, with the rate of 29.7 per 100,000 children in the first year of life. The rate of AHT in the first year of life was seven times the rate in the second year of life.^{xii}

A three-person panel of a nurse, a child abuse pediatrician, and a PICU physician, blinded to the race and income of the child, reviewed the original treating physician and social service agency determinations of intentional or unintentional cause. In only two of 154 cases were there disagreements with the original classifications; one case classified as undetermined by the medical examiner's office was classified as inflicted injury, and

another undetermined case in the medical examiner's office was classified as unintentional. No PICU case was found to be misclassified by the clinical treatment teams.

Other studies have produced very similar estimates of incidence.

- A Scottish study for the years 1998 and 1999 produced an estimate at 24 per 100,000 infants.^{xiii}
- Neurosurgeon Dr. Mark Dias used a ratio of all AHT deaths in the first three years of life as the numerator and live births per year as the denominator to derive a ratio of 41 cases per 100,000 live births in western New York State.^{xiv}
- Using the Healthcare Cost and Utilization Project (HCUP) discharge database for 33 states, a study by Ellingson and Leventhal reported a national rate of 27.5 to 32.2 per 100,000.^{xv}
- A study in Estonia generated the frequency of AHT as 28.7 per 100,000.^{xvi}

The estimates of cases from the studies noted above align well with other estimates of the incidence of serious physical abuse of children. In 2012, Leventhal et al., estimated the incidence of serious occurrences of all child physical abuse in the United States that resulted in hospitalizations.^{xvii} They utilized the 2006 Kids' Inpatient Database (KID), prepared by the Healthcare Cost and Utilization Project (HCUP), as a dataset that generated an 80 percent sample of hospital discharges of children, weighted to represent all hospitalized children in the United States. Using International Classification of Diseases (ICD) -9 CM and ICD-10 codes from these hospital discharge data, the investigators calculated the yearly incidence of hospitalization due to all forms of serious physical abuse for children less than 18 years of age to be 6.2 per 100,000, increasing to 58.2 per 100,000 for children less than one year of age in 2006. (See Appendix A for additional information on ICD codes.)

In 2011, Gumbs et al. applied a draft CDC coding algorithm for ICD-9 and ICD-10 discharge diagnoses of AHT to the Department of Defense Birth and Infant Health Registry. The registry was originally established as surveillance for birth defects that might be related to parental military service, and records all hospitalizations of children born to active duty servicemen and women during the first year of life. The authors linked the military family advocacy program determination of abuse to children whose health records were in the registry. The authors also linked registry health records to children where the military family advocacy program had made a determination of abuse. Among 676,827 registry infants, 230 had substantiated AHT; there were an additional 35 probable AHT and 38 possible AHT cases using the CDC algorithm. The rate of substantiated AHT among all military families was 34 per 100,000 infants in the first year of life. In the examination of risk factors within the birth cohort of children born to service men and

women, the rate ranged from 105 per 100,000 infants for parents less than 21 years of age to just 5 per 100,000 infants for the children of officers.^{xviii}

Shanahan et al. conducted a study that applied the published CDC algorithm to multiple years of KID data to estimate state, regional, and national trends in hospital discharges for AHT. KID data for a single year are prepared and distributed at three-year intervals. KID data were available for the years 2000, 2003, 2006, and 2009. The investigators calculated rates for AHT admissions for children less than one year old in each year to generate national estimates as well as examine regional variation across the US. They found an average national annual incidence of “definite or presumptive” AHT to be 33.4 cases per 100,000 children. With the inclusion of “probable” cases, the AHT national rate was calculated to be 38.8 per 100,000 children in the first year of life.^{xix}

Importantly, Shanahan et al. also demonstrated significant regional variations in AHT occurrence across the country, with the highest incidence of AHT in the Midwest and the lowest rate in the Northeast. Of note, there was a significant decline in the rate for the western United States although most of that decline occurred prior to the 2005 publication on SBS prevention by Dias et al.

Finally, it is estimated that in the United States about 30 children younger than one year of age per 100,000 are injured from AHT, resulting in at least 1,200 seriously injured infants and at least 80 deaths each year.^{xx} In addition to overall incidence, the April 2012 CDC report stated that the “case fatality rate for abusive head trauma has been estimated to exceed 20%, with significant disability for nearly two-thirds of the survivors.”

B. Approaches to Monitoring Abusive Head Trauma

The studies conducted on AHT to date have used both active surveillance and administrative data surveillance. There are advantages and disadvantages to both of these approaches, which affect the likelihood of collecting uniform data from states.

1. Administrative Data Surveillance

Administrative data surveillance, sometimes referred to as passive surveillance, means using records compiled or maintained for other purposes: for example, the KID database constructed and maintained by the Agency for Healthcare Research and Quality (AHRQ). Current research using methods of surveillance is based upon administrative data, and more specifically, ICD-9 CM coding for hospital discharges and ICD-10 coding of death certificates.

The approach involving hospital discharge data, as exemplified by the studies of Ellingson et al., Shanahan et al., and Gumbs et al., is able to provide important trend analysis. However, there are significant limitations to using administrative data as a form of surveillance, as discussed below.

Variations in Definitions

Before any system of measurement is created, the most basic question of what to measure has to be answered. As with many, if not most, forms of child maltreatment, the issue of case definition has been a historical challenge with abusive head injury.

First, variations in accepted terminology have contributed to barriers in determining incidence. Multiple terms have been used to define clinical findings. Early terms, such as Shaken-Whiplash Syndrome and Shaken Baby Syndrome, imply mechanistic causation of injury. Later terms describe general categories of injury without identifying a specific mechanism. These more encompassing terms such as abusive head injury, inflicted traumatic brain injury, and inflicted neurotrauma were meant to reflect a wider scope of clinical presentation. These semantic complications represent a significant challenge to case ascertainment of AHT across jurisdictions.

