



Sudden Unexplained Infant Death (SUID) Prevention

STATE OF UTAH
Office of Health Promotion and Prevention
Violence and Injury Prevention Program
September 30, 2022

To: Social Services Appropriations Subcommittee
From: Teresa Brechlin, VIPP Program Manager &
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Subject: Sudden Unexplained Infant Death (SUID) Prevention

Purpose

The Legislature intends that the Department of Health and Human Services report by October 1, 2022 to the Social Services Appropriations Subcommittee on the cost and likely impact of suggested interventions to reduce the number of sudden unexplained infant deaths (House Bill 7 Item 102).

Executive Summary

The Violence and Injury Prevention Program (VIPP) of the Utah Department of Health and Human Services (DHHS) has housed and facilitated Utah's Child Fatality Review Committee (CFRC) since 1989. In 2018, VIPP successfully applied for funding to implement a Sudden Unexplained Infant Death (SUID) and Sudden Death in Young (SDY) Program and Registry from the Centers for Disease Control and Prevention (CDC). It required the development of an Advanced Clinical Review Committee (ACRC), composed of specialists in pathology, genetics, pediatric neurology, epileptology, cardiology and electrophysiology. The ACRC performs a more in-depth clinical review of cases determined by the CFRC to meet the SDY categorization criterion and develops recommendations to improve the system and decrease the number of unexplained, untimely, deaths of Utah's infants and youth. Several recommendations have been developed by the committee and three of these recommendations have been prioritized. They are: 1) Improve data sharing and care coordination between health systems, healthcare providers, mental health providers, schools, human services, Medicaid, and other states, 2) Increase funding for and

expand evidence-based home visitation services, and 3) Increase access and funding for mental health, behavioral health, and substance abuse services across Utah to support parents.

Background

Utah's population is unique. According to the U.S. Census Bureau (2018: ACS 5-Year Estimates), it has the nation's youngest population as well as the largest household size. Utah's median age is 30.7 compared to 37.9 nationally, and children under the age of 18 comprise 30.2 percent of Utah's total population compared to 22.8 percent nationally. From 1990 to 2015, approximately two-thirds of Utah's growth can be attributed to natural increase (births minus deaths) and Utah continues to have one of the highest fertility rates in the nation according to the CDC.

The CDC defines Sudden Unexpected Infant Death as the "sudden and unexpected death of a baby less than 1 year old in which the cause was not obvious before investigation." The Violence and Injury Prevention Program (VIPP) of the Utah Department of Health and Human Services (DHHS) houses and facilitates the states' child fatality review team. Though the Utah Child Fatality Review Committee (CFRC) performs reviews of all child deaths statewide, it has been difficult to perform accurate surveillance of SUID due to reporting and classification inconsistencies. In response to these inconsistencies and to better understand these tragic deaths in order to prevent them, VIPP applied for grant funding from CDC to participate in The Sudden Death in the Young (SDY) Case Registry.

The registry is a collaboration between the CDC and the National Institutes of Health. The purpose of the registry is to conduct public health surveillance of SDY cases and to explore and provide greater understanding of the prevalence, causes and risk factors associated with infants and children who die suddenly and unexpectedly.

