REPORT OF THE
JOINT COMMISSION ON HEALTH CARE

Shaken Baby Syndrome and Abusive Head Trauma (HJR 632, 2011)

TO THE GOVERNOR AND
THE GENERAL ASSEMBLY OF VIRGINIA

HOUSE DOCUMENT NO. 10

COMMONWEALTH OF VIRGINIA
RICHMOND
2012

COMMONWEALTH of VIRGINIA

Joint Commission on Health Care

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March 27, 2012

The Honorable Robert F. McDonnell
Governor of Virginia
Patrick Henry Building, 3rd Floor
1111 East Broad Street
Richmond, Virginia 23219

Members of the Virginia General Assembly
General Assembly Building
Richmond, Virginia 23219

Dear Governor McDonnell and Members of the General Assembly:

House Joint Resolution 632, introduced by Delegate G. Glenn Oder and agreed to by the 2011 General Assembly, directed the Joint Commission on Health Care to determine the costs to the Commonwealth of Shaken Baby Syndrome and abusive head trauma incidents as well as to identify best practices in reducing the occurrence of such incidents.

In keeping with the requirements of House Joint Resolution 632, this report of the Joint Commission is enclosed for your review and consideration.

Respectfully submitted,

Benjamin L. Cline

Code of Virginia § 30-168.

The Joint Commission on Health Care (the Commission) is established in the legislative branch of state government. The purpose of the Commission is to study, report and make recommendations on all areas of health care provision, regulation, insurance, liability, licensing, and delivery of services. In so doing, the Commission shall endeavor to ensure that the Commonwealth as provider, financier, and regulator adopts the most cost-effective and efficacious means of delivery of health care services so that the greatest number of Virginians receive quality health care. Further, the Commission shall encourage the development of uniform policies and services to ensure the availability of quality, affordable and accessible health services and provide a forum for continuing the review and study of programs and services.

The Commission may make recommendations and coordinate the proposals and recommendations of all commissions and agencies as to legislation affecting the provision and delivery of health care.

For the purposes of this chapter, "health care" shall include behavioral health care.

Members of the Joint Commission on Health Care

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The Honorable Benjamin L. Cline

Vice-Chair
The Honorable Linda T. Puller

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Preface

House Joint Resolution 632, introduced by Delegate Glen Oder, was passed during the 2011 Session of the General Assembly. The resolution directed JCHC "to study the cost of Shaken Baby Syndrome and abusive head trauma in Virginia and identify best practices in reducing the incidence" of this type of intentional injury to children.

The National Center on Shaken Baby Syndrome, describes shaken baby syndrome/abusive head trauma as "the constellation of signs and symptoms resulting from violent shaking or shaking and impacting of the head of an infant or small child." Shaken baby syndrome (SBS) usually occurs in children under the age of two, but has been seen in children up to the age of five. Shaking typically happens when an angry parent or caregiver shakes a child to punish or quiet him/her during a period of inconsolable crying. The perpetrators are most often males and often are not the victim's father. The majority of infants who survive severe shaking will have some form of neurological or intellectual disability; many will require lifelong medical care. Studies have shown that a number of victims of less severe shaking develop serious behavioral problems and may be placed in the foster care or juvenile justice systems. Incidence calculations and there is no universally accepted method or terminology used in calculating incidence. As such, our preliminary findings support the research of others that the incidence of SBS is under-reported. Additionally, the costs to the Commonwealth of caring for survivors of SBS are substantial and under-reported.

There are a number of established prevention programs, most of which seek to teach new parents how to handle their frustration when their infant cries for long periods of time. These prevention programs typically have a hospital-based component which includes educational activities such as discussions with new parents, pamphlets, and videos describing the consequences of SBS and alternative ways to deal with frustration. While the hospital-based form of prevention is vital, additional prevention activities designed to reach men who are not the children's fathers and informal caregivers are needed also.

Based on the study findings, the Joint Commission on Health Care voted to introduce a joint resolution to establish the third week of April as Shaken Baby Awareness Week in Virginia and to request by letter of the chairman that the Departments of Health, Social Services, Behavioral Health and Developmental Services, Rehabilitative Services, and Education collaborate with other public and private sector stakeholders to identify current best practices, statewide programs, and initiatives and interventions dedicated to addressing infant mortality in Virginia, with specific attention to Shaken Baby Syndrome, and to report back by July 2013.

On behalf of the Joint Commission, I would like to thank the individuals and organizations who assisted with this study, including Steve and Kathy Stowe of Shaken Baby of Virginia; Mary Kay Goldschmidt, a UVA graduate student who completed a complementary review of case studies to develop cost estimates associated with caring for specific SBS victims; James Emerson; the Virginia Department of Social Services, Virginia Department of Medical Assistance Services, and the Virginia Department of Health including the Office of the Chief Medical Examiner and the Office of Family Health Services Virginia Health and Hospital Association, Virginia Association of Midwives, Virginia Nurses Association, Medical Society of Virginia, and Emergency Physicians.

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ATTACHMENTS

Shaken Baby Syndrome and Abusive Head Trauma

House Joint Resolution 632, introduced by Delegate Glen Oder and passed during the 2011 Session of the General Assembly, directed the Joint Commission on Health Care (JCHC) to:

- Study "the costs of Shaken Baby Syndrome and abusive head trauma in Virginia and identify best practices in reducing the incidence…and work "with stakeholders to determine, to the degree practicable given existing data and information, the number of cases of shaken baby syndrome or abusive head trauma among children in the Commonwealth" and the related costs.
- "[I]dentify evidence-based practices that have been shown to reduce the rate of occurrence of shaken baby syndrome and abusive head trauma, including potential costs of those practices if implemented;
- [I]dentify any potential source of grant funding or funding other than state general funds that may be used to pay the cost of implementing evidence-based practices as pilot programs for the prevention of shaken baby syndrome and abusive head trauma in child care delivery settings in the Commonwealth."

Methodology

In completing the study, JCHC staff conducted an extensive literature review on shaken baby syndrome (SBS) and researched and analyzed state and national law, as well as various policy options and implementation. Staff also convened a workgroup whose members included Steve Stowe, Mary Kay Goldschmidt, James Emerson and representatives of the Medical Society of Virginia, Virginia Association of Midwives, Virginia College of Emergency Physicians, Virginia Department of Health including the Office of the Chief Medical Examiner and the Office of Family Health Services, Virginia Department of Medical Assistance Services, Virginia Department of Social Services, Virginia Hospital and Healthcare Association, and Virginia Nurses Association.

In addition, Mary Kay Goldschmidt, a graduate student at the University of Virginia, completed a complementary review in an effort to develop Virginia-specific incidence and cost estimates related to shaken baby syndrome.

Background

Shaken baby syndrome/abusive head trauma, as defined by the National Center on Shaken Baby Syndrome describes, "the constellation of signs and symptoms resulting from violent shaking or shaking and impacting of the head of an infant or small child." Shaken Baby Syndrome is a form of abusive head trauma (AHT), also called inflicted traumatic brain injury, and it is a preventable and severe form of physical child abuse.

Risk Factors for Shaken Baby Syndrome. Those at greatest risk of injury from shaking are babies, newborn to four months, with abusive head trauma typically occurring within the first two years of life. Persistent and inconsolable crying, which is

a characteristic of normal infant development typically between two and sixteen weeks of age, is the primary trigger for shaking a baby.

The prevailing characteristics of caregivers most at risk of shaking a baby include:

- Male (64 percent of perpetrators –usually father or father-figure)
- Young parental age
- Low educational level
- Impulsive behavior
- Unstable family environment
- Low socioeconomic status
- Single parenthood
- Need for nurturing
- Unrealistic child-rearing expectations
- Rigid attitudes and impulsivity
- Feelings of inadequacy, isolation or depression
- Negative childhood experiences including neglect or abuse
- Parents or caretakers who have been involved with substance abuse
- Domestic violence

The infants most likely to suffer SBS have been found to display or have these attributes: frequent crying, sometimes inconsolably; difficult temperaments; product of a multiple pregnancy; premature and/or low birth weight; special needs, inherited substance abuse exposure; medically fragile, congenital defects or syndromes, poor bonding with caregivers.

