Shaken Baby Syndrome

Purpose of this Report:

House Joint Resolution 632 of the 2011 Session of the General Assembly directed the Joint Commission on Health Care (JCHC) to study the costs of Shaken Baby Syndrome (SBS) and abusive head trauma (AHT) in Virginia and to identify best practices in reducing their incidence. As a result of their study, the JCHC identified several policy options, one of which requested that the Virginia Department of Health (VDH), collaborating with the Virginia Departments of Aging and Rehabilitative Services, Behavioral Health and Developmental Services, Education, and Social Services and other public and private sector stakeholders further the work of the JCHC related to the 2011 House Joint Resolution 632 in addressing SBS and AHT as a cause of infant mortality. The request includes identifying best practices, statewide programs, surveillance data, and initiatives and interventions dedicated to addressing SBS as a cause of infant mortality. This document, which pulls information from the JCHC study on SBS as well as additional resources, provides an overview of background information on SBS and AHT. It also provides a summary of feedback and recommendations from community leaders regarding ways of addressing SBS as a cause of infant mortality.

An introduction to Shaken Baby Syndrome:

Shaken Baby Syndrome (SBS) is a form of AHT, also called inflicted traumatic brain injury, and refers to "the constellation of signs and symptoms resulting from violent shaking or shaking and impact of the head of an infant or small child".[1] Inconsolable crying – a normal part of infant development – is a primary trigger for shaking a baby; babies (newborn to 4 months) are at great risk of injury from shaking and most AHT occurs in the first two years of life. 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. SBS is a leading cause of child abuse in the U.S. and the most common cause of long-term disability and permanent damage in physically abused infants and children.

Dr. Catherine Adamsbaum, Professor in Radiology at Paris Descartes University, presented her published research on confessions by perpetrators at the 12th International Conference on Shaken Baby Syndrome/Abusive Head Trauma, October 2012. [2] Her research identified that in the majority of SBS cases (55%), the shaking is repeated, sometimes on a daily basis, over weeks or months from 2 to 30 times. Moreover, the perpetrators stated that the reason behind the repeated shaking is that the shaking "works" on the baby, who stops crying. The medical explanation for the "silence" that follows violent shaking is most likely a transient loss of consciousness. This violent and often repetitive shaking may explain the hypoxic-ischemic injuries and provides new insights into the mechanism of injury. The high frequency of habitual AHT helps to explain the

difficulty in dating the injuries. Shaking may have begun during the first six months or weeks of life and continued growing in strength until the injury was so great that it could not be ignored. As stated by Dr. Ronald G. Barr, from the University of British Columbia, who found similar findings in his research; "The shaking episode that brings the child to the emergency room may only be the last in a series of shaking episodes that began days to weeks earlier."[3]

Recognized SBS perpetrator risk factors include: male (64% of perpetrators), young parental age, low educational level, low socioeconomic status, unstable family environment, single parenthood, impulsive behavior, need for nurturing, unrealistic child-rearing expectations, feelings of inadequacy or depression, substance abuse, and domestic violence.

Data surveillance – monitoring incidence and cost:

As outlined in the JCHC report[4] (see below), current statewide data available from the Virginia Departments of Health, Social Services, and Medical Assistance Services may not provide sufficient accuracy for calculation of a reliable SBS incidence. Therefore the provision of a SBS cost of disease burden for Virginia is not possible.

From the JCHC report:

> 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 SBS. 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.
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> 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).
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> 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).
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> 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).

The JCHC report goes on to discuss a case study of SBS treated at UVA. This case resulted in an estimated total cost to Medicaid of $500,000 (acute and subsequent home-based care) over a period of two and a half years following diagnosis, with the overall cost to Virginia estimated at $250,000 (based on the state's approximate 50% required contribution). This data is based upon analysis of a single case and thus cannot be used to estimate the average costs per case, or the total costs of treatment for SBS.