In 2008, the CDC organized a panel to address standardization in identifying AHT by using ICD-9 and ICD-10 codes from hospital discharge databases. At that time, a coding algorithm was established, including operational definitions for cases of both nonfatal and fatal AHT. A subsequent report issued in April 2012 entitled *Pediatric Abusive Head Trauma: Recommended Definitions for Public Health Surveillance and Research* defined AHT as “any injury to the skull or intracranial contents of an infant or young child (less than/ under 5 years of age) due to inflicted blunt impact and/or violent shaking.” Narrow and broad definitions of AHT were specified in order to account for the degree of certainty of the diagnosis based on the ICD-9 and ICD-10 codes, allowing for further distinction of “definite or presumptive” AHT and “probable” AHT. The definition excludes unintentional injuries resulting from neglectful supervision, as well as penetrating trauma, e.g., gunshot wounds/stab wounds.^{xxi} While this action largely resolved concerns regarding consistent case definition in institutions that utilize ICD coding, other challenges to accurate measurement and identification remain.

Variations in Approach to Diagnosis

Differences in approach to diagnosis have also created barriers to identifying cases. Unlike many diseases, there is no single set of diagnostic criteria or a single characteristic finding that makes the diagnosis clear. Intracranial and associated external injuries can take multiple forms depending upon the specific direction and strength of the force applied, the

age of the child, and the duration of the event causing injury. There is no specific radiographic or laboratory test for AHT. X-rays may miss abusive fractures initially and laboratory tests for bleeding problems can be confounded by damage to brain tissue. In short, each diagnosis of AHT requires a comprehensive review of all clinical information and diagnostic testing results that often requires several days. While the research literature on the medical phenomenon has grown tremendously in the past decade, challenges remain. Without a uniform diagnosis approach in the implementation of the clinical definition, consistent ICD coding of medical records/death certificates and collecting incidence data is more difficult.

Another challenge to identifying or diagnosing AHT is related to the fact that implicit in the definition of AHT is the assumption that the injury was inflicted by a caregiver and not as a result of an accidental cause. Surveying caregiver behavior could augment efforts at administrative data surveillance; however, measuring a negative, stigmatizing, or illegal behavior for which there are no witnesses is very difficult. In the case of AHT, the abuse may be the result of a split-second, impulsive reaction to a triggering behavior, such as the child's crying, about which the caregiver experiences frustration. For this reason, acts often occur in private and are not witnessed. The victim is by definition young and not highly verbal, often unable to explain what happened. Anonymous telephone surveys have demonstrated that caregivers will admit to shaking as a form of discipline. The data reveals rates of shaking behavior that exceed the rate of clinical cases of AHT, suggesting that not every episode of shaking behavior will cause injury.^{xxii} Because of this variance, anonymous surveys of caregiver behavior may best be reserved for assessing prevention efforts as opposed to estimating incidence.

Variations in Coding

Even with consensus definitions for AHT, the limits of hospital discharge coding using ICD codes have been well described in research literature.^{xxiii, xxiv} According to studies, now over a decade old, though the ICD-9 codes are likely to have quite adequate specificity (i.e., children who haven't experienced AHT are correctly identified as not having been a victim of AHT), they are insufficiently sensitive; that is, even with appropriate use at the leading centers, they only pick up 54 to 84 percent of children who have been victims of AHT. While there has been insufficient time for researchers in the field to comprehensively study the implementation and sensitivity of the new ICD-9-CM and ICD-10 codes, since they are based on advances in the knowledge base, it is fair to assume that they improve sensitivity while maintaining adequate specificity.

One reason for this lack of sensitivity is that ICD-9 CM and ICD-10 codes are assigned at the time a child is discharged from the hospital when ongoing CPS and law enforcement

investigations may limit the ability to conclusively diagnose AHT. Another issue is that most hospital medical record coders, who assign most ICD-9 CM and ICD-10 codes for the records, do not have specific AHT or child abuse expertise. Further, the language used by clinicians in their notes, which is reviewed by medical record coders to establish a code, may be misinterpreted; clinicians may be oblique in their wording or cautious in their statements in order to either avoid involvement in criminal cases or seek to avoid premature conclusions while a CPS or a criminal investigation is proceeding. As an example, a physician's conclusion that "these injuries are indicative of severe blunt force trauma, and could not plausibly have resulted from the short fall described" may be clear to other medical providers but may be coded as "accident, NOS ("Not Otherwise Specified")" by the medical record technician. Even when the diagnosis is clear, child abuse pediatricians use carefully crafted language to avoid preempting legal and social service conclusions.

Administrative data surveillance, which relies on ICD-9 CM and ICD-10 coding, is dependent on a consistent interpretation of these codes across hospitals and over time. Unfortunately, there is a lack of consistency in standards for coding. In addition, secular trends, such as changes in broad or local economic conditions or the specific impact of a well-publicized case of abuse in a community, can affect the coding assigned for similar cases. These factors suggest the use of active surveillance may be necessary to correct and hone AHT estimates.

Dependency on Children Reaching the Health Care System

Administrative data surveillance at the hospital level also depends on victims of AHT reaching the health care system. While many children with AHT are likely to be reported and investigated by CPS with the involvement of the health care system, children with less acute AHT may not be seen at a hospital. Likewise, children with severe AHT identified postmortem may not have survived long enough to come to a hospital before death. It is difficult to estimate the number of children in this latter category as there is no systematic assessment of the numbers of cases that are seen by coroners and medical examiners without passing through the health care system. In the future, ongoing surveillance of death certificates, by searching for the relevant ICD-9 CM and ICD-10 codes established by the CDC consensus conference, should better identify children with AHT.

Legal and Ethical Issues

One important caveat is that administrative data surveillance is unlikely to capture all of the data important to clinicians, policy makers, researchers, and other stakeholders seeking to examine or reduce risk factors for AHT. Meaningful use of the data will require patient-

level data that is not well-captured by administrative data, and access to patient-level data is likely to be complicated by restrictions in the Health Insurance Portability and Accountability Act of 1996 (HIPAA) Privacy Rule. Specific examples of desired information would include, but are not limited to:

- Information about the presenting condition of the child;
- Findings of the clinical examination;
- Laboratory or radiographic testing; and
- Specific details about the history offered by the child’s caregiver.

The HIPAA Privacy Rule permits hospitals and other health care providers and health plans to share individually identifiable health information with social service agencies under certain circumstances such as for public health or health oversight purposes, where required by law, for reporting neglect or abuse, or for research if certain conditions in the Rule are met. Even where permitted, some health care organizations do not share this information because they fear that if they make an improper disclosure, they may face large penalties.. Even if the data is provided, hospital records will not include a comprehensive description of perpetrator characteristics such as: age; gender; relation to victim; access to prevention resources and supports; and history of substance abuse, domestic violence, and mental illness.