Indications and Consequences of Shaken Baby Syndrome. Nearly all victims of SBS suffer serious health consequences and at least one of every four babies violently shaken dies from this form of child maltreatment. Furthermore, SBS is a leading cause of child abuse deaths in the United States, and the most common cause of long-term disability and permanent damage in physically abused infants and children. Recent studies in Cleveland and the University of Pittsburgh found there have been twice as many SBS cases since the recession started.

The clinical manifestations of SBS can range from mild to severe. SBS symptoms are often vague and may mimic symptoms of an infectious process, a metabolic disorder, an unusual neurological disorder, or trauma. Frequently no external sign of injury is apparent. As a result and although symptoms are likely present immediately after shaking, medical attention may be delayed. For instance, caretakers may place the infant in the crib with the hope he recovers, thus losing the opportunity for early intervention. The typical symptoms of SBS include:

- Irritability and crying (41%)
- Bruising /superficial injury (41%)
- Vomiting/ anorexia (38%)
- Apnea/ respiratory symptomology (38%)
- Muscular stiffness (34%)
- Seizures (21%)
- Cyanosis “bluish discoloration of skin or mucus membranes” (29%)
- Depressed consciousness state (21%)

While SBS can be difficult to diagnose, if a subdural hemorrhage, retinal bleeding, and encephalopathy (cerebral swelling) are present without a bruise or a fracture, diagnosis of SBS is typically made. This triad of symptoms has started some controversy in the prosecution of SBS cases. Some argue prosecution of SBS requires additional evidence beyond the triad, and suggest the absence of injury to the neck or the absence of spinal trauma calls shaking as the cause of the symptoms into question.

The prognosis of SBS victims ranges from no adverse effects to death.[1] However, the majority will have significant neurological or intellectual disability and will require lifelong medical care. A 2008 report on abusive head trauma in infants and young children and published in *Pediatric Clinics of North America* indicated that 61% had severe disabilities, and an additional 35% had moderate disabilities (64% had speech and language difficulties, 25% had cranial nerve abnormalities, and/or 20% had visual deficits and epilepsy).

SBS victims also are at risk for having potential educational issues, such as learning disabilities and speech problems. Additionally, many SBS victims will have an intellectual disability. As such, they may lack the ability to learn as do other children and may possess "below average intelligence." They also are at risk for attention problems with or without hyperactivity. Studies indicate a number of victims of less severe shaking develop serious behavioral problems which may result in foster care placement or commitment to the juvenile justice system. Children who were abused, including those who suffered abusive head trauma, were five times more likely to be arrested for juvenile delinquency and twice as likely to be arrested for criminal behavior as an adult.[2]

Costs Associated with Shaken Baby Syndrome

In the United States, medical costs for SBS victims typically range from $300,000 to $1,000,000 per child.

- The average cost of an emergency room visit related to SBS can be as high as $30,000.
- For survivors of SBS with severe long-term consequences (paralysis, seizure disorders, learning/vision/hearing deficits), the cost for physical and educational therapy as well as custodial care, can be as much as $3,000,000 during the first 5 years of a child's life.
- Additional costs include loss of future productivity and wages, as well as the legal costs of prosecuting and incarcerating jailing perpetrators.

Review by Mary Kay Goldschmidt. Mary Kay Goldschmidt, a graduate student at the University of Virginia, completed a complementary review in an effort to develop Virginia-specific incidence and cost estimates. Ms. Goldschmidt examined incidence information available from several State agencies:

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[1] The Potential Ramifications of SBS include: Blindness and/or hearing loss, Cerebral Palsy, Emotional Problems, Explosive anger, Self injurious behavior, Depression, Attachment disorder, Gastrointestinal and/or respiratory problems, Brain-related issues, such as, fluid on the brain or an unusually small head, Seizures, Paralysis, Persistent Vegetative State, Death.

[2] Centers for Disease Control and Prevention, Injury Center: Violence Prevention, Child Maltreatment: Consequences. Available at http://www.cdc.gov/violenceprevention/childmaltreatment/consequences.html. *See also* https://www.childwelfare.gov/pubs/factsheets/long_term_consequences.pdf *and* http://www.nij.gov/topics/crime/child-abuse/impact-on-arrest-victimization.htm *and* http://www.sagepub.com/upm-data/38655_Chapter4.pdf.

- Virginia Department of Health – hospital discharge data for SBS as compiled by Virginia Health Information and deaths attributed to SBS by the Office of the Medical Examiner.
- Department of Social Services – child protective services investigations in which SBS was suspected as the cause of harm or death.
- Department of Medical Assistance Services – costs in providing SBS-related outpatient or long-term medical services for eligible children.

Ms. Goldschmidt also undertook a clinical data repository review of SBS cases treated at the University of Virginia hospital between March 1, 2008 and December 29, 2009. Ms. Goldschmidt concluded that "current data may not provide sufficient accuracy for calculation of a reliable SBS incidence. Provision of a SBS cost of disease burden analysis for Virginia is not possible without accurate SBS data."[3] Ms. Goldschmidt's written report, *The Incidence and Cost of Shaken Baby Syndrome in Virginia*, is included as an appendix to this document.

Prevention of Shaken Baby Syndrome

In recognition of the serious and completely preventable nature of SBS, a number of prevention programs have been established; generally these programs are designed to reach new parents and caregivers and focus on how to handle frustration when their infant cries for long periods of time. These prevention programs typically have a hospital-based component which includes educational activities such as discussions with new parents, pamphlets, and videos describing the consequences of SBS and alternative ways to deal with frustration. While the hospital-based form of prevention is vital, additional prevention activities designed to reach men who are not the children's fathers and informal caregivers are needed also.

A number of prevention strategies have been undertaken in various states. These strategies include:

- Prenatal and postnatal programs in hospitals and physician's offices
- Home visitation
- Stress management education
- Educational programs on:
  - Child development for parents and caregivers
  - Triggers of infant shaking and strategies for dealing with frustration and exhaustion
  - Stress management

The best-known hospital-based programs are the Period of PURPLE Crying and the Dias Model. A number of states have implemented these programs using videos that feature families and medical professionals from their states.

The Period of PURPLE Crying Program. PURPLE, which is supported by the National Center on Shaken Baby Syndrome, uses an 11-page booklet and 10-minute DVD for parents of new infants. The program teaches new parents and caregivers that crying is a normal state in infant development, not a rejection of the caregiver. It emphasizes leaving an infant in a safe situation when the crying becomes intolerable for the caregiver, and states to never shake a baby. PURPLE materials describe SBS and

[3] Goldschmidt, M.K., *The Incidence and Cost of Shaken Baby Syndrome in Virginia*, May 2012, p. 7.

emphasize telling caregivers other than the parents about the "period of PURPLE crying," the frustration of caring for a crying child, the dangers of shaking, and the recommended responses.

PURPLE is evidence-based and has been shown to lead to higher scores in knowledge about early infant crying and the dangers of shaking, as well as an increased sharing of information and behaviors considered to be important for the prevention of shaking. The National Center on Shaken Baby Syndrome conducted research-testing on PURPLE; and the research has been published in two peer-reviewed journals. Programs have been implemented in 800 hospitals and there are related organizations in 49 states.[4] PURPLE is available in ten languages and includes closed captioning; presented at a third grade language level and is representative of multicultural and ethnic backgrounds. With large quantity orders, it can be available for as low as $2 per package.

North Carolina, with funding provided by the Centers for Disease Control and Prevention (CDC) and the Doris Duke Foundation, has implemented PURPLE statewide using a three-dose approach that targets all families of newborns. First, all new parents receive their own DVD and booklet with information about the Period of PURPLE Crying while in the hospital or birthing center. The key messages are reinforced by brief bedside education from a nurse and parents are asked to share the information with other caregivers. Second, parents receive materials at the first pediatric visit that reinforce the message of the program. Third, a sustained media effort targets the community at large.

The DIAS Model. The DIAS Model was developed in western New York at the Children's Hospital of Buffalo. DIAS is a hospital-based program that teaches new parents about the dangers of SBS through the *Portrait of Promise*, an 11-minute video shown in the hospital post-delivery. It also includes an educational brochure and a five- to 10-minute discussion with a nurse on staff. Participating parents are asked to sign an acknowledgement/evaluation form (commitment statement) that affirms their receipt and understanding of the materials they received. These commitment statements are returned by participating hospitals and are tracked to determine the effectiveness of the program. DIAS has served as a model of SBS prevention and sparked creation of other programs worldwide. Dr. Dias estimated that the program would cost $10 per birth.

