

Chairman King and members of the committee, I am Vicki Collie-Akers, Assistant Research Professor in the Life Span Institute at the University of Kansas and Associate Director of Health Promotion Research at the University of Kansas Work Group for Community Health and Development. Thank you for the opportunity to speak to you about Senate Bill 77 which will ensure access for public health researchers and practitioners to analysis conducted by the State Child Death Review Board (SCDRB).

Sadly, Kansas experiences a disproportionately high rate of child death, and is ranked 40th in the United States for child death rate. Over the last several years, more than 400 children have died annually in Kansas from causes including Sudden Infant Death Syndrome, violence, and unintentional injury. Although it is challenging to say what percentage of these deaths may have been prevented, it is clear that information about the factors that contributed to death can be used to identify patterns and trends, which is important information to efforts attempting to prevent future child death.

As a public health researcher working to address health disparities, particularly those related to infant mortality in Kansas, I need more specific information about the circumstances and conditions surrounding child death in multiple ways. Public health strategies used by researchers and practitioners alike require information about common factors across cases of child death to assure that they are effective in targeting the right risk factors. Further, detailed information regarding child death can be used to examine the efficacy of strategies once implemented. Other researchers and I use data about health problems throughout the course of a research study to assess progress toward outcomes, and if improvements in our outcomes are not being made, we adjust our approaches. In the absence of complete information about the problem, researchers cannot ensure that their research will have the greatest impact in reducing child death.

Additionally, funders of public health research, expect that researchers ground their interventions in a thorough analysis of the risk factors that contribute to child death. The absence of detailed information, such as that available from the SCDRB, opens prospective research to critiques about the adequacy of proposed projects for targeting the appropriate risk factors. Additionally, stakeholders expect compelling information that relays the urgency, severity, and consequences of the issue of child death, and the information currently available through the annual report of the SCDRB, although helpful, is insufficient for the purpose of persuading research grant reviewers and other decision-makers that addressing the issue of child death through specific strategies is of critical importance and likely to have an impact.

The potential of the SCDRB findings to have a positive effect on guiding researchers and practitioners in preventing infant mortality is not yet fully realized. The findings are largely under-utilized, despite the fact that they can be used within an existing infrastructure and can be used ethically. In addition to the bill requiring only de-identified data be released, researchers, such as myself, receive training and have institutional oversight into the ethical use of data through protocols that assure confidentiality, especially sensitive data. Confidentiality is further assured by the manner in which data is used and reported. The objective of public health research into child death is not to find what is unique about each case, but rather to aggregate similar cases to find patterns and trends that provide a solid grounding for public health strategies, thus further limiting threats to confidentiality.

For all of these reasons, I am here today to request support for SB 77 which includes an amendment that will allow researchers and practitioners to access de-identified data to be used in to develop and examine the effectiveness of robust strategies for reducing child death in Kansas.