2. Active Surveillance

Active surveillance has proven to be a more effective approach to studying and reliably quantifying AHT than administrative data surveillance. Active surveillance by Keenan et al., for example, involved weekly calls to all pediatric intensive care units within a state for two years for any child less than two years of age with a traumatic brain injury. These cases were then reviewed by blinded assessment of the history (i.e., reviewed by qualified individuals who were not provided with details of the case history, a quality assurance feature). Combined with regular contact with the state medical examiner’s office for cases in which children died from AHT, this approach is unlikely to have missed any serious case of AHT. While it seems that milder cases that were clinically stable might have been missed, the investigators reviewed hospital state discharge data and found no missed cases. (They also reviewed surrounding states to determine that no children had been transported to hospitals outside the state.)

Active surveillance of AHT has also been demonstrated to achieve accurate incidence estimates. Prospective identification of cases can improve surveillance through administrative data by ensuring that all cases are captured, thus validating the system.

Furthermore, population-based active surveillance has the added benefit of detecting children who are missed through inappropriate coding or who die before entering the medical system. It also allows for the estimation of a population denominator, a fundamental requirement for calculating incidence.

Active surveillance is not without its challenges, however. It is much more costly, time-intensive, and logistically difficult to complete or execute.

Overall Costs

Active surveillance is a time-consuming and relatively expensive approach. While a more in-depth assessment would need to be undertaken to estimate the cost of incorporating active surveillance into state reporting systems, the work of Keenan et al. provides some insight. In that case, the study required half-time employment of a nurse calling weekly to 11 Intensive Care Units (ICUs) as well as traveling to each hospital for record review and coding. Salary and personnel costs in the North Carolina study are estimated at almost \$1,000 per actual AHT case, with about 40 cases per year among the ICUs and the medical examiner's office.

Logistics

Large-scale monitoring requires participation of multiple institutions. Ideally, a network of healthcare facilities is created, but each may have very different practice or budgeting constraints for conducting research. There must be consideration of whether all cases seen in a hospital should be included: for example, ICUs, general ward units and emergency departments (EDs). The more patients included, the more challenging it becomes to coordinate the enrollment of subjects. Research coordinators are essential, and treating providers must be engaged and willing to participate. Core administrative oversight is needed. An administrative central office can manage the relationships between network partners, complete and maintain requisite records, and provide research infrastructure for data collection, analysis, and dissemination.

Legal and Ethical Issues

Legal and ethical issues related to conducting real-time research in child abuse must be addressed up front. Research investigators are likely to be mandated reporters, and questions will arise about the possibility of the research team identifying abuse not previously recognized. Institutional Review Boards and hospital risk management or legal teams will require the creation of policies and procedures to handle these issues.

While convictions are public record, human services and health records are confidential and, as with surveillance relying solely on administrative data, access to these data are likely to be complicated by data disclosure restrictions in the HIPAA Privacy Rule. In rural states or counties where incidence rates are very low, protecting the privacy of a single case of AHT may pose a significant challenge due to the frequency of occurrence, and therefore potentially allowing related information to be identifiable by the public. The HIPAA Privacy Rule permits sharing of individually identifiable health information in accordance with state and local laws. For example, sharing would be permitted as provided in state laws mandating such disclosures, or where such sharing is with a public health authority as authorized by law. HIPAA would also permit sharing of information if there was a federal law that mandated disclosures in this situation.

Dependency on Children Reaching the Health Care System

As with surveillance relying on administrative data, active surveillance of AHT cases limited to when children enter a hospital or ICU will miss those who don't come to the hospital or who die before arrival. Death records also need to be part of a comprehensive accounting, as fatalities represented 26.4 percent of the cases seen in the Keenan study. (Other studies have suggested lower fatality rates, which may reflect the severity of cases seen in ICUs.) Studies have shown the death certificates can misclassify cases and lead to underestimation of incidence. Authorities suggest that this is especially problematic in rural counties where training and experience in the investigation of child death are less consistent. Additionally, as discussed above, there are challenges to the use of ICD codes in death certificate review. Available abuse codes are few and not specific. The use of new ICD-10 codes in death certificate coding should result in improvements over past practices; however, the new codes in and of themselves cannot completely overcome errors or variations resulting from the lack of training and experience.

Despite these limitations, there should be a component of death certificate review in any active surveillance methodology. States that have a centralized medical examiner's system may be more reliable settings to capture death cases. Presumably, a medical examiner can enforce investigation and autopsy standards, ensure ongoing training, and even review each case for the appropriate diagnosis. A state medical examiner's system will likely mitigate the potential lack of recognition of AHT fatalities in smaller jurisdictions or rural counties where the frequency of AHT is such that a coroner may not carefully consider the diagnosis.

3. Mixed Approach

Surveillance of AHT undertaken without active surveillance is likely to both underestimate the impact of AHT and to produce data with limited utility for some policy or programmatic purposes. Active surveillance of more limited samples of children with AHT, undertaken in concert with surveillance utilizing administrative data, could overcome many of the challenges noted. The examples provided of several prior active surveillance programs demonstrate the strengths and weaknesses of these approaches. To date, no active surveillance approach has been able to consistently identify the full clinical spectrum of AHT in a way that is both suitable for longitudinal surveillance and cost-effective. However, several of these prior attempts might be combined with administrative data surveillance to offer an approach that is feasible and more comprehensive.

C. Sources of Data to Monitor Abusive Head Trauma

There are multiple sources of data on AHT to be used in administrative data and active surveillance (or in combination), each with its own challenges to obtaining accurate and complete data.

1. Hospital-based Data

As the vast majority of children with AHT are hospitalized at some point, several researchers have used active hospital-based surveillance to identify and quantify AHT. Other health care research projects have used similar points that all persons with a condition or diagnosis have to pass through, such as an emergency department or an operating room, to identify all patients with specific conditions or types of trauma. With AHT, the most common service locations or ‘pass-through’ points available for measuring care are hospital EDs and pediatric intensive care units. Active surveillance may find cases which otherwise may not be reported and is a more intensive and expensive approach to ensure that no case is missed. However, as noted previously, data from hospital records will not include a comprehensive description of both victim and perpetrator characteristics.