Evaluation continues but interim results indicate that the Dias Model has significantly reduced SBS injuries in western New York. Results show that parents remember the information, recommend the video over brochures, and use the information. The program subsequently was expanded to 17 counties with grant assistance from a trust fund and the two-year evaluation reported a 60 percent reduction in SBS cases in the area. The hospitals are still using model, but have modified it to fit their needs. Currently, the DIAS program is being implemented in Arizona, Connecticut, Pennsylvania, Massachusetts, Michigan, and New York.

Shaken Baby Syndrome of Virginia. Shaken Baby Syndrome of Virginia was founded by Steve and Kathy Stowe, whose grandson, Jared, lived for three years before dying

[4] North Carolina, Utah, Maine, Kansas, and Iowa have implemented PURPLE statewide; Oklahoma, Washington, West Virginia, Montana, New Hampshire, Oregon, and Connecticut have implemented PURPLE in 80% of the state.

from SBS. Jared's death was the impetus behind this study resolution and "Jared's Law", a 2010 Virginia statute related to SBS. Mr. and Mrs. Stowe speak at conferences, hospitals, and universities to raise awareness about SBS and how it can be prevented. Mr. and Mrs. Stowe advocate for Virginia to implement a program that includes using the Dias *Portrait of Promise* DVD (they would like to produce and then use a video that features Virginia families and physicians) and would like to have a letter of promise and plan of action for parents/caregivers (based on the Dias Model but modified for Virginia). They would also incorporate follow-up calls to determine program effectiveness and estimate the cost of their SBS prevention program would be $3.50/per child.

Statutory Requirements for Prevention Programs. Some states, including Virginia, have implemented laws to require hospitals to offer education for new parents. [5] Missouri, Nebraska, New York, Washington and Wisconsin specifically request parents view a video approved by their state health department. New Jersey requires hospitals to provide information on home visitation programs. Iowa, Massachusetts and Montana have implemented hospital-based programs as part of a larger, comprehensive, statewide prevention initiative required in statute.

Some states also require SBS-related training for child care providers and educators; Florida, New York, Tennessee, Texas, and Wisconsin specify that a video must be shown and Minnesota requires SBS training to be documented.

Prevention through Public Awareness. While parent-oriented educational approaches can be effective, additional outreach is needed to reach informal caregivers. Potential approaches, some of which have been implemented in other states and others discussed in our workgroup meeting, include:

- Public service announcements, brochures, transit stop posters, rest room advertisements, and other creative approaches targeting the general public.
- Parenting classes for high school students, teen parents, inmates, and through community organizations (such as Big Brothers/Big Sisters, Red Cross babysitting classes).

A number of states have implemented public awareness campaigns which can involve as little as distributing prevention materials.[6] New York and Wisconsin have incorporated SBS prevention into the school curriculum and New York has included education on SBS within its correctional facilities. While there have been many unsuccessful efforts by Congress to designate the third week in April as National Shaken Baby Awareness Week, Illinois and Nevada designated a Shaken Baby Syndrome Awareness Week as part of their states' Child Abuse Prevention Month. (Note that April was designated as National Child Abuse Prevention Month in 1983.)

Virginia Laws Related to SBS Target Parents and Caregivers. In 2005, the Virginia General Assembly enacted SB 1296 (Senator Wampler) modifying the information that midwives and hospitals were required to provide to maternity patients. The bill amended *Code of Virginia* § 32.1-134.01 to require that "information to increase

[5] California, Hawaii, Iowa, Massachusetts, Missouri, Montana, Nebraska, New Jersey, New York, Ohio, Tennessee, Texas, **Virginia**, Washington, and Wisconsin.
[6] California, Iowa, Indiana, Nebraska, New York, Rhode Island, Tennessee, Virginia, and Washington.

awareness of shaken baby syndrome and the dangers of shaking babies" should be made available to the patient, father, other family member, or caretaker and discussed with any "relevant family members or caretakers who are present at discharge."

In 2010, the Virginia General Assembly enacted HB 411 (Delegate Oder). The bill known as "Jared's Law" added language to sections of Title 63.2 of the *Code of Virginia* to require the Department of Social Services to:

> Make "information about shaken baby syndrome, its effects, and resources for help and support for caretakers in a printable format, and information about how to acquire information about shaken baby syndrome and its effects in an audiovisual format, available to the public on its website. Such information shall be provided to every child welfare program required to be licensed by the Department at the time of initial licensure and upon request [as well as made] available to foster and adoptive parents and other persons, upon request."

Policy Options and Public Comment

Six policy options were presented for JCHC-member consideration and for public comment. Two public comments were received regarding the policy options:

- Commissioner Karen Remley commented on behalf of the Virginia Department of Health in support of a revised Option 4.
- Steve Stowe, President of Shaken Baby of Virginia, commented in support of Options 2 through 6 and to suggest an additional option, shown as "Potential Addition to Option 4" (meaning both Option 4 and Revised Option 4).

Option 1: Take no action.

Option 2: Introduce budget amendments (language and funding) to allow the Virginia Department of Health to undertake or contract for a hospital-based prevention program to include training maternity staff to talk with parents of newborn babies, and provide those parents with a video presentation on the dangers of shaking infants.

- A. Statewide program (estimated cost to be determined but not expected to exceed $300,000 per year)
- B. One or more demonstration projects at $10,000 or $50,000 per year

Option 3: Introduce budget amendments (language and funding) to allow the Virginia Department of Health to undertake or contract for a pediatric office-based prevention program to provide staff training and video presentations on the dangers of shaking infants.

- A. Statewide program (estimated cost to be determined but not expected to exceed $300,000 per year)
- B. One or more demonstration projects at $10,000 or $50,000 per year

Option 4: Request by letter of the JCHC chairman that such State agencies as the Departments of Health, Social Services, Behavioral Health and Developmental Services, Rehabilitative Services, and Education collaborate with other public and private stakeholders to develop a more comprehensive SBS prevention initiative. The initiative,

which would be reported to the chairmen of the Joint Commission and the Virginia Disability Commission, should include:

- A collection of prevention and training programs designed for use in hospitals, pediatricians' offices, child day care and foster-care training, middle school classes, and juvenile and adult court and correctional settings.
- Public service announcements and advertisements.
- Supportive programs for victims of Shaken Baby Syndrome and their families.
- Creation of a surveillance and data collection program to measure the incidence of SBS and traumatic brain injury in infants and children in the Commonwealth of Virginia.

Commissioner Karen Remley, in discussing a revision to Option 4, indicated that VDH "has several ongoing initiatives that promote the prevention of Shaken Baby Syndrome....These targeted tactics are part of a larger, comprehensive strategy by VDH to focus on the critical issue of infant mortality, of which Shaken Baby Syndrome is one aspect…..VDH has, for the last several years, addressed infant mortality through the Health Commissioner's Workgroup on Infant Mortality. The Workgroup brings together representatives from private, public, and non-profit sectors. Members include representatives from hospitals, DMAS, obstetricians, academia, neonatal experts, and others. One current initiative is to survey Virginia hospitals regarding the content of prenatal courses provided to expectant families. The results will be analyzed to identify opportunities to enhance the use of messages and tools capable of preventing the death of infants….[We] will be looking at whether key messages to prevent Shaken Baby Syndrome are being shared. By taking this broad approach to infant health and safety, we believe we can promote synergy as well as efficient use of resources.

VDH would like to recommend that the Joint Commission consider approaching infant mortality and safety policy with a comprehensive strategy parallel to that of the Health Commissioner's Workgroup on Infant Mortality….[since] factors increasing the risk of an infant's death are often linked….A comprehensive approach can potentially address root causes and leverage resources."

Revised Option 4: *Request by letter of the chairman that the Departments of Health, Social Services, Behavioral Health and Developmental Services, Rehabilitative Services, and Education collaborate with other public and private sector stakeholders to identify current best practices, state-wide programs, surveillance and data, initiatives and interventions dedicated to addressing infant mortality in Virginia, including those efforts dedicated with specific attention to Shaken Baby Syndrome as a cause of infant mortality. The Virginia Department of Health, by July 1, 2013 and in collaboration with other agencies and stakeholders, shall submit a report to the Joint Commission on Health Care* [and the Virginia Disability Commission] *detailing these efforts with recommendations for improving public awareness and professional intervention and collaborative practices, and future program and policy development, supported by appropriate* evaluation and outcome measures.