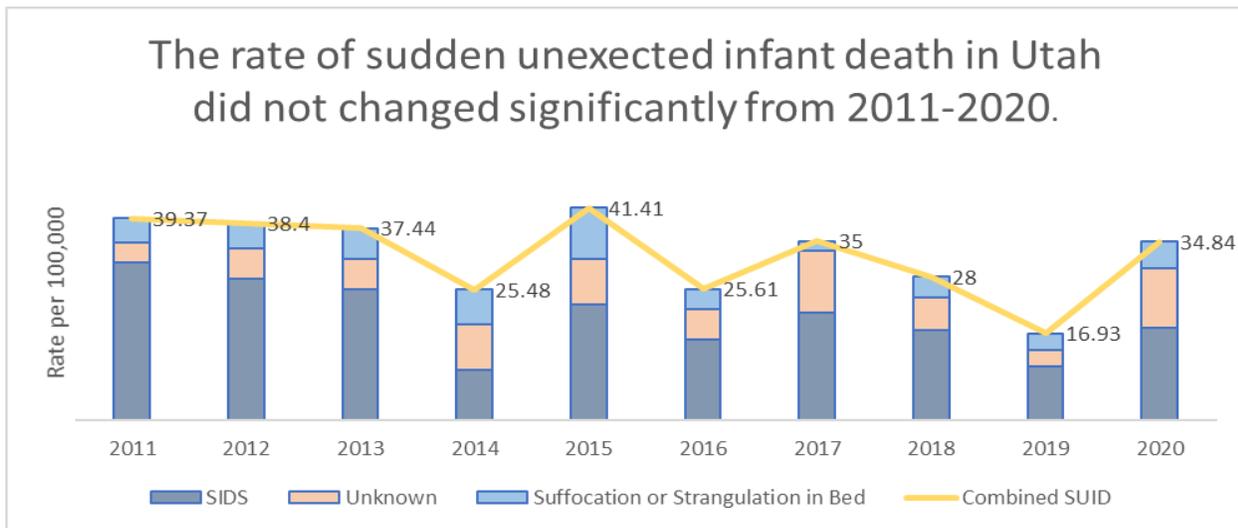
Utah receives approximately \$80,000 per year (funding will end in 2023) to partner with the Maternal Infant Health Program and Office of the Medical Examiner, to conduct a clinical review of all SUID and SDY deaths and to: 1) Increase data completeness, timeliness and case ascertainment resulting in a robust SUID and SDY surveillance system in Utah and 2) Increase policies and practices that are informed by SUID and SDY Case Registry data among partner agencies serving families and working to prevent sudden and unexpected infant and child deaths and 3) Reduce the incidence of SUID and SDY in Utah. This leads to a continually improving child death surveillance system that collects high quality and comprehensive information in a timely manner that complies with CDC guidelines, provides timely and useful data to partners, and ultimately, reduces the incidence of SUID and SDY.

The funding required that VIPP establish an Advanced Medical Review Committee (ACRC) to review all identified sudden unexpected deaths in young that are autopsy negative. The ACRC is composed of specialists in pathology, genetics, pediatric neurology, epileptology, cardiology and electrophysiology. The Committee meets virtually on a quarterly basis, at the Office of the Medical Examiner. The ACRC performs a more in-depth clinical review of cases determined by the CFRC to

meet the SDY categorization criterion and develops recommendations to improve the system and decrease the number of unexplained, untimely, deaths of Utah’s infants and youth.

Scope of the Problem

In Utah, an average of around 32 infants died each year from SUID from 2011-2020 (a rate of 64.92 per 100,000 infants). SUID have no immediately obvious cause but are commonly captured on death certificates as SIDS, unknown cause, and unintentional suffocation or strangulation in bed. In 2020, there were 33 SUID cases in Utah (17 were categorized as SIDS, 11 were categorized as unknown cause, and 5 were categorized as accidental suffocation or strangulation in bed). These 33 SUID cases accounted for 13.1% (or ~1 in 8) of the 251 Utah infant deaths in 2022.



As SUID cases are categorized for the national case registry, one prominent risk factor that always rises to the top is the presence of unsafe sleep factors (co-sleeping, not on the back, soft surfaces, other things in the crib, caregiver substance abuse/smoking, etc...). Of the combined 59 SUID cases reviewed and categorized in 2019 and 2020, 52 (88.1%) had unsafe sleep factors present (100% of 29 cases in 2019 and 78.8% of 33 cases in 2020).

Recommendations of the Child Fatality Review Committee and the Advanced Clinical Review Committee

Recommendation	Likely Impact
<i>Recommendations specific to improving data collection and understanding of SUID</i>	
<p>Priority Recommendation Improve data sharing and care coordination between health systems, healthcare providers,</p>	<ul style="list-style-type: none"> ● Increase in quality and quantity of data and information ● Increase in data sharing with partners

Recommendation	Likely Impact
<p>mental health providers, schools, government services, and other states. (2020 child fatality action committee priority)</p> <ul style="list-style-type: none"> Expand caregiver interviews for infant deaths to understand regular sleep habits and identify individuals capable of handling these complex interviews. Hire Spanish-speaking investigators/interviewers 	<ul style="list-style-type: none"> Increase in quality recommendations Increase in cases with generational family history collected
<p>Priority Recommendation Expand evidence-based home visitation (2020 child fatality action committee priority)</p> <ul style="list-style-type: none"> Expand home visiting for parents with children with complex medical conditions, those experiencing homelessness, parents with substance abuse issues, parents of multiples, and, ideally, every first-time parent should be eligible. (Different levels of home visiting according to need) Develop telehealth/virtual options for home visiting 	<ul style="list-style-type: none"> Improve caretakers understanding and effective implementation of a safe sleep environment for their infants Compared with their counterparts, caregivers enrolled in home visiting have higher monthly incomes, are more likely to be <u>enrolled in school</u>, and are more likely <u>to be employed</u>. Babies are less likely to be born at a low birthweight. Other outcomes include: <ul style="list-style-type: none"> Reduced developmental and health problems Parents can better prepare their children for school Long-term, positive impacts on children's academic achievement Fewer injuries between the ages of two and four Less likely to visit an emergency room Less likely to be a victim of child maltreatment Reduction in the number of infant death
<p>Priority Recommendation Increase access and funding for mental health, behavioral health, and substance abuse services</p>	<p>The impact of increasing behavioral healthcare has been identified by the Office of Substance Use and Mental Health, the</p>