It should be noted that reductions in hospital beds, increased understanding about the natural course of AHT in children, and efforts to reduce costs in medicine nationally mean that there is an increasing probability that young children who are medically stable in the face of a smaller hemorrhage may be observed outside of the hospital. Thus, less severe cases might not come to attention with an approach that solely contacted hospitals, thereby limiting ability to accurately capture AHT incidences, along with both victim and perpetrator characteristics, even with active surveillance.

Pediatric Intensive Care Units

Surveillance conducted using only PICUs will be limited by the potential to miss two types of cases: less severe cases in which the child presents with stable vital signs and symptoms and never requires intensive monitoring or intervention, and immediately fatal forms of AHT where the child does not survive long enough for an admission. Since children are in PICUs for a short time—only as long as there is concern about medical instability or while the child needs intensive treatment—the PICU health care providers will likely have limited information about final social and legal investigations, which typically continue after a child leaves the PICU.

Pediatric Emergency Departments

Surveillance in pediatric EDs could address the problem of not including children who are not critically ill, or who die after arrival to the hospital before a PICU admission. The Pediatric Emergency Care Applied Research Network (PECARN) has already demonstrated the ability to produce practice-altering research with large numbers of pediatric ED subjects. Surveillance that contrasted data with the large number of injured children without AHT might improve early AHT recognition by clarifying the prevalence and importance of so-called ‘sentinel’ injuries. A ‘sentinel’ injury is a clinical indicator of an adverse event that either leads to or has potential to lead to catastrophic outcomes, therefore often mandating initiation of emergency intervention or of preventive measures. For example, bruising or oral injury in infants who are not yet standing is a sentinel injury that should raise suspicion, as such injuries are common in abused infants and rare in infants who are not abused.

However, an approach based solely in EDs would not include children admitted directly to an inpatient setting nor those who die before hospital admission. ED surveillance shares the limitation of being unable to include data from police and social service investigations subsequent to the child’s medical encounter, and the ED diagnosis or conclusion may be in error. Further, an approach that directly leverages PECARN would lack generalizability, since PECARN has an over-representation of leading, tertiary care academic centers. Such centers are more likely to receive victims of AHT in transfer directly to the PICU without being seen in the ED.

Trauma Centers

Level 1 pediatric trauma centers already support registries for quality assurance purposes, and these registries have provided valuable data for physical abuse research. Because trauma teams evaluate children in the ED, on the inpatient floor, and in the ICU, they overcome limitations of location-based surveillance systems. Clinical data and disposition data are routinely obtained in trauma registries. Pediatric level 1 trauma centers are required to have hospital-based child protection teams (CPTs), improving the reliability of assessments of abuse likelihood. While the numbers and the characteristics of children seen for AHT are likely to be well-recorded by trauma registries, rates are difficult to ascertain and trend data are unlikely to be useful as there is no clear population base served by a specific trauma center and the portion of the population using one trauma center or an alternative center may change. Indeed, as specific centers become known for having special expertise, specific types of trauma patients may come from a wider service population. For example, in the case of neurosurgical trauma, children may be driven or flown past one trauma center to go to another center known for more specialized expertise in neurosurgery.

Further, the available history in the medical record for children with AHT is often incomplete or misleading at these trauma centers. Some children with AHT are not initially recognized as having this form of trauma until several days after admission or after recognition of brain injuries; therefore, the trauma center record may not reflect what has been learned during the admission. In other cases, the trauma team is not directly asked to evaluate the child, raising the possibility of missed cases. Finally, in some metropolitan areas, the level 1 pediatric trauma center is not co-located with the majority of pediatric sub-specialty care. In such centers, it is possible that surveillance based in the pediatric trauma center would not identify subjects with more subtle presentations (isolated vomiting, lethargy or seizure) that are sent by referring physicians to specialty clinics for evaluation.

Hospital Based Child Protection Teams

With Child Abuse Pediatrics now an officially certified pediatric sub-specialty, hospital-based CPTs are becoming more common, better developed, and collaborative. Because pediatric level 1 trauma centers are required to have hospital social workers and access to CPS, CPTs are commonly present at pediatric level 1 trauma centers. Networks based in CPTs have published longitudinal estimates of AHT incidence that seem less vulnerable to secular trends for coding and recognition. Other CPT-based networks have shown promise to improve testing for physical abuse. More than any other hospital-based entity, CPTs can provide ongoing contact with patients, medical examiners, CPS and law enforcement to capture data obtained outside the hospital, or after discharge.

It is important to emphasize that the amount of information routinely available to medical providers after a child is discharged varies tremendously. Confidentiality policies of CPS, medical examiners, or coroners can differ substantially among states, counties, or even individual professionals. However, some established CPTs have built close relationships with CPS and medical examiners in their largest or closest communities.

2. Data Sources Beyond the Hospital

Medical Examiners and Coroners

Surveillance of death certificates is an important step in identifying cases of fatal AHT that did not reach the medical care system. However, there is substantial variability in the skill and willingness to recognize AHT among children with fatal head trauma across communities and even by individual coroners or medical examiners. Changes in personnel and practice as influenced by local norms and culture may produce wildly disparate pictures of the problem in a state or community with little underlying change in occurrence.

Law Enforcement

Police records are another method for tracking caregiver behavior, though this system is not without its limitations. Law enforcement records document criminal cases where a perpetrator is identified. This can be difficult in AHT cases where the abuse is often unwitnessed and multiple caregivers may need to be ruled out. A system based solely on criminal cases will underestimate incidence.

Child Protective Services

CPS systems in every state have the responsibility of investigating allegations of child abuse and neglect and taking steps to protect children with recognized maltreatment. CPS workers often complete their own investigations and coordinate with law enforcement to make a final determination. As such, CPS state systems are likely, at some point, to have data about whether a child with head trauma was ultimately determined to be a victim of AHT if the case was reported properly. The caution is that few states currently collect the medical or anatomic location data required to develop a specific and sensitive measure of AHT. CPS data generally includes all available information about the suspected perpetrator of abuse, which is central to developing prevention strategies. CPS data are important in assessing the national rates of, and risk factors for, child maltreatment more broadly.