Steve Stowe, President of Shaken Baby of Virginia, commented in support an additional policy option. Mr. Stowe wrote, "In reference to the Policy Options for what we believe should be named, "Jared's Law." Our professional opinion which has been derived from not only hundreds of hours of research, but also the two years, eight

months, and two days that we cared for our grandson, Jared Nicholas Patton, which was a demanding twenty four hour a day task....We feel that we are more than qualified to be of service to the State while the needed time is being spent on the decisions such as medical coding issues, policy procedures, and the many hours ahead of tireless work from the members of the Department of Health and the J.C.H.C. As Shaken Baby Syndrome of Virginia, Inc., we have trained over 5000 soldiers at Ft. Eustis. We have been called upon from too many family advocacy groups to list. We have literature in the offices of Pediatricians, Vision specialists, and various professional stations throughout the community wherever education and awareness about Child Abuse is in need. Up to this point we have been self-funded. We are determined to do what we can to prevent SBS in Virginia. We have created a training version very close to the Diaz Model. Postpartum is the most effective setting for educating parents and helping them keep their new born babies safe. We would like to request that the J.C.H.C. consider contracting SBS of VA., Inc. to train staff, help hands on at postpartum, or any part of the needed options within perhaps a certain area of the State while the above mentioned work is in progress. We feel strongly that just standing by while so many decisions need to be governed would be neglecting the safety of all new born babies during this time frame. Whatever it costs the State to contract someone during this tenor, we all know it is just a fraction of what it will cost the State to do nothing."

Potential Addition to Option 4: After *collaborate with other public and private sector stakeholders,* add the language "including officers of Shaken Baby Syndrome of Virginia" if either version of Option 4 is approved.

Option 5: Introduce a joint resolution to establish the third week of April as Shaken Baby Awareness Week in Virginia. The resolution would be in memory of Jared and the many other victims of Shaken Baby Syndrome in Virginia.

Option 6: Include in the 2012 work plan for the Behavioral Health Care Subcommittee, continuation of the study for a second year to consider definitional and medical coding issues.

Subsequent Actions by the Joint Commission on Health Care. Based on the study findings and public comment, JCHC members approved Revised Option 4 and Option 5.

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A report for the Joint Commission on Health Care, May 2012

PREPARED BY:
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Incidence and Cost of Shaken Baby Syndrome in Virginia

Shaken baby syndrome (SBS), is the leading cause of child abuse fatality (Jenny, 1999). The first published US population based study on SBS concluded that 53% of all serious to fatal head trauma in children under the age of two, is inflicted traumatic brain injury (SBS), with an annual incidence rate of approximately 30 per 100,000 infants (Keenan, 2003).

In February 2010, the Virginia General Assembly directed the Joint Commission on Health Care to develop a report on the incidence, cost, prevention programs and grant funding for a SBS pilot prevention program (Goldschmidt M. K., Joint Commission on Health Care: Study of Shaken Baby Syndrome and Abusive Head Trauma (HJ 632/Delegate Oder), 2011).

The Virginia Department of Health (VDH) collects Virginia's SBS incidence data via Virginia Health Information (VHI) hospital discharge data, using ICD-9 code – 995.55. From 2004 - 2008, VDH reported 98 children under the age of four were coded as shaken baby syndrome. The Office of the Chief Medical Examiner (OCME) of Virginia reported 26 SBS deaths for a similar period of time (2004-2007) (Virginia Department of Health, 2010). More recently, VDH data for March 1, 2008 through December 21, 2009 (2010 data unavailable), showed an incidence of 23 SBS cases, with a death rate of 43.5%; 87% of Virginia's SBS cases were under the age of one.

Interestingly, the Virginia Department of Social Services Child Protective Services (CPS) Division reported more than twice the number reported by VDH (50 cases), with 16 deaths (32%) from 03/01/08 – 02/28/10 (Goldschmidt M. K., 2011). The true incidence may be higher than either figure; the *Fourth National Incidence Study of Child Abuse and Neglect* (NIS-4), estimated that only 30% of Harm Standard Physical Abuse – Serious Severity cases were investigated by Child Protective Services, subsequently, a closer approximation of Virginia's incidence for this two year period may be as many as 167 cases (Fourth National incidence Study of Child Abuse and Neglect, 2010).

The discrepancy between VDH and CPS data for Virginia's SBS incidence may be reflective of VDH's use of ICD-9 hospital discharge codes as an incidence calculation tool; ICD-9 code 995.55 is thought to be specific, but not sensitive (Wirtz, 2008). Cases that were not correctly coded or were non-hospitalized fatality cases were not included in VHI data sets. The use of SBS fatality data from Virginia's OCME may capture the "missed" non-hospitalized SBS case fatalities, but it may also "double-count" those SBS cases which were hospitalized prior to death. Lastly, VDH data relies on the valid and accurate use of hospitals' ICD-9 coding (Virginia Department of Health, 2010).

The Virginia Department of Medical Assistance Services (DMAS) reported a total of 92 children received SBS related (out- patient or long- term) medical care from 03/01/2008 – 02/28/2010; while this figure cannot be utilized as an incidence indicator (a portion of these cases were likely diagnosed prior to March 1, 2008), it may prove helpful in understanding the scope of Virginia's SBS incidence and costs (Goldschmidt M. K.,2011).

University of Virginia CDR Retrospective Case Review

For the period of time between 03/01/2008 – 12/29/2009, VDH data indicated 2 cases of SBS were treated at UVA hospital (Goldschmidt M. K., 2011). In an effort to determine the accuracy of the VDH's SBS incidence data for UVA during the time frame listed above, in September 2011, a review of UVA's Clinical Data Repository (CDR) was undertaken by University of Virginia School of Nursing Principal Investigator, Mary Kay Goldschmidt, RN, MSN, and co-investigator Robert Goldschmidt, MD, board certified pediatric radiologist (UVA IRB exempt approval # 15797).

Methodology

A CDR based retrospective case review was conducted, following the study framework established by Keenan et al, in their population based study of brain injury in children (Keenan, 2003). Utilizing ICD-9 code 995.55, as well as those International Classification of Disease, Ninth Revision codes indicative of serious to fatal traumatic brain injury, and including (but not limited to) the following codes: 800.1 to 801.49, 801.6 to 801.99, 803.1 to 803.49, 803.6 to 803.99, 804.1 to 804.99, 850.0 to 850.99, 851.0 to 851.99, 852.0 to 852.59, 853.0 to 853.19, 854.0 to 854.19, and 959.8 to 959.9, all cases of brain injury in children aged 2 and under, over a two-year time frame (03/01/08 – 02/28/10) were examined. The initial set of cases was further refined by eliminating any cases where a CT scan and/or MRI of the brain had not been performed. Based on radiology impressions and radiology reports contained in the CDR and Keenan's definition of serious to fatal TBI, a total of 64 cases were reviewed with 37 categorized as having sustained serious to fatal traumatic brain injury (Keenan, 2003).

Results

CDR review results suggest that between 03/01/2008 and 02/28/2010, 37 children under the age of 2 sustained serious to fatal head trauma. Following the parameters established by Keenan et al, 53% (20) of these head trauma cases were likely SBS (Keenan, 2003). Four of the 37 identified serious TBI cases were coded as SBS (ICD-9 code 995.55) (Goldschmidt, 2011). Limitations of the UVA CDR study include the preliminary nature of the findings; validation of review results will require direct examination of medical records.

These findings suggest a significant gap between those cases identified at UVA (during this time frame) by the VDH as SBS (2), and those coded as SBS at UVA (4) and finally, the estimated number of actual cases (20).

The preliminary UVA CDR SBS review provides insight in to institutional issues which affect accurate SBS incidence calculation, including coding and documentation concerns. Additional issues which affect accurate incidence calculation of SBS include clinician failure to recognize SBS because many patients initially present with non-specific clinical signs, social bias, inadequate training and/or experience, practice setting and mis-interpretation of radiologic studies; as a result; 40% or more of missed SBS cases will develop complications from delayed diagnosis, contributing in some cases to the child's death (Jenny, 1999).

