STATE CHILD DEATH REVIEW BOARD



Memorial Hall Building 120 S.W. 10th Avenue, 2nd Floor Topeka, KS 66612 (785) 296-7970 (785) 291-3875 Fax

Christine Ladner, JD Chairperson Assistant Attorney General Topeka

Brian Dempsey, JD Dept. for Children and Families Topeka

Sarah Johnston, MD, M.P.H. Kansas State Board of Education El Dorado

Mary McDonald, JD Children's Advocate Wichita

Katherine Melhorn, MD Pediatrician Wichita

Donald Pojman, MD Forensic Pathologist Topeka

Lou Saadi, Ph.D. KDHE, Bureau of EPHI Topeka

David Klamm Senior Special Agent Kansas Bureau of Investigation Wichita

Jaime Oeberst, MD District Coroner Wichita

Kim Parker, JD Sedgwick County ADA Wichita

Angela Nordhus, Exec. Director Susan Croucher, Admin. Specialist State Child Death Review Board Topeka Kansas State Child Death Review Board's Testimony in Support of SB77

Dr. Sarah Johnston's Testimony to Senate Judiciary

Kansas State Child Death Review Board, Member Commissioner of Education Appointment

February 11, 2013

Chairman King and members of the committee, I am Dr. Sarah Johnston, Clinical Associate Professor of Internal Medicine with the University of Kansas School of Medicine in Wichita and the Commissioner of Education's appointee on the Kansas State Child Death Review Board (SCDRB). Thank you for the opportunity to speak on Senate Bill 77 which seeks to amend the statutory authority of the SCDRB by incorporating language that will allow the Board to share de-identified information and records for research and public health purposes.

As you may be aware, the SCDRB is a multi-disciplinary, multi-agency board administered by the Office of Attorney General. The SCDRB was created in 1992 for the purpose of reviewing circumstances surrounding the death of every child age birth to 17-years who was a Kansas resident or died in the State of Kansas. Since 1994, the board has reviewed and summarized facts surrounding the deaths of approximately 8,400 children. The SCDRB collects records regarding child deaths, while maintaining confidentiality; they do not have authority to share records or information other than through its highly summarized annual report.

Child deaths are tragic events that are extremely painful for family members, healthcare and law enforcement professionals, school personnel, and society as a whole. Many have asked, "How did this happen when it could have been prevented?" Through the years, legitimate requests have been made to the SCDRB for access to de-identified records and information on child deaths to help answer that exact question. The requests have been routinely denied due to the SCDRB's existing statutory language which will not allow the sharing of the records and information. Confidentiality is a prime concern for the SCDRB and staff; however, we believe confidentiality can be preserved while providing access to pertinent information.

A copy of the State Child Death Review Board's 2011 annual report has been provided to each of you. This is the only public work product allowable under the SCDRB's statutes. It is the opinion of the members of the board, that the current statutory language does not sufficiently allow for the effective use of the board's data, which could be used to improve the health and well-being of Kansas children.

I would like to share with you a timely example of the limitations of the current statute. Since the Board's creation in 1992, the Board has reviewed 252 deaths by suicide of Kansas children. These deaths have been reviewed in great detail, including review of nine risk factors, medical and psychiatric records, school records, autopsy results, and suicide notes. There is no other database available which includes this information. Although the CDC has begun a national database on suicide deaths, states participate voluntarily, and the only information included is derived from death certificates. In the aftermath of the December 2012 tragedy at Sandy Hook Elementary School in Newtown, Connecticut, our country has begun the process of understanding the complexities of this and other school shootings. We know that suicide of the perpetrator was an integral part of the Newtown massacre, suicide was an integral part of the Columbine school shooting, and indeed suicide has been an integral part of 78% of school shootings. However, the existing language of the Board's statute prevents the Board and other qualified researchers from sharing valuable information which may be helpful in preventing not only suicide but also perpetration of violence like that which occurred at Sandy Hook Elementary School.

With the benefit of time, we have seen that the statute falls short of its intended purpose. Thus, I am here today requesting your support for SB 77 which includes an amendment that will allow the SCDRB to disclose deidentified information and records preserved for child death reviews for research and public health in accordance to rules and regulations adopted by the board.

Thank you for the opportunity to appear before the committee today. I will now stand for questions.