However, information from current CPS data collection systems is unlikely to support accurate AHT surveillance. First, local variability about what cases are accepted by CPS is quite broad. Agencies also differ by jurisdiction in whether they investigate AHT if a ‘third party,’ such as a childcare provider, the non-married partner of a parent, or a stranger, perpetrates the abuse. Substantiation criteria are also tremendously variable and may be vulnerable to secular trends. Most importantly, CPS systems are unlikely to capture the medical data necessary to distinguish AHT from other forms of physical abuse and child maltreatment, as they do not routinely collect data about ICD-9 codes or medical diagnoses.

Even if collecting this data were possible, not every CPS system has access to medical expertise to reliably distinguish between different forms of physical abuse. As such, the CPS system may be unable to determine whether the best clinical description is AHT versus another clinical diagnosis or description of maltreatment. In cases where medical involvement is complex or incomplete, a case may be designated as indeterminate, contributing to the difficulty in case ascertainment. Therefore, some CPS systems may benefit from having collaborative medical expertise available to make the appropriate medical diagnosis when a report or allegation includes serious bodily injury.

Child Fatality Review Teams

Child Fatality Review Teams are multi-disciplinary teams based in state, county or local communities tasked with reviewing unexpected child deaths and making recommendations for prevention. AHT is a common focus for these review teams, which benefit from multi-disciplinary evaluation of all fatal cases of AHT, whether or not the child survives to hospital admission. These teams will not have access to the majority of AHT cases that are not fatal, but they may be a useful supplement to hospital-based approaches, which miss children with immediately lethal AHT.

3. National Hospital-related Databases

There are three national hospital-based databases currently providing information to researchers. However, each has a number of the challenges and limitations noted earlier in this report, including reliance on administrative data, prospective coding errors, and missing data elements.

Pediatric Health Information Systems Database

The Pediatric Health Information Systems (PHIS) database is owned by the Children's Hospital Association (CHA), a business alliance of 44 free-standing children's hospitals. PHIS data are most often used for quality improvement, benchmarking, and research purposes. Data are readily available since January 1, 2001. PHIS has some advantages over typical administrative databases: specific resource utilization codes are used for each medication, imaging study, laboratory test, nursing or respiratory therapy, hospital room, or supplied material. Although identifiers are masked within the database, patients have one medical record number at a given hospital, making longitudinal studies of hospitalizations possible.

The PHIS database has most often been used to identify practice variation, track trends in utilization, and analyze readmissions. Several studies of AHT have used the PHIS, including analyses of hospital charges, intracranial pressure monitoring, rehabilitation therapy, and trends in child abuse.

National Trauma Data Bank

The National Trauma Data Bank (NTDB) of the American College of Surgeons Committee on Trauma contains standardized adult and pediatric trauma registry data. Each year, several hundred hospitals submit records from 500,000 to 800,000 injury admissions, including more than 100,000 pediatric records. An annual Research Data Set (RDS) is

available for use, beginning with the admission year 2002. The primary advantages of the NTDB over other administrative databases include the presence of vital signs, pre-hospital data, injury severity measures, and hospital capabilities. Limitations include evolving data standards and variable inclusion criteria by site.

The NTDB has been used to study race and insurance associations with outcome, cervical spine, and spinal cord injury epidemiology, interventions in children with solid organ injuries, disaster triage methods, and mortality prediction.

Kids' Inpatient Database

The Kids' Inpatient Database (KID) is part of a family of databases and software tools developed through a federal-state-industry partnership sponsored by the AHRQ for the Healthcare Cost and Utilization Project (HCUP). HCUP inpatient data are based on administrative data—discharge abstracts created by hospitals for billing. The KID is the largest publicly-available all-payer pediatric inpatient care database in the United States. Unweighted, it contains data from approximately three million pediatric discharges each year. Weighted, it estimates roughly seven million hospitalizations. The KID is available every three years from 1997 through 2012. The KID stratifies hospitals by geographic region, hospital control, urban/rural location, teaching status, bed size, and hospital type to obtain a nationally representative sample. Within each hospital, normal newborn birth-related discharges are sampled at 10 percent and all other pediatric hospitalizations are sampled at 80 percent. This allows for excellent statistical power to detect relatively rare conditions such as AHT. The KID has been used to study pediatric traumatic brain injury in general and national rates of AHT. As noted above, Shanahan et al. used KID data in its study to estimate state, regional, and national trends in hospital discharges for AHT.

With variation by state and by year, some states have been contributing data to HCUP since 1990; others began as late as 2009. Currently, HCUP is collecting data based on AHT deaths in all 50 states and on hospitalizations in 18-21 states using ICD-9-CM and ICD-10 codes. HCUP data is publically available, but access to the data must be purchased. Limitations of this data include lack of identifying information or identifiers, and missing data including certain victim characteristics and perpetrator characteristics.

4. Linked Data

There is a growing interest in developing linked data resources to support a range of public policy and surveillance functions at the state and county level in the United States. New Zealand has recently developed a shared national data resource that includes linked health, social services, law enforcement, and vital statistics data. Linked data may offer new

opportunities to improve the administrative data surveillance capacity, but it is difficult to see how this will translate into national data resources at least in the short term given the variability in systems, laws, and policies at the local jurisdictional level. Nevertheless, data linkage may have important benefits for AHT surveillance within these jurisdictions and over time.

* * *

In addition to the hospital-based databases described above, the federal government collects data on child maltreatment through the National Child Abuse and Neglect Data System and the National Incidence Study. Each of these is discussed in greater detail in the following section.

IV. Feasibility of Collecting Uniform, Accurate Data from All States

In considering the feasibility of collecting data from the states on AHT, it is useful to examine current national data collection efforts around child maltreatment.

A. Current ACF Data Collection Efforts on Child Maltreatment

ACF gathers information on child maltreatment in the United States through the National Child Abuse and Neglect Data System, and actively through the National Incidence Study.

1. National Child Abuse and Neglect Data System

The National Child Abuse and Neglect Data System (NCANDS) is a voluntary data collection system that gathers information annually from all 50 states, the District of Columbia, and Puerto Rico about reports of child abuse and neglect to state CPS agencies. NCANDS was established in response to the Child Abuse Prevention and Treatment Act of 1988. States participate on a voluntary basis and submit their data after going through a process in which the state's administrative system is mapped to the NCANDS data structure.

Submitted data consists of all investigations or assessments of alleged child maltreatment that received a disposition in the reporting year. Records are provided at the level of each child on a report, also known as the report-child pair. Data elements include the demographics of children and their perpetrators, types of maltreatment, investigation or assessment dispositions, risk factors, and services provided as a result of the investigation or assessment. The data are used to examine trends in child abuse and neglect across the country, and key findings are published in *Child Welfare Outcomes Reports to Congress* and annual *Child Maltreatment* reports.