Hospital discharge data as a source of SBS surveillance

Hospital discharge data are critical to epidemiologic surveillance, public health reporting, economic impact of disease studies and hospital reimbursement (Cheng, 2009); however, hospital discharge data may have issues with data quality, excluded populations (e.g. non-hospitalized SBS cases) and missing data ((Schoenman, 2005). Data quality problems may be related to coders' understanding of diagnostic coding, misclassifications or the deliberate altering of codes to maximize reimbursement (Schoenman, 2005). Inaccurate coding may contribute to faulty epidemiologic surveillance (Cheng, 2009).

Findings in UVA SBS coding

In examining coding issues with the UVA CDR study, it was determined that UVA's coders may not classify a case as SBS unless specific nomenclature (shaken baby or shaken infant syndrome) was used in the medical documentation; more specifically, this documentation had to be present in the physician's discharge summary, discharge orders or physician's progress notes. Since the term "shaken baby syndrome" has more recently come to be known as abusive head trauma or non-accidental head trauma or injury, coders may fail to recognize a case as SBS unless their recognized nomenclature was used, subsequently some cases may be misclassified.

According to UVA's coding compliance officer, there may be problems with clinicians' inaccurate or incomplete discharge summary documentation which also contribute to misclassified cases. Discharge summaries, physician's progress notes or discharge orders must include a diagnosis (or suspected diagnosis) of SBS in order to be coded as a SBS/AHT case. Though there may be reference to SBS in other portions of the medical record, including radiology reports, a case may not be coded as such unless the discharging clinician includes the diagnosis in the appropriate location.

Summary: Virginia's Incidence of SBS

The utilization of VHI hospital discharge data as an indicator of SBS incidence may lead to an underestimation of Virginia's SBS incidence. While combining VHI data with fatality data from the OCME as indicators of Virginia's SBS incidence may be helpful, duplication of case counting may occur. Virginia's CPS provide data on cases seen by their case workers, but exclude cases that were never referred. DMAS data provide a glimpse of SBS cases currently being served by Medicaid and Medicare, but exclude SBS cases that are being cared for through private insurers.

A collaborative form of data sharing across agencies is an essential part of obtaining an accurate SBS incidence (The United States Government Accountabiliy Office, 2011). On an institutional level, consistent use of appropriate ICD-9 coding as well as diagnosis and documentation procedures is suggested, in order to provide accurate SBS hospital discharge data.

Cost Analysis

As part of the Commonwealth of Virginia's JCHC report on SBS, a needs assessment and cost analysis was performed, utilizing a Virginia SBS case, results were reported to the JCHC on October 17, 2011 (Goldschmidt, 2011).

Methodology

A needs assessment and cost analysis was performed by Mary Kay Goldschmidt, RN, MSN, CCM, CLCP, utilizing the Certified Life Care Planner (CLCP) standards and guidelines, an established framework for calculating costs of medical (and other) care in catastrophic illness or injury (International Commission on Healthcare Certification, 1996). The International Commission on Healthcare Certification established the first research-based, peer-reviewed practice and ethical guidelines for life care planning, this framework is widely utilized within the legal system as a basis for expert testimony on future medical and life care expenses.

A Virginia Medicaid case study served as the basis for analyzing medical care and UVA regional costs (for outpatient care), UVA hospital charges, insurance reimbursement and Medicaid reimbursement rates specific to the UVA Health System. CPT codes were utilized to maintain consistency in cost data across payment sources. Out of pocket expenses incurred by the family were not included in the cost figure to Virginia's Medicaid plan and include such items as architectural renovation, specialized seating and stroller systems, back-up whole house generator, video monitoring equipment, and back-up battery systems. In addition, costs due to lost wages related to home care for the infant are not included in Virginia's Medicaid costs.

Results

The UVA SBS case study cost analysis showed a total cost to Medicaid of $500,000 (acute and subsequent home-based care) for a period of 2 and ½ years following diagnosis, after which the infant expired. The overall cost to Virginia was estimated to be $250,000, based on Virginia's (approximate) 50% required contribution to the child's healthcare (Goldschmidt M. K., SBS Future Needs Assessment: A University of Virginia cost analysis, 2011).

A limitation of this cost analysis is the lack of additional case study reviews, (cost is highly dependent upon the severity of SBS sequelae and life expectancy). There is a significant lack of evidence-based literature detailing the cost of caring for SBS victims in the United States and no known prior cost analyses in Virginia.

Summary

In order to provide a SBS incidence count to the Joint Commission on Health Care, the data utilized for the count must reflect the actual incidence of SBS. The UVA CDR retrospective review suggests that current data may not provide sufficient accuracy for calculation of a reliable SBS incidence. Provision of a SBS cost of disease burden analysis for Virginia is not possible without accurate SBS data.

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A report for the Joint Commission on Health Care, May 2012

PREPARED BY:
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UNIVERSITY OF VIRGINIA SCHOOL OF NURSING

Incidence and Cost of Shaken Baby Syndrome in Virginia

Shaken baby syndrome (SBS), is the leading cause of child abuse fatality (Jenny, 1999). The first published US population based study on SBS concluded that 53% of all serious to fatal head trauma in children under the age of two, is inflicted traumatic brain injury (SBS), with an annual incidence rate of approximately 30 per 100,000 infants (Keenan, 2003).

In February 2010, the Virginia General Assembly directed the Joint Commission on Health Care to develop a report on the incidence, cost, prevention programs and grant funding for a SBS pilot prevention program (Goldschmidt M. K., Joint Commission on Health Care: Study of Shaken Baby Syndrome and Abusive Head Trauma (HJ 632/Delegate Oder), 2011).

The Virginia Department of Health (VDH) collects Virginia's SBS incidence data via Virginia Health Information (VHI) hospital discharge data, using ICD-9 code – 995.55. From 2004 - 2008, VDH reported 98 children under the age of four were coded as shaken baby syndrome. The Office of the Chief Medical Examiner (OCME) of Virginia reported 26 SBS deaths for a similar period of time (2004-2007) (Virginia Department of Health, 2010). More recently, VDH data for March 1, 2008 through December 21, 2009 (2010 data unavailable), showed an incidence of 23 SBS cases, with a death rate of 43.5%; 87% of Virginia's SBS cases were under the age of one.

Interestingly, the Virginia Department of Social Services Child Protective Services (CPS) Division reported more than twice the number reported by VDH (50 cases), with 16 deaths (32%) from 03/01/08 – 02/28/10 (Goldschmidt M. K., 2011). The true incidence may be higher than either figure; the *Fourth National Incidence Study of Child Abuse and Neglect* (NIS-4), estimated that only 30% of Harm Standard Physical Abuse – Serious Severity cases were investigated by Child Protective Services, subsequently, a closer approximation of Virginia's incidence for this two year period may be as many as 167 cases (Fourth National incidence Study of Child Abuse and Neglect, 2010).

The discrepancy between VDH and CPS data for Virginia's SBS incidence may be reflective of VDH's use of ICD-9 hospital discharge codes as an incidence calculation tool; ICD-9 code 995.55 is thought to be specific, but not sensitive (Wirtz, 2008). Cases that were not correctly coded or were non-hospitalized fatality cases were not included in VHI data sets. The use of SBS fatality data from Virginia's OCME may capture the "missed" non-hospitalized SBS case fatalities, but it may also "double-count" those SBS cases which were hospitalized prior to death. Lastly, VDH data relies on the valid and accurate use of hospitals' ICD-9 coding (Virginia Department of Health, 2010).

The Virginia Department of Medical Assistance Services (DMAS) reported a total of 92 children received SBS related (out- patient or long- term) medical care from 03/01/2008 – 02/28/2010; while this figure cannot be utilized as an incidence indicator (a portion of these cases were likely diagnosed prior to March 1, 2008), it may prove helpful in understanding the scope of Virginia's SBS incidence and costs (Goldschmidt M. K.,2011).

