

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.



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



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.



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

Mary Kay Goldschmidt, RN, BSN, CCM, CLCP
University of Virginia School of Nursing
Graduate Student, Public Health Nursing Leadership

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Virginia Department of Health (VDH) statewide Incidence data* for 03/01/2008 to 12/31/2009 (2010 data not available):

- 23 Cases of Abusive Head Trauma:
 - 20 (87%) infants under the age of 1
 - 3 (13%) children - 1 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

UVA'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.
- ❖ 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.

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



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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@jhc.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://jhc.virginia.gov>