A primary method of monitoring SBS incidence is to analyze hospital discharge data using the CDC ICD-9 codes for AHT. As noted above, this has limitations of being specific, but not sensitive, thus potentially underestimating the true incidence of SBS. A more intensive and timely method, which is being used in a study conducted through the University of North Carolina (UNC), is surveillance through phone calls to each of the 12 pediatric ICUs in the state each week for admissions related to TBI and assessment as to whether the cases are intentional or not.[5]

In North Carolina, an estimate of the cost of SBS was conducted examining UNC data for every case of SBS for a period of 8 years and examining medical bills over time. It was determined that acute medical costs averaged $99,977 per child. This is almost twice the cost compared to $49,900 per child in cases of unintentional TBI; 70% of these costs were paid by Medicaid. Dr. Desmond Runyan and others in North Carolina are investigating whether Medicaid and Blue Cross, the main insurers in the state, would subsidize the cost of SBS prevention programs and materials because of the potential for savings in these acute medical costs.[6]

Current best practices and model interventions:

All SBS-related interventions and prevention programs that have been evaluated and found to be effective involve parent education at the time of birth, using video and printed materials, as well as a conversation with a nurse, about preventing SBS.

Three critical components of all SBS education include informing parents that inconsolable crying is a normal part of development for a baby; making parents aware of signs of frustration in themselves and other caretakers and teaching parents strategies to de-escalate those feelings.

Period of PURPLE Crying

Period of Purple Crying was developed by Dr. Ronald Barr and colleagues at the National Center on Shaken Baby Syndrome (NCSBS). Two randomized controlled trials of the program showed increases in knowledge about the developmental role of crying and appropriate "walk away behavior when the mother was frustrated." The program is now working with the NCBS to institutionalize the program at a cost of $2.50/infant. A new version of the Period of PURPLE Crying video that has been revised to be consistent with current safe sleep recommendations from the American Academy of Pediatrics was released November 2012.[7]

The Letters in PURPLE Stand for

P	U	R	P	L	E
PEAK OF CRYING	UNEXPECTED	RESISTS SOOTHING	PAIN-LIKE FACE	LONG LASTING	EVENING
Your baby may cry more each week. The most at 2 months, then less at 3-5 months	Crying can come and go and you don't know why	Your baby may not stop crying no matter what you try	A crying baby may look like they are in pain, even when they are not	Crying can last as much as 5 hours a day, or more	Your baby may cry more in the late afternoon and evening

As part of CDC-funded research, Dr. Desmond K. Runyan of The Kempe Children's Centre in Colorado is testing the Period of Purple Crying in North Carolina. The state-wide program educates parents about normal infant crying patterns, how to respond to crying, and the dangers of shaking. New parents receive education in three venues:

- Statewide media campaign to disperse program messages
- Program messages disseminated at prenatal classes and/or at 2 week well baby checks.

- Prior to discharge the following are provided to parents:
    - Period of PURPLE Crying video: focus is on crying is normal,
    - Period of PURPLE booklet,
    - discussion with a nurse, and
    - materials available in ten languages and presented at a grade 3 language level.

Using these venues, Dr. Runyan has found that the Period of PURPLE messaging is being received by 84% of new parents of babies in North Carolina. This has been determined through the use of hospital surveys and a random digit dial survey. Results from this study were further discussed at the12th International Conference on Shaken Baby Syndrome/Abusive Head Trauma, October 2012.[8,9] Parent recall of this information approximately nine months later identified that 93% reported hearing the information at the hospital; 84% remembered getting a copy of the materials; 34% watched the DVD; 63% read the booklet; and 25% showed the DVD to others. Reported use and sharing of the materials was found to be more common among women of lower educational levels and of Hispanic ethnicity. When analyzing call data from a nurse advice hotline there was a 17% reduction in calls about crying children under one year of age and a 21% reduction in calls about crying children under 3 months of age. Results related to message dissemination at sick and well baby visits in the first month of life were determined to be not as universal as hospital-based education, but is a reasonable strategy for reinforcement.