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Attachments

Joint Commission on Health Care

Study of Shaken Baby Syndrome and Abusive Head Trauma (HJ 632/Del. Oder)

October 17, 2011

Jaime Hoyle
Sr. Staff Attorney/Health Policy Analyst

HJR 632 Study Mandate

HJR 632 (Delegate Oder) directed JCHC :

- To study the costs of Shaken Baby Syndrome and abusive head trauma in Virginia and identify best practices in reducing the incidence;
- To "work with stakeholders to determine, to the degree practicable given existing data and information:
  - The number of cases of SBS or abusive head trauma among children in the Commonwealth;
  - The cost of cases of SBS or abusive head trauma…;
- Identify evidence-based practices that have been shown to reduce the rate of occurrence of SBS and abusive head trauma, including potential costs of those practices if implemented;
- Identify any potential source of grant funding or funding other than state general funds that may be used to pay the cost of implementing evidence-based practices as pilot programs for the prevention of SBS and abusive head trauma in child care delivery settings in the Commonwealth."

Working With Stakeholders

- Throughout the study, staff worked closely with:
  - Shaken Baby Syndrome of Virginia,
  - Virginia Department of Health
  - Virginia Office of the Chief Medical Examiner
  - Virginia Department of Medicaid Assistance Services
  - Mary Kay Goldschmidt, a University of Virginia graduate student and a Certified Life Planner
- A workgroup meeting was held to allow the group to discuss preliminary findings and potential policy options. The Workgroup included those listed above, as well as:
  - Virginia Department of Social Services
  - Virginia Health and Hospital Association
  - Virginia Association of Midwives
  - Virginia Nurses Association
  - Medical Society of Virginia
  - Emergency Physicians

What is Shaken Baby Syndrome (SBS)?

- Form of abusive head trauma (AHT), also called inflicted traumatic brain injury (ITBI)
- Preventable and severe form of physical child abuse.
- Results from violently shaking an infant by the shoulders, arms, or legs.
  - SBS may result from both shaking alone or from impact (with or without shaking). The resulting whiplash effect can cause bleeding within the brain or the eyes.
- Nearly all victims of SBS suffer serious health consequences and at least one of every four babies violently shaken dies from this form of child maltreatment.

Shaken Baby Syndrome

- SBS is a leading cause of child abuse deaths in the United States, and the most common cause of long-term disability and permanent damage in physically abused infants and children.
  - Recent studies in Cleveland and the University of Pittsburgh found that there have been twice as many SBS cases since the recession started.
- Babies (newborn to 4 months) are at greatest risk of injury from shaking.
  - Most ITBI occurs in the first 2 years of life.
- Inconsolable crying is a primary trigger for shaking a baby.
  - Peak crying times are part of normal infant development.
  - Persistent and inconsolable crying usually happens between two and 16 weeks.

Clinical Manifestations

- Can range from mild to severe
- Often vague and may mimic symptoms of an infectious process, a metabolic disorder, an unusual neurological disorder, or trauma
- Frequently no external sign of injury is apparent
- Although symptoms are likely present immediately after shaking, medical attention may be delayed for many reasons.
- Caretakers may place infant in crib with the hope that he recovers – as a result, the opportunity for early intervention may be lost.

Symptoms

- Irritability and crying (41%)
- Bruising /superficial injury (41%)
- Vomiting/ anorexia (38%)
- Apnea/ respiratory symptomology (38%)
- Muscular stiffness (34%)
- Seizures (21%)
- Cyanosis “bluish discoloration of skin or mucus membranes” (29%)
- Depressed consciousness state (21%)

Triad for SBS diagnosis

- While SBS can be difficult to diagnose, if these three symptoms are present without a bruise or a fracture, diagnosis of SBS is typically made:
  - Subdural Hemorrhage
  - Retinal bleeding
  - Encephalopathy (Cerebral Swelling)
- This Triad has started some controversy in the prosecution of SBS cases.
  - Argue other evidence is needed before prosecuting.
  - Suggest that absence of injury to neck or spinal trauma makes shaking as a cause questionable

Infant Risk Factors

- Cry frequently, are inconsolable, have difficult temperaments
- Product of a multiple pregnancy
- Premature and/or low birth weight
- Special needs
- Suffering from inherited substance abuse exposure
- Medically fragile
- Congenital defects or syndromes
- Bond poorly with caregivers

Small body size, but large head compared to body.

Weak muscles and underdeveloped and elastic neck ligaments.

Lack of head control, high brain water content, and large space between the brain and the tissues that surround the brain.

9

Joint Commission on Health Care

Caregiver Risk Factors

- Male (64% of perpetrators –usually father or father-figure)
- Young parental age
- Low educational level
- Impulsive behavior
- Unstable family environment
- Low socioeconomic status
- Single parenthood
- Need for nurturing
- Unrealistic child-rearing expectations
- Rigid attitudes and impulsivity
- Feelings of inadequacy, isolation or depression
- Negative childhood experiences including neglect or abuse
- Parents or caretakers who have been involved with substance abuse
- Domestic violence

10

Joint Commission on Health Care

Prognosis of Victims

- Range from no adverse effects to death.
- The majority will have significant neurological or intellectual disability and will require lifelong medical care.
- A 2008 report on AHT in infants and young children and published in *Pediatric Clinics of North America* indicated that:
  - 61% had severe disabilities, and an additional 35% had moderate disabilities
    - 64% had speech and language difficulties
    - 25% had cranial nerve abnormalities, and/or
    - 20% had visual deficits and epilepsy

Potential SBS Consequences

- Blindness and/or hearing loss
- Cerebral Palsy
- Emotional Problems
  - Explosive anger
  - Self injurious behavior
  - Depression
  - Attachment disorder
- Gastrointestinal and/or respiratory problems
- Brain-related issues, such as, fluid on the brain or an unusually small head
- Seizures
- Paralysis
- Persistent Vegetative State
- Death

Potential Educational Issues

- Learning disabilities and speech problems
  - Visual, language, reading, attention, computational (math)
- Intellectual Disability
  - May not have the ability to learn as do other children
  - IQ below 70, and "below average intelligence"
- Attention problems with or without hyperactivity

Early health risk factors for violence

- Studies have shown that a number of victims of less severe shaking develop serious behavioral problems and may be placed in the foster care or juvenile justice systems.
- Children who were abused (including those who suffered abusive head trauma) were:
  - 5 times more likely to be arrested for juvenile delinquency
    - Caucasian youth, with a history of child abuse, 20 times more likely to commit a violent crime
  - Twice as likely to be arrested for criminal behavior as an adult

Costs of Medical and Therapeutic Care

- In the United States, medical costs for SBS victims can be $300,000 to $1,000,000 per child.
  - The average cost of an emergency room visit related to SBS can be as high as $30,000.
  - For survivors of SBS with severe long-term consequences (paralysis, seizure disorders, learning/vision/hearing deficits), the cost for physical and educational therapy as well as custodial care, can be as much as $3,000,000 during the first 5 years of a child's life.
  - Additional costs include loss of future productivity and wages, as well as the legal costs of prosecuting and incarcerating jailing perpetrators.

Shaken Baby Syndrome/Abusive Head Trauma in Virginia: Cost Analysis for UVA Health Systems

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Virginia Department of Health (VDH) statewide Incidence data* for 03/01/2008 to 12/21/2009 (2010 data not available):

- 23 Cases of Abusive Head Trauma:
  - 20 (87%) infants under the age of 1
  - 3 (13%) children - I year of age
  - 10 (43.5 %) children expired
  - 16 (70%) children - Medicaid recipients

Survivor Disposition:

- 1 (4.35%) child at home under the care of home health services
- 11 (47.8%) children at home (family, custodial, foster care)
- 1 (4.35%) child is "missing"

*Based on ICD 9 code 995.55 "Shaken Infant Syndrome".
Stephanie Goodman, MPH, Injury Data and Evaluation Coordinator, Office of Family Health Services

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VA Child Protective Services (CPS) data for Approximately the same period of time: 03/01/2008 – 02/28/2010*

- 50 cases statewide
- 11 deaths (22%)
- 14 currently in foster care (28%)

*Rebecca Toni Hjelm, Acting Program Manager
Outcome Based Reporting and Analysis, VA Department of Social Services

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DMAS statewide claim data 03/01/08 – 02/28/10:

- 92 children (of note: this number reflects new and existing cases currently utilizing Medicaid for SBS related medical care; this number does not reflect privately insured SBS cases).
- This data reflects the likelihood of a higher statewide incidence than Virginia's published data currently reflect .