Currently, no detailed information on the cause of death is reported on a child fatality in NCANDS—only the type of maltreatment. There is no specific differentiation between AHT and other causes of serious physical abuse. Neglect is the largest category of maltreatment associated with reported child abuse and neglect fatalities; physical abuse is the second largest. Some detailed information is collected on the perpetrator associated with the fatality, based on information known to CPS, and not related to either law enforcement or medical professional assessments or determinations. Nearly 80 percent of fatalities were associated with parents.

There have been various conversations between states and the HHS Children's Bureau on collecting more detailed information on the cause of death. The discussions have identified the following components of a child abuse fatality:

- Type of maltreatment that brought the case to the attention of CPS.
- Other reasons that might have brought the case to the attention of CPS (such as surviving siblings).
- Cause of death identified by an attending physician.
- Cause of death as recorded by the medical examiner or coroner.
- Factors contributing to the cause of death, such as lack of supervision or beating.
- Possible exclusion of "unintentional or accidental" injuries leading to death.
- Person identified as probably or possibly causing the death, as assessed by child welfare.

Assessment and decision making for each of these components are the responsibility of different local and state agencies and organizations.

The discussions also have recognized that the standard causes of death as recorded by CDC's National Vital Statistics System (NVSS) may not provide sufficient detail to identify child abuse and neglect fatalities. NVSS reports the following as leading causes of infant mortality:

- Congenital malformations, deformations, and chromosomal abnormalities
- Disorders related to short gestation and low birth weight, not classified elsewhere
- Sudden infant death syndrome
- Newborn affected by maternal complications of pregnancy
- Accidents
- Newborn affected by complications of placenta, cord, and membranes
- Bacterial sepsis of newborn
- Respiratory distress of newborn
- Disease of the circulatory system
- Neonatal hemorrhage

It is noteworthy that AHT is not included in the NVSS list, although neonatal hemorrhage—which may be a symptom of AHT—is included. The infant mortality rate for 2011 is estimated at 6.05 deaths per 1,000 live births.

Feasibility of Adding AHT to NCANDS

In considering the feasibility of adding AHT reporting to NCANDS, it is important to emphasize that NCANDS is a voluntary data collection system that gathers information annually from all 50 states, the District of Columbia, and Puerto Rico. The federal-state partnership is key to the success of this data collection effort, and the involvement of NCANDS state contacts in considering the feasibility and implications of any possible additions to NCANDS is essential. States are encouraged to participate to the extent practicable.

If NCANDS were to address the issue of AHT as a cause of death, it would also need to consider other causes of death and work in close cooperation with the CDC’s Division of Vital Statistics to develop the appropriate classification schema and appropriate information sources. Based on the research literature, it is unlikely that death certificates would be a useful source of information.

One approach to generating national estimates of AHT might be to invest in enhancing the capacity of states to report all causes of death to NCANDS. CPS agencies may need to work with hospitals and child death review teams to obtain more detailed information. It would be beneficial if a common typology for the classification of causes of death were established prior to data collection. Another possibility would be to cross-walk each agency’s classifications to a common typology.

Such a typology for cause of death could be designed and piloted with states to determine the feasibility of future enhancements to statewide data collection systems. A commitment from the medical profession and hospital staff to work closely with local CPS agencies to contribute to data collection on cause of death would be necessary for this to be successful.

While this cooperation and coordination could be beneficial, one consequence could be the delay in collecting annual data related to fatalities. HHS may have to consider updating annual data on specific fatalities in subsequent years, based on further consultation by CPS with other professions. It might only be possible to conduct such an endeavor periodically. Additionally, it is important to note that an undertaking of this kind would require considerable effort and cost on the part of states. States participate in NCANDS voluntarily and cover the majority of the financial burden associated with the data collection effort. States would need technical assistance and funding to support such initiatives.

2. National Incidence Study

The National Incidence Study (NIS) is a congressionally mandated, periodic effort by HHS to estimate the number of abused and neglected children in the United States. In the NIS classifications, abuse includes physical abuse, sexual abuse, and emotional abuse. Neglect includes physical neglect, emotional neglect, and educational neglect. The NIS does not specifically address AHT as a subset of physical abuse.

The NIS offers an expansive perspective on the scope of the problem beyond the children that CPS agencies investigate. While the NIS includes children who were investigated by CPS agencies, it also obtains data on other children who were not reported to CPS or who were screened out by CPS without investigation. These additional children were recognized as maltreated by community professionals. Thus, NIS estimates include both abused and neglected children who are in the official CPS statistics and those who are not.

The NIS employs a sentinel survey methodology. In this approach, community professionals who work in certain categories of agencies and who typically encounter children and families in the course of their job duties serve as “lookouts” for victims of child abuse and neglect. In each county, these professionals, called “sentinels,” represent all staff having contact with children and families in police and sheriffs’ departments, public schools, child care centers, hospitals, voluntary social service agencies, mental health agencies, the county juvenile probation and public health departments, public housing, and shelters for runaway and homeless youth and for victims of domestic violence.

Of particular relevance to this report, NIS collects information on:

- Child’s Characteristics: age, race/ethnicity, disability, school enrollment
- Family Characteristics: parent’s employment, socioeconomic status, family structure and living arrangement, grandparents as caregivers, family size, county metropolitan status
- Perpetrator Characteristics: relationship to the child, sex, age, alcohol use, drug use, and mental illness

Physical abuse, which is included within the definitions for maltreatment forms and categories in the NIS, has six codes including the action to “shake, throw or purposefully drop.” Additionally, the NIS data are coded for the severity of harm. An example for the coding under severity of harm includes *moderately* harmed and *seriously* harmed; the report also includes coding for fatalities.