However, a survey examining the incidence rate in North Carolina over the last 21 months indicates that the rate remains unchanged. Whether this indicates a lack of impact is unclear. It is still possible that the program has impacted the incidence given the recent research indicating that SBS cases rose nationally during the recent economic recession.

The DIAS Model (also known as the New York Shaken Baby Prevention Program)

The DIAS Model is a comprehensive hospital-based program centered on parent education at the time of birth. The program was developed by Dr. Mark Dias, a Pediatric Neurosurgeon. The program administration costs are estimated to be $10/infant, though these figures include research costs.

SBS education is presented to new parents through the following avenues:

- Viewing of a video “Portrait of Promise: Preventing Shaken Baby Syndrome”: focus is on the danger and consequences of shaking,
- Review of a brochure,
- 5-10 minute conversation with a nurse,
- Signing of a commitment statement, and
- Materials available in English, Hmong, Somali and Spanish languages.

Five year implementation of the program (1998-2003) in Upstate New York evidenced a 47% decline in SBS/AHT incidence, with another 10% incident decrease with the addition of education provided by pediatricians at first check-up.[10]

The DIAS model has been implemented in Arizona, Connecticut, Pennsylvania, Massachusetts, Michigan, and New York. Philadelphia is attempting implementation with additional non-repetitive reminder education at 2, 4, and 6 month immunization visits. Recent evaluation data released at the 12th International Conference on Shaken Baby Syndrome/Abusive Head Trauma, October 2012 indicate that the preliminary results of implementation in Philadelphia have not been nearly as promising as results in New York[11].

The Connecticut Children's Trust Fund reported results of a comparison study of the only two evidence-based SBS parent education videos currently available: The Portrait of Promise and The Period of PURPLE Crying in a home visiting setting. The videos were evaluated for effectiveness across four dependent variables: crying knowledge, SBS knowledge, behavioral responses to infant crying, and sharing information with other caregivers. The Period of PURPLE Crying video was found to be provide statistical significant improvements in crying knowledge, behavioral responses to infant crying and sharing information with other caregivers compared to no significant improvements resulting from The Portrait of Promise video. Both groups reported high baseline knowledge of SBS.[12]

SBS Efforts in Virginia

While there are a number of SBS related resources in Virginia, there are no apparent statewide efforts to implement evidence based programs such as Period of PURPLE Crying or the Dias model. The following is a preliminary list of identified efforts in Virginia:

- Requirements and Legislation
  - HJR 632 (2011) directed the Joint Commission on Health Care "to study the cost of SBS and AHT in Virginia and identify best practices in reducing the incidence" of this type of intentional injury to children.
  - HB 411 (2010), referred to as Jared's Law, requires the Department of Social Services to make information about SBS available in a printable and audiovisual format on its website.
  - SB 1296 (2005) required hospitals and midwives providing maternity care to make available to patients, family members and other caregivers, "information" to increase awareness of SBS.
- Period of Purple Crying materials are currently used by:
  - Army Community Services-Fort Belvoir
  - Family Advocacy Program-Fort Lee
  - Fleet and Family Support Center-Virginia Beach, VA
  - Langley Air Force Base