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VDH ICD 9 code 995.55 data for University of Virginia Health Services, 03/01/2008 to 12/21/2009:

2 Cases of Abusive Head Trauma

U VA's Clinical Data Repository (CDR)

ICD 9 code 995.55 (SBS) data, 03/01/2008 to 12/21/2009:

4 cases of Abusive Head Trauma

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UVA Health System's incidence using a broadened SBS definition (Wirtz,2008),(Keenan et al,2003) 03/01/08 – 02/28/10 :

20 Cases of abusive head trauma*

*Utilizing a pattern of ICD9 codes considered reflective of SBS diagnoses.

"Passive Surveillance of Shaken Baby Syndrome Using Hospital Inpatient Data". American Journal of Preventive Medicine, 2008;34(4S)

"A Population-Based Study of Inflicted Traumatic Brain Injury in Young Children". JAMA. 2003;290(5)

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What creates the disparity with SBS Incidence data?

Incidence calculation varies between agencies as well as individual institutions.

No universally accepted method or terminology used in calculating incidence of SBS .

Subsequently,
statistical data may not accurately represent true incidence.

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Virginia Case Study: The cost of caring for one SBS survivor at home:

- 22 diagnoses including quadriplegic cerebral palsy, developmental delay and mental retardation, visual impairment
- 3 major surgeries, including neurosurgery, tracheostomy and gastrostomy feeding tube placement
- Survived 2 ½ years following diagnosis
- Virginia's Medicaid cost/year: $95,448.43
- Total lifetime Virginia Medicaid cost for out patient medical care:

$238,621.00

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Virginia's Medicaid costs for intermediate/long term Care (institutional costs) central Virginia:

$139,612.50/year/child -plus the cost of medications, outside physician consults, certain durable medical equipment and re-hospitalizations.

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Total Virginia Medicaid cost for UVA Health Systems AHT cases:

- Acute care:
  $11,227.30/average reimbursement per case
- Out patient care:
  $95,448.43/year – 139,612.50/year per case (serious AHT)
- 61% of cases will have severe disabilities (Frazier, 2008)
- Incidence range: 2 – 10 cases/year
- Number of cases estimated to have severe long term sequelae/ medical needs: 1-6/year

  Total outpatient cost per year: $95,448.43 - $837,675.00

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Total cost to Virginia for one severe AHT case treated at UVA Health Systems:

Approximately $249,848.30*

- *Includes acute and outpatient care.

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Additional costs to Virginia (Wang, 2007):

Direct:
- Child Services Welfare System
- Foster Care
- Mental Health Care System
- Law Enforcement

Indirect:
- Special Education
- Juvenile Delinquency
- Adult Criminal Justice System
- Lost Productivity to Society

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Costs and Prevention

- Our study findings support the research of others that SBS is under-reported and the costs associated with the trauma are under-estimated.
  - In addition to the emotional devastation that families experience, the costs to the Commonwealth of caring for survivors of SBS are substantial and under-reported.
  - As demonstrated by Ms. Goldschmidt's research, the actual cost to the Commonwealth of assisting one SBS survivor for 2.5 years was almost $240,000.
- In recognition of the serious and completely preventable nature of SBS, a number of prevention programs have been established; typically these programs are designed to reach new parents and caregivers.

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Prevention Targeted to Parents and Caregivers

- A number of prevention strategies have been undertaken in various states. These strategies include:
  - Prenatal and postnatal programs in hospitals and physician's offices
  - Home visitation
  - Stress management education
  - Educational programs on:
    - Child development for parents and caregivers
    - Triggers of infant shaking and strategies for dealing with frustration and exhaustion
    - Stress management
- The best-known hospital-based programs are the Period of PURPLE Crying and the Dias Model.
  - A number of states have implemented programs using videos that feature families and medical professionals from their states.

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PURPLE Crying Program Supported by the National Center on Shaken Baby Syndrome

- Prevention program that includes an 11-page booklet and 10-minute DVD for parents of new infants.
  - Teaches that crying is a normal state in infant development, not a rejection of the caregiver.
  - Emphasizes leaving infant in a safe situation when the crying becomes intolerable for the caregiver.
  - States to never shake a baby.

Peaks at around two months of age
Unpredictable, often happening for no apparent reason
Resistant to soothing
Pain-like expression on the baby's face, even without any source of pain
Long bouts, lasting two to four hours
Evening crying

- The PURPLE materials describe SBS and emphasize also telling caregivers other than the parents about the "period of PURPLE crying," the frustration of caring for a crying child, the dangers of shaking, and the recommended responses.

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PURPLE Crying

- PURPLE is evidence-based and has been shown to lead to higher scores in knowledge about early infant crying and the dangers of shaking, as well as an increased sharing of information and behaviors considered to be important for the prevention of shaking.
  - The National Center on Shaken Baby Syndrome conducted research testing on PURPLE. The research has been published in 2 peer-reviewed journals.
- Programs have been implemented in 800 hospitals and organizations in 49 states. (Tidewater and DC)
  - NC, UT, ME, KS, IA have implemented PURPLE statewide; OK, WA, WV, MT, NH, OR, CT have implemented PURPLE in 80% of the state.
- PURPLE is available in 10 languages and includes closed captioning; presented at a 3rd grade language level and is representative of multicultural and ethnic backgrounds.
- With large quantity orders, it can be available for as low as $2 per package.

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NC Has implemented PURPLE Statewide

- North Carolina has developed a statewide, 3-dose approach that targets all families of newborns with funding provided by the Centers for Disease Control (CDC) and the Doris Duke Foundation.
  - 1st all new parents receive their own DVD and booklet with information about the Period of PURPLE Crying while in the hospital or birthing center.
    - The key messages are reinforced by brief bedside education from a nurse and parents are asked to share the information with other caregivers.
  - 2nd parents receive materials at the first pediatric visit that reinforce the message of the program
  - 3rd a sustained media effort that targets the community at large.
    - With PURPLE, the public awareness portion is included at no additional cost.

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DIAS Model Was Developed in Western New York

- Developed at the Children's Hospital of Buffalo, NY
- Hospital-based program that presents education to new parents about the dangers of SBS through:
  - Use of Portrait of Promise, an 11-minute video
    - Video is shown in the hospital post-delivery
  - SBS educational brochure
  - 5-10 minute discussion with a nurse on staff
  - Participating parents are asked to sign an acknowledgement/evaluation form (commitment statement)

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Upstate New York SBS Education Program

- Participating parents are asked to voluntarily sign a commitment statement that affirms their receipt and understanding of the materials they received
  - These commitment statements are returned by participating hospitals and are tracked to determine the effectiveness of the program
  - Has served as the model of SBS prevention and sparked creation of other programs worldwide.
  - Dr. Dias estimated that the project would cost $10 per birth

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Dias Model Findings

- Evaluation continues but interim results indicate that it has significantly reduced SBS injuries in western NY.
- Parents remember the information
- Parents recommend the video; brochures are insufficient
- Parents use the information
- Most parents only get information in the hospital
- The program was expanded to 17 counties with grant assistance from a trust fund.
- The 2-year evaluation reported a 60% reduction in SBS cases in the area.
- Hospitals still using model, but tweak it to fit their needs
- Now this program is being implemented in: AZ, CT, PA, MA, MI, NY
  - The CDC is funding this statewide initiative in PA.

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Shaken Baby Syndrome of Virginia

- Founded by Steve and Kathy Stowe, whose grandchild, Jared lived for 3 years before dying from SBS.
  - Impetus behind this study resolution and "Jared's Law" the 2010 Virginia statute related to SBS.
- The Stowes speak at conferences, hospitals, and universities to raise awareness about SBS and how it can be prevented.
- They advocate that Virginia implement a program that includes using:
  - The Dias "Portrait of Promise" DVD
    - The Stowes would like to produce and then use a video that features Virginia families and physicians
  - A letter of promise and plan of action for parents/caregivers (that are based on the Dias Model but modified for Virginia)
  - Follow-up calls to determine effectiveness
  - Estimated cost of $3.50/per child

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Current Statutory Requirements: Hospital and Caregiver-Based

- Required hospitals to offer education for new parents: CA, HI, IO, MA, MO, MT, NE, NJ, NY, OH, TN, TX, **VA**, WA, WI
  - Specifically request parents view video approved by state department of health: MO, NE, NY, WA, WI
  - Including information on home visitation programs: NJ
  - Implemented hospital-based program as part of a larger, comprehensive, statewide prevention initiative that is in statute: IO, MA, MT.
- SBS-related training for child care providers and for educators:
  - FL, NY, TN, TX, WI (specifies a video be shown)
  - MN requires the SBS training be documented.