Feasibility of Adding AHT to NIS

It is important to note that the NIS collects data on maltreatment acts or omissions that are perpetrated by a parent or caregiver. AHT, as defined within this report and elsewhere, is largely a clinical diagnosis consisting of certain clinical medical markers. Because of the methodology employed by the NIS, it is not designed to capture a clinical diagnosis such as AHT, and therefore it would not be feasible to use this study to capture ongoing AHT surveillance. Information about the incidents of physical abuse that include the actions to “shake, throw or purposefully drop,” and the perpetrators and the victims, could be obtained from the NIS, but it would be unknown if the clinical diagnosis of AHT would be applied to each of these incidents. Furthermore, while NIS represents a valuable source of information, costs have limited the NIS to roughly one snapshot per decade. This is likely insufficient for purposes of ongoing tracking of the rate of AHT and perpetrator and victim characteristics, much less the additional benefits of determining whether interventions or policy changes are associated with decreased burden of AHT.

B. Findings of a Related Study

HHS recently conducted a study to determine the feasibility of establishing a national registry of child maltreatment perpetrators (often referred to as a national child abuse registry). The September 2012 document, *Report to the Congress on the Feasibility of Creating and Maintaining a National Registry of Child Maltreatment Perpetrators*, and its predecessor, the May 2009 *Interim Report to the Congress on the Feasibility of a National Child Abuse Registry*, identified a number of challenges similar to those associated with collecting AHT data from the states:

- A lack of incentives for participation could result in a database that includes little information and fails to fulfill its intent.
- There are likely to be HIPAA Privacy Rule considerations.
- Potential benefits are largely unknown.

V. Conclusions

Abusive head trauma is a leading cause of death from abuse in children under two years of age, with greatest risk to those aged 0-4 months. Survivors of AHT can suffer lifelong cognitive and physical consequences, and the economic impact on families and society is significant. AHT is also widely regarded as preventable.

As discussed in this report, there are significant challenges to estimating the incidence of AHT, along with both victim and perpetrator characteristics, on state and national scale. Factors contributing to our current inability to accurately identify and count AHT, along with capturing both victim and perpetrator characteristics include:

- Challenges in the application of ICD code definitions of AHT and the complexity of diagnosing AHT for both living children and for children who have died;
- The spectrum of severity, with milder cases of traumatic brain injury not necessarily being admitted to the hospital;
- Changing patterns of medical care, with intensive care unit admissions being increasingly available to only the most medically unstable patients;
- Variations in state social service agencies and social service data systems in the detail and nature of the events recorded;
- The number of health, social services, and law enforcement agencies involved; and
- Variation in state coroner and medical examiner systems, without central policy and programmatic control over which children receive autopsies.

Relying on the use of administrative data from hospitals has its own limitations. These include:

- Variations in the use of accepted terminology;
- Variations in the approach to diagnosis;
- Variations in coding, which can result from oblique wording by physicians, coders who are unfamiliar with AHT and/or child abuse, and codes being assigned at discharge before ongoing child protective services (CPS) and law enforcement investigations are concluded, among other reasons;
- Legal and ethical issues related to accessing patient-level data;
- Missing data elements, most notably certain victim characteristics and perpetrator information; and

- Dependency on children reaching the hospital (excluding mild cases of AHT where a child is not admitted to the hospital, or severe cases that resulted in death without a hospital admission).

Existing methods of collecting data on the incidence of child abuse and neglect are not currently well-suited or feasible vehicles for gathering the data on AHT. As it exists today, NCANDS does not collect detailed information on the cause of death reported on a child fatality—only the type of maltreatment. There is no specific differentiation between AHT and other causes of serious physical abuse. If NCANDS were to address the issue of AHT as a cause of death, it would also need to consider other causes of death and invest in developing a typology and enhancing capacity of states to report all causes of death to NCANDS. There are myriad issues involved in attempting to enhance statewide data collection systems. Additionally, it is important to reiterate that states participate in the NCANDS data collection effort on a voluntary basis in which their data from their state’s administrative system is mapped to the NCANDS data structure. While enhancing these collection efforts might be useful, more careful study is needed to assess feasibility and costs versus benefit.

The use of the NIS study is limited by design, costs, and frequency of data collection. It is not designed to capture clinical diagnosis, including AHT. Information about the incidents of physical abuse that include the actions to “shake, throw or purposefully drop,” and the perpetrators and the victims, could be obtained from the NIS, but it would be unknown if the clinical diagnosis of AHT would be applied to any of these incidents. The NIS is also undertaken infrequently—roughly every 10 years. Therefore, it would not be feasible to use the NIS study to capture ongoing AHT surveillance.

To overcome some of the existing challenges described, combining administrative data with active follow-up of more limited samples of children with AHT presents the best possibility of addressing some of these concerns. The inclusion of an active surveillance component, though, increases such factors as cost, logistics, and legal and ethical issues to be addressed. Moreover, some of the broader issues discussed earlier would remain unresolved. While the transition to the ICD-10 and updates to the ICD-9-CM codes will help overcome definitional challenges in institutions that utilize this coding system, it will take time and the complexity of diagnosing AHT for both living children and for children who have died will remain problematic, diminishing the feasibility of collecting uniform data on the incidence rates of AHT at a national level.

Additionally, it is important to note that information about the true costs of collecting this data at state and national levels is very limited. From studies identified in this report, we know that some data collection methods, such as extensive active surveillance, may be

costly and possibly cost prohibitive. It will be necessary to determine these costs with further study. Costs to consider include:

- Federal start-up costs;
- State and local start-up costs, including those related to exchanging and storing the information securely and meeting minimum procedural protections;
- Technical assistance and training costs; and
- Ongoing operational costs.

With a fatality rate in excess of 20 percent, and significant disability for nearly two-thirds of the survivors, there is no question that AHT is a devastating form of abuse—all the more so since it is widely regarded as preventable. However, this feasibility assessment has determined that there are very substantial challenges involved in moving to collect uniform, accurate data from the states on the incidence rates of AHT, along with characteristics of perpetrators and victims. It may be possible to overcome some of these challenges, but doing so may involve substantial costs and could be burdensome to state and local systems. In the end, it is unclear whether or by how much AHT identification and prevention would be improved through a national data collection effort. Future feasibility study activities and pilot programs could assess further the implications of such an effort and explore ways of addressing a number of the challenges identified to date.