  - Naval Health Clinic-Quantico
  - Healthy Families Partnership-Hampton, VA
  - Children's Advocacy Center of Bristol/Washington Co, Inc.-Bristol, VA
- Shaken Baby Syndrome of Virginia
  - A nonprofit organization that promotes awareness through presentation at conferences, hospitals and universities and leads SBS advocacy efforts. SBS of Virginia advocates that Virginia implement a SBS prevention program that would include the creation of a Virginia-specific version of The Dias "Portrait of Promise" DVD; a letter of promise and plan of action for parents/caregivers, and follow up calls to determine effectiveness. This proposal is estimated to cost $3.50/child.
- Department of Social Services
  - SBS prevention information is available on the public DSS website http://www.dss.virginia.gov/family/cps/shaken_baby.cgi. Most of the materials are only available online, although a small quantity of flyers is mailed out annually to stakeholders during Child Abuse Prevention Month in April and annual workshops conducted on SBS/AHT conducted during the Child Abuse Conference in April.
- Virginia Department of Health
  - Some local health districts support various community-based home visitation programs. Comprehensive Health Investment Project (CHIP) of Virginia and Healthy Families are two such programs. Both employ Parents as Teachers training that includes a focus on SBS. Healthy Families Virginia also uses the San Angelo curriculum which addresses SBS education. BabyCare does not utilize a standard curriculum.
  - VDH provides state level support for Healthy Start/Loving Steps and Resource Mothers. Both of these programs teach parenting skills, e.g. coping with the needs of an infant and caregiver frustrations. The strategies used are derived from Florida State University's Partners for a Healthy Baby program, which is a research-based, practice-informed curriculum, used in evidence-based programs that have achieved positive parenting outcomes including reduced rates of physical abuse and neglect and improved child development.
  - There are 10 home visiting sites that are coordinated by VDH through the Home Visiting Consortium. These programs use online education modules to promote healthy child development, enhance safe physical and emotional home environments, enhance coping skills of distressed parents and report child abuse and neglect. A SBS on-line module is currently being added.

Promising Approach:

During the 12th International Conference on Shaken Baby Syndrome/Abusive Head Trauma, research was presented on SBS in the context of overall infant mortality and health. In this framework, the importance of integrating SBS prevention into education and efforts that address these issues more broadly was stressed as a promising approach. Additionally, CDC has developed a Guide on Preventing SBS that highlights steps to take in integrating specific SBS related education messages into existing programs for new parents, caregivers, professionals and the general public.

Input from Community Leaders

A community opinion leaders meeting for those who have a vested interest in reducing infant mortality across the Commonwealth was held on November 16, 2012. This was one of several meetings that VDH has held to engage key stakeholders, community partners and grassroots organizations to develop a strategic plan to address the issue of infant mortality. SBS, as one cause of infant mortality, was one of the areas addressed at this meeting. Specifically, participants were asked for their input as to the current best practices within Virginia and recommendations on how best to address SBS to reduce morbidity and mortality of infants in the Commonwealth.

There was consensus that while many of the current efforts are worthwhile, they are not sufficient and do not address all of the potential caregivers at risk for inflicting harm on an infant. For example, while much of the education and intervention related to SBS targets the primary care giver (often the mother) during discharge from the hospital, many incidents of SBS are inflicted by male caregivers who may or may not be the parent of the child, and may not have been present when the infant was discharged from the hospital. Recommendations from the meeting centered on three general areas; 1) integrating shaken baby information into existing parenting programs and making it an agency policy that all healthcare personnel receive SBS information in any existing mandatory training; 2) expanding the reach of interventions to a more generalized population (outside the health arena) and to specifically target men; and 3) expanding messages about SBS and the use of nontraditional partners within specific communities to disseminate the information (e.g., human services, community-based programs and local businesses). Some of the specific recommendations in each of these areas is outlined below.

Integrating Shaken Baby Information into Existing Programs (examples listed below)

- Baby Basics
- WIC Partnership
- Daddy Boot Camp
- Centering Pregnancy

- Text4Baby messaging
- Plan First
- Family Life Education
- Make SBS information part of mandatory curriculum for child care certification
- Incorporate into mandatory teacher re-certification requirements
- Assure that 911, 211, and poison control personnel are trained in SBS

Expanding Reach to New Populations

- Increase efforts to target education, information, and intervention toward men
  - Possible venues could include sports events, barbershops, YMCA, boys & girls clubs, local or regional jails, substance abuse programs.
  - Associate or link with National Football League (NFL) messages regarding traumatic brain injury, such as "don't concuss babies"
  - Look for opportunities to tie in with Father's Day messaging
  - Identify ways to have men carry the message regarding SBS
- Develop/market hotline for stressed parents (similar to suicide hotline)
  - Refrigerator magnets with hotline information