Recommendation	Likely Impact
<p>across Utah to support parents. (2020 child fatality action committee priority)</p> <ul style="list-style-type: none"> • Increase diversity in the behavioral health care workforce. 	<p>University of Utah, Kem C. Gardner Institute and numerous federal plans, reports, and investigations. While this is a priority for the Child Fatality Review Committee, we depend on partners to help advance this recommendation.</p>
<p>Implement legislation that requires police agencies to share reports with Utah’s child fatality review committee</p>	<ul style="list-style-type: none"> • Increased information on SUID circumstances
<p>Change the Utah statute to give the OME authority to investigate infant deaths regardless of where death is pronounced.</p>	<ul style="list-style-type: none"> • More robust investigations of SUID • Better information about the circumstances surrounding SUIDs that will lead to better response and prevention
<p>Create a state rapid response team to assist investigators in smaller law enforcement agencies with fatalities, near fatalities, or suspected abuse</p>	<ul style="list-style-type: none"> • Increase in thorough investigation of SUIDs • Improved trauma-informed debriefing of caretakers and family members • Increased information on SUID circumstances
<p><i>Recommendations specific to preventing SUID</i></p>	
<p>Secure dedicated funding to improve data collection which informs prevention efforts</p> <ul style="list-style-type: none"> • Increase the number of full-time death scene investigators to improve scene investigation, including an alternate person to fill out sudden unexpected infant death investigation (SUIDI) form in situations where police might be unwelcome. • Provide training and encourage investigating law enforcement to use doll reenactments at the scene. • Provide funding to hire a staff member to abstract all Child Fatality Reporting System (CFR) cases. 	<ul style="list-style-type: none"> • Increase in thorough investigation of SUIDs • Improved, accurate depictions of the sleep environment of the infant • Improved trauma-informed debriefing of caretakers and family members • Increased information on SUID circumstances

Recommendation	Likely Impact
<p>Increase access to paid leave for families, including maternal/paternal leave, and quality, affordable childcare</p>	<p>Family-friendly workplace policies for employees benefit families, businesses and economies. These include paid parental leave, breastfeeding breaks, childcare and child grants. A lack of these policies compromise parents' ability to securely bond with their babies.</p> <p>Evidence shows that these policies are linked to healthier, better-educated children, greater gender equality and sustainable growth, better workforce productivity and the ability to attract, motivate and retain employees.</p> <p>Impacts:</p> <ul style="list-style-type: none"> ● Reduce family financial insecurity ● Improved employee retention and productivity ● Boosts labor force participation ● Improves children's healthy development ● Improves maternal mental and physical health ● Supports fathers' involvement in care¹
<p>Increase broadband internet access across the state and access to telehealth</p>	<ul style="list-style-type: none"> ● Increase educational and employment opportunities ● Increase access to clinical services ● Improved Health ● Increase in connectedness²
<p>Funding for effective safe sleep education and parental supports (home visitors, crisis nurseries, Pack'n Plays)</p>	<ul style="list-style-type: none"> ● Increase in understanding of the dangers of co-sleeping ● Increase in understanding of the dangers of substance use and co-sleeping

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<https://www.cbpp.org/research/economy/a-national-paid-leave-program-would-help-workers-families#:~:text=families%20economic%20security,-Paid%20medical%20and%20caregiving%20leave%20lets%20workers%20care%20for%20themselves,can%20boost%20labor%20force%20participation.>

² Broadband Access as a "Super-Determinant" of Health - Network for Public Health Law Broadband Access as a "Super-Determinant" of Health - Network for Public Health Law. (2018). Retrieved 23 September 2022, from <https://www.networkforphl.org/news-insights/broadband-access-as-a-super-determinant-of-health/>