ICD Code Definitions for Fatal and Non-fatal AHT

To address definitional challenges, the CDC convened a conference of abusive head trauma experts, pediatricians, epidemiologists, coding experts, and public health professionals in 2008. The main charge to the group was to develop International Classification of Disease (ICD) code definitions for fatal and non-fatal abusive head trauma for children less than 5 years of age. The findings were published by Parks et al. in the 2012 report *Characteristics of Fatal Abusive Head Trauma among Children in the USA: 2003-2007: An Application of the CDC Operational Case Definition to National Vital Statistics Data*.^{xxv}

The authors of the CDC recommendations pointed out that historical problems with consistency, thoroughness, and specificity hindered the use of hospital discharge and death certificate coding schema for administrative data surveillance. For this reason, they set out to define a “standard set of ICD-9-CM diagnosis and E codes for nonfatal abusive head trauma,” as well as a “standard set of ICD-10 diagnosis and external cause of injury codes (Y codes) for fatal abusive head trauma.”^{*} These sets of codes include injuries, symptoms, and findings relevant to cases of abusive head trauma (i.e., codes for traumatic brain injury and cause codes for abuse).

The authors first determined a working definition of pediatric abusive head injury as “an injury to the skull or intracranial contents of an infant or young child (<5 years of age) due to inflicted blunt impact and/or violent shaking,” excluding “unintentional injuries resulting from neglectful supervision” and penetration trauma. The authors then determined coding schemes for: (1) definitive or presumptive abusive head trauma; and (2) probable abusive head trauma. The distinction between these two categories is based on external cause of injury codes. Definitive cases include assault or abuse-specific codes, whereas the probable category includes only indeterminate cause codes. The authors further delineated the classification system into “narrow” (increased specificity) and “broad” (increased sensitivity) categories. (See Tables 1, 2, 3 below, adapted from Parks et al. 2012.) Similar methodologies were used for ICD-9-CM and ICD-10 systems.

The authors noted that consideration of the certainty of diagnosis or the specificity/sensitivity may be different depending on the use of the scheme. They

^{*} ICD-9-CM stands for International Classification of Diseases, Ninth Revision, Clinical Modification; E codes are supplemental codes that capture the external cause of injury or poisoning, the intent and the place where the event occurred. E codes are intended to provide data for injury research and prevention strategies, but are not used for diagnosis.

suggested that broader case definitions would be appropriate for surveillance of large populations and the narrower definitions would be appropriate for evaluation of targeted interventions.

Data suggest that the coding algorithms for ICD-9 are reliable and valid. These coding algorithms have been used successfully in several recent studies. One caution is that the United States will be changing over to ICD-10 coding for hospitalizations in the coming years, and similar work has not yet been done to validate the coding for ICD-10. Other countries have already begun using ICD-10. In a Canadian study by Fujiwara et al.^{xxvi}, the authors attempted to create an ICD-10 coding system for AHT. Cases (probable or presumptive, narrow or broad) and degrees of certainty were defined in a similar fashion as described in the CDC report. The findings from this study revealed rates much lower than detected in the ICD-9 analysis using CDC definitions by Parks et al.; however patterns in age-related injury were similar to prior studies. The reason for this discrepancy is unclear but further studies assessing validity will be needed using active surveillance.

<u>Table 1.</u> <u>ICD-9-CM</u>	Narrow (TBI) Injury/Disease	Broad (AHT) Injury/ Disease	Cause Code
Definite or Presumptive Abusive Head Trauma: Narrow requires one of the Narrow injury codes and an associated cause code while Broad column expands the forms of injury and still requires a history of assault or maltreatment	Head Injury Codes 800.1-800.4, 800.6-800.9 801.1-801.4, 801.6-801.9 803.1-803.4, 803.6-803.9 804.1-804.4, 804.6-804.9 850.0-850.9, 851.0-851.9 852.0-852.5, 853.0-853.1 854.0-854.1, Child Physical Abuse Codes 950.0-950.3 995.55**, Eye Injury Codes: 361, 361.0, 361.00-361.05, 361.1, 361.10, 361.3, 361.30, 361.33, 361.8, 361.81, 361.89, 361.9, 362.4, 362.40, 362.81, 379.23***, Neurological Injury Codes 781, 781.0-781.4. 781.8	Head Injury Codes 800.0-800.9 801.0-801.9 803.0-803.9 804.1-804.4, 804.6-804.9, 850.0-850.9, 851.0-851.9, 852.0-852.5, 853.0-853.1, 854.0-854.1, Child Physical Abuse Codes 959.01, 925.1, 950.0-950.3, 995.55**, Eye Injury codes 361, 361.0, 361.00-361.05, 361.1, 361.10, 361.3, 361.30, 361.33, 361.8, 361.81, 361.89, 361.9, 362.4. 362.40, 362.81, 379.23***,	With one of the following “E “ or cause codes: Assault (E960 only under 5 years, E967-E967.9, E968.1-E968.2, E968.8-E968.9) Maltreatment syndrome (995.5*, 995.50*, 995.54, 995.59*) Late effects of assault (exclude because of duplicate counts but still impacts burden)

<u>Table 2.</u> <u>ICD-9-CM</u>	Narrow (TBI) Injury/ Disease	Broad (AHT) Injury/Disease	Cause Code
Probable Abuse Probable AHT includes all of the injury codes except the specific AHT code and undetermined intent.	All of those above (except 995.55)	All of those above (except 995.55)	Undetermined intent cause codes (E987's, E988.8-E988.9)
Probable Head Injury Probable Head Injury includes skull fracture or alteration of consciousness with a child abuse code		804.0, 804.5 780.0, 780.3 (exclude 780.31)	AHT specific codes 995.50*, 995.5*, 995.59* With any cause code above
Unexplained Indicates that	All of those above (except 995.55)	All of those above (except 995.55)	Absence of any "E" or cause code

<u>Table 3.</u> <u>ICD-10</u>	Narrow (TBI) Injury/Disease	Broad (AHT) Injury/Disease	Cause Code
Definite or Presumptive	S06.0-S06.9****, S09.7-S09.8, T90.5	S02, S02.0-S02.1, S02.7-S02.9, S04.0, S06.0-S06.9****, S07.1, S07.8-S07.9, S09.7-S09.8, T90.2, T90.5, T90.8-T90.9	With any of the following Assaults Y00, Y01, Y04, Y07, Y07.0-Y07.3, Y07.8-Y07.9, Y08, Y09, Y87.1, T74.1, T74.8-T74.9,
Probable Abuse		All those above	Undetermined cause codes Y29, Y30, Y33, Y34, Y87.2,
Probable Head Injury		S07.0	
Unexplained			Y89.9

Endnotes

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