Expanding Messaging/Use of Non-traditional Partners

- Explore ways to partner with the Department of Motor Vehicles as a way to get messages to a broad audience (similar to organ donation program)
- Identify corporate sponsors, such as Wal-Mart or Toys-R-Us
- Include messaging for SBS on diaper boxes
- Specific messages to include:
  - It's ok/normal to let your baby cry
  - Never shake a baby
  - It's not spoiling a baby to pick them up when they cry
- Model messaging after other successful social marketing campaigns, such as Back to Sleep for SIDS

Incorporation into Infant Mortality Strategic Plan

The overall infant mortality rate in Virginia has declined during the past several years decreasing by 13.0% between 2007 and 2011. While an improvement, the Virginia 2011 infant mortality rate, 6.7 infant deaths per 1,000 live births remains above the national 2011 average of 6.06 per 1,000 live births. Also concerning is the significant infant mortality disparity between minorities and underserved communities compared to whites. In Virginia in 2011, the infant mortality rate for Hispanics (5.7 per 1,000 births) was higher than for whites (4.5 per 1,000 births) and the rate of infant mortality for African Americans (13.0 per 1,000 births) remains three times that of whites.

VDH is committed to continuing efforts to reduce infant mortality particularly eliminating racial disparities. Infant mortality is a multi-dimensional problem with several contributing factors such as ethnicity, race, age, income, access to health care, availability of support systems including father involvement, and level of education that can interact and impact pregnancy outcome in a multitude of ways. In order to be successful in the goal to reduce infant mortality, it is crucial that VDH develop partnerships with governmental agencies, other private entities, and community-based organizations. In 2012, the State Health Commissioner initiated a strategic planning process to reduce infant mortality in order to: 1) evaluate current practices; 2) explore new and innovative approaches; 3) build public and private partnerships throughout the state; and 4) identify and mobilize resources to effectively focus efforts on infant mortality reduction.

To ensure accuracy and thoroughness of the process and results, priority was placed on authentic stakeholder engagement. A multi-disciplinary VDH team met periodically from August 2012 until the present to design, implement, and monitor the strategic planning process.

This group adopted an iterative strategic planning process that started with a comprehensive review of all related available data; critical review of current VDH Maternal and Child Health programs, practices and services; meta-analysis of best practices in current research, literature and national models; compilation of expert opinions; and an analysis of current resources.

The results of this research were used to inform, and provide a catalyst for, discussions among sixty-five external stakeholders and experts from across the Commonwealth including the Health Commissioner's Infant Mortality Workgroup. These individuals represented practitioners of obstetrical and women's health care; pediatric health care, leadership from state and private agencies, non-profits, educational research institutions, and community organizations. The five goals identified to address infant mortality in Virginia are as follows:

- Goal 1: To improve the preconception health status among women of childbearing age in Virginia.
- Goal 2: To reduce premature births across the Commonwealth.
- Goal 3: To improve interconception care and family planning across the Commonwealth.
- Goal 4: To improve injury prevention and positive parenting efforts within Virginia.
- Goal 5: To improve the data collection, standardization, dissemination and utilization of perinatal data.

Three to four objectives have been identified for each goal and two to four strategies for each objective have been proposed. The prevention of SBS in Virginia has specifically been identified as an objective under Goal 4: To improve injury prevention and positive parenting efforts within Virginia. The next step for implementation of the strategic plan is to engage stakeholders and community partners to establish expert led subgroups for each of the five sections of the plan. VDH will facilitate these subgroups to develop action steps for rapid, measurable change and initiate activities across the state through shared resources. VDH will then lead the development of a detailed implementation plan based upon the activities proposed.

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