Recommendation	Likely Impact
<ul style="list-style-type: none"> • Education about the dangers of substance use and co-sleeping, special emphasis on harm reduction if bed sharing happens (no substance use, removing blankets and pillows, etc.) • Back is Best education (visualization materials) to show the why) • Education campaign on supporting new parents and the importance of parental help-seeking. • Ensure equity by confirming resources and education are available to all regardless of income, geography (rural/urban), language, race/ethnicity, disability status, religion, or criminal history 	<ul style="list-style-type: none"> • Increase in safe sleep environments for infants • Increase in number of infants sleeping on their backs • Increase in parental help seeking • Decrease in the number of SUID deaths
<p>Work with hospital systems to screen parents and provide support</p> <ul style="list-style-type: none"> • Parental mental health screenings and safe sleep review at well-child visits along with resources available to provide based on the results of the screening • Screen parents dealing with newborn intensive care unit (NICU) situational stress and ensure necessary needs like childcare are being met 	<ul style="list-style-type: none"> • Decrease in maternal and post-natal depression • Increased help seeking behavior by parents • Decrease in maternal mortality • Decrease in infant mortality
<i>Recommendations specific to decreasing the harms/negative impacts of SUID</i>	
<p>Audit/evaluate the practices of those who respond during SUID/SIDS deaths to identify gaps in trauma-informed practices and confirm families are not being further traumatized by the state when a death occurs.</p>	<p>Increased trauma-informed approaches by EMS, law enforcement, death investigators, and the professionals who review SUID deaths</p>

Costs of Intervention

Priority Recommendation	Costs of Intervention	Estimated Cost Savings
<p>Improve data sharing and care coordination between health systems, healthcare providers, mental health providers, schools, human services, Medicaid, and other states. (2020 child fatality action committee priority)</p> <p>Expand caregiver interviews for infant deaths to understand regular sleep habits and identify individuals capable of handling these complex interviews.</p> <ul style="list-style-type: none"> - Include Spanish-speaking investigators/ interviewers in the response workforce 	<p>Hiring a SUID coordinator who speaks Spanish, and can conduct interviews with families who have lost a child unexpectedly. Approximate cost for a forensic interviewer \$105,000/yr.</p>	<p>A further study of the cost savings would have to be conducted but the frightening fact about sudden unexpected infant death is that it can happen without warning and to infants who seem otherwise healthy</p>
<p>Expand evidence-based home visitation</p> <ul style="list-style-type: none"> • Expand home visiting under the following eligibility criteria outlined by the federal Maternal Infant Early Childhood Home Visiting (MIECHV): <ul style="list-style-type: none"> ○ At or below 100% of the Federal Poverty Level ○ Parents who are pregnant and under the age of 21 ○ History of child abuse or neglect, or history of interactions iwth child welfare services ○ History of substance abuse or in need of 	<ul style="list-style-type: none"> • Home visiting costs about \$6,500 per family per year. • Utah currently serves 2.6% of Utah families. • Increasing reach to 10% of all Utah families would cost about \$15.5M. The main federal funding source for home visiting (MIECHV) is up for reauthorization and will require a state match in the future. This match will likely require data collection and reporting to align with the requirements of this federal funding. 	<p>Home visiting saves between \$1.80 to \$5.70 for every dollar spent.³ Increasing the number of families served by 8.4% would save from \$16,260,000 to \$70,500,000⁴</p>

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https://www.pewtrusts.org/-/media/legacy/uploadedfiles/pcs_assets/2011/homevisitingmodelpolicyframeworkorkpdf.pdf

⁴ Miller, T. R. "Nurse-Family Partnership Home Visitation: Cost, Outcomes, and Return on Investment." Beltsville, MD: HBSA, Inc., January 2013

Priority Recommendation	Costs of Intervention	Estimated Cost Savings
<ul style="list-style-type: none"> ○ substance abuse treatment ○ Tobacco use ○ Low student achievement ○ A child with developmental delays or disability ○ A household member who is serving or has served in the U.S. armed forces ● Sustain telehealth/virtual options for home visiting 		
<p>Increase access and funding for mental health, behavioral health, and substance abuse services across Utah to support parents.</p>	<p>The impact and costs of increasing behavioral healthcare has been identified by the Office of Substance Use and Mental Health, the University of Utah, Kem C. Gardner Institute and numerous federal plans, reports, and investigations.</p>	