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Prevention through Public Awareness

- While parent-oriented educational approaches can be effective, additional outreach is needed to reach informal caregivers.
- Potential approaches, some of which have been implemented in other states and others discussed in our workgroup meeting, include:
  - Public service announcements, brochures, transit stop posters, rest room advertisements and other creative approaches targeting the general public.
  - Parenting classes for high school students, teen parents, inmates, and other community organizations (such as Big Brothers/Big Sisters, Red Cross babysitting classes).

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Prevention through Public Awareness

- Public Awareness Campaigns
  - Distribution of Materials: CA, IA, IN, NE, NY, RI, TN, VA, WA
  - SBS Awareness Week as part of Child Abuse Prevention Month: IL, NV
  - School Curriculum: NY, WI
  - Correctional facility education: NY
  - National Shaken Baby Awareness Week – efforts by Congress for designation during the third week in April

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Virginia Laws Related to SBS Target Parents and Caregivers

- In 2005, the Virginia General Assembly enacted SB 1296 (Sen. Wampler) which required hospitals and midwives providing maternity care to make available to patients, family members and other caregivers, "information" to increase awareness of shaken baby syndrome and the dangers of shaking infants.
  - "This information shall be discussed with the maternity patient and the father of the infant, other relevant family members, or caretakers who are present at discharge."

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Virginia Laws Regarding SBS

- In 2010, the Virginia General Assembly enacted HB 411 (Del. Oder) which is referred to as Jared's Law.
  - The Department of Social Services is required to make information about shaken baby syndrome, its effects, and resources for help and support…in a printable format, and …in an audiovisual format, available to the public on its website….
- Upon request, information is to be provided to licensed child welfare programs, "foster and adoptive parents and other persons."

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Policy Options

- **Option 1**: Take no action.
- **Option 2**: Introduce budget amendments (language and funding) to allow the Virginia Department of Health to undertake or contract for a hospital-based prevention program to include training maternity staff to talk with parents of newborn babies, and provide those parents with a video on the dangers of shaking infants.
  - A. Statewide program (cost to be determined but not expected to exceed $300,000 per year)
  - B. Demonstration projects

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Policy Options

- **Option 3**: Introduce budget amendments (language and funding) to allow the Virginia Department of Health to undertake or contract for a pediatric office-based prevention program to provide staff training and video presentations on the dangers of shaking infants.
  - A. Statewide program (cost to be determined but not expected to exceed $300,000 per year)
  - B. Demonstration projects

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Policy Options

- **Option 4:** Request by letter of the chairman that such State agencies as the Departments of Health, Social Services, Behavioral Health and Developmental Services, Rehabilitative Services, and Education collaborate with other public and private agencies to develop a more comprehensive SBS prevention initiative. The initiative, which would be reported to the chairmen of the Joint Commission and the Virginia Disability Commission, should include:
  - A collection of prevention and training programs designed for use in hospitals, pediatricians' offices, child day care and foster-care training, middle school classes, and juvenile and adult court and correctional settings.
  - Public service announcements and advertisements.
  - Supportive programs for victims of Shaken Baby Syndrome and their families.
  - Creation of a surveillance and data collection program to measure the incidence of SBS and traumatic brain injury in infants and children in the Commonwealth of Virginia.

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Policy Options

- **Option 5**: Introduce a joint resolution to establish the third week of April as Shaken Baby Awareness Week in memory of Jared and the many other victims of Shaken Baby Syndrome in Virginia.
- **Option 6**: Include in the 2012 work plan for the Behavioral Health Care Subcommittee, continuation of the study for a second year to consider definitional and medical coding issues.

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Public Comments

- Written public comments on the proposed options may be submitted to JCHC by close of business on November 7, 2011.
- Comments may be submitted via:
  - E-mail: jhoyle@jchc.virginia.gov
  - Fax: 804-786-5538
  - Mail: Joint Commission on Health Care
    P.O. Box 1322
    Richmond, Virginia 23218
- The comments will be summarized and included in the Decision Matrix which will be discussed during the November 22nd JCHC meeting.

JCHC website - http://jchc.virginia.gov

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ENROLLED

HOUSE JOINT RESOLUTION NO. 632

Directing the Joint Commission on Health Care to study the costs of Shaken Baby Syndrome and abusive head trauma in Virginia and identify best practices in reducing the incidence of Shaken Baby Syndrome and abusive head trauma. Report.

Agreed to by the House of Delegates, January 27, 2011
Agreed to by the Senate, February 22, 2011

WHEREAS, Shaken Baby Syndrome or abusive head trauma is a form of inflicted head trauma occurring when a child is vigorously shaken; and

WHEREAS, Shaken Baby Syndrome or abusive head trauma is the leading cause of death in child abuse cases in the United States; and

WHEREAS, the vast majority of victims of Shaken Baby Syndrome or abusive head trauma are infants younger than one year old; and

WHEREAS, the perpetrators in these cases of Shaken Baby Syndrome or abusive head trauma are most often parents or caregivers, most frequently male parents or caregivers; and

WHEREAS, children of families who live at or below the poverty level are at an increased risk for these injuries as well as any type of child abuse; and

WHEREAS, children who have suffered injuries associated with Shaken Baby Syndrome or abusive head trauma may require extremely expensive long-term health care and other services; and

WHEREAS, awareness, education, and training for parents and caregivers can reduce the risk that a child will be shaken and that a child will suffer injuries associated with Shaken Baby Syndrome or abusive head trauma; now, therefore, be it

RESOLVED by the House of Delegates, the Senate concurring, That the Joint Commission on Health Care be directed to study the costs of Shaken Baby Syndrome and abusive head trauma in Virginia and identify best practices in reducing the incidence of Shaken Baby Syndrome and abusive head trauma.

In conducting its study, the Joint Commission on Health Care shall work cooperatively with the Department of Health, the Department of Social Services, the Governor's Advisory Board on Child Abuse and Neglect, the Medical Society of Virginia, the Virginia Association of Children's Homes, the Virginia Association for Early Childhood Education, the National Association to PROTECT Children, Prevent Child Abuse Virginia, the American Academy of Pediatrics, the American College of Nurse-Midwives, the Commonwealth Midwives Alliance, the Virginia Hospital and Healthcare Association, and other stakeholders to (i) determine, to the degree practicable given existing data and information, the number of cases of Shaken Baby Syndrome or abusive head trauma among children in the Commonwealth; (ii) determine, to the degree practicable given existing data and information, the cost of cases of Shaken Baby Syndrome or abusive head trauma, including but not limited to costs directly attributable to initial and inpatient medical treatment for Shaken Baby Syndrome or abusive head trauma, and follow-up health care and social services over a period of 12 months immediately following initiation of medical treatment; (iii) identify evidence-based practices that have been shown to reduce the rate of occurrence of Shaken Baby Syndrome and abusive head trauma, including potential costs of those practices if implemented; and (iv) identify any potential source of grant funding or funding other than state general funds that may be used to pay the cost of implementing evidence-based practices as pilot programs for the prevention of Shaken Baby Syndrome and abusive head trauma in child care delivery settings in the Commonwealth.

All agencies of the Commonwealth shall provide assistance to the Joint Commission on Health Care for this study, upon request.

The Joint Commission on Health Care shall complete its meetings by November 30, 2011, and the chairman shall submit to the Division of Legislative Automated Systems an executive summary of its findings and recommendations no later than the first day of the 2012 Regular Session of the General Assembly. The executive summary shall state whether the Joint Commission on Health Care intends to submit to the General Assembly and the Governor a report of its findings and recommendations for publication as a House or Senate document. The executive summary and report shall be submitted as provided in the procedures of the Division of Legislative Automated Systems for the processing of legislative documents and reports and shall be posted on the General Assembly's website.

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