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HRSA Information Collection Clearance Officer Room 14N39 5600 Fishers Lane Rockville, Maryland 20857

Submitted via paperwork@hrsa.gov

Re: Title V Maternal and Child Health Services Block Grant to States Program: Guidance and Forms for the Title V Application/Annual Report, OMB No. 0915–0172—Revision

Dear Secretary Johnson and Health Resources & Services Administration Staff:

Thank you for your service and leadership to our nation and for the opportunity to submit comments pertaining to revisions of the Title V Maternal and Child Health Services Block Grant (MCH Block Grant).

We submit this letter on behalf of Evermore, a national nonprofit dedicated to improving the lives of bereaved children and families. Evermore was founded to help raise awareness of the consequences of bereavement in our society, advance sound research that drives policy and program investments, and advocate on behalf of bereaved children and families, including those 60 million pregnant women, infants, and children who are attended to by the MCH Block Grant.

The scale and reach of the MCH Block Grant—with current appropriations of \$712,700,000—is indisputable, as 93 percent of pregnant women, 98 percent of infants, and 60 percent of children are touched. While impressive progress has been made in important benchmarks, including the 25 percent decline in infant mortality since 1997, bereavement remains absent from the MCH Block Grant scope. This omission is notable as the agency's technical advisement manual to state programs¹ mentions death more than 150 times and supports fetal and child death review panels throughout the United States; however, attending to bereavement or grief in the aftermath of these deaths is not included even once in the Health Resources and Services Administration's (HRSA) guidance.

Bereavement—the loss of a significant relationship by death—is one of the most traumatic stressors a

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¹ Title V Maternal and Child Health Services Block Grant to States Program: Technical Assistance Resources (in draft) https://mchb.tvisdata.hrsa.gov/Admin/FileUpload/DownloadContent?fileName=Title%20V%20Block%20Grant%20Technical%20Assistance%20R esources.pdf&isForDownload=False

person endures, and extensive scientific evidence domestically and internationally points to the significant, enduring, and life-altering impacts bereavement has on grieving individuals in the short- and long-term. Similar to the MCH Block Grant program, the scale and reach of bereavement in the United States is extensive, particularly as concurrent mortality epidemics—COVID-19, overdose, suicide, homicide, maternal mortality, traffic fatalities, and the emergence of more extreme and deadly climate events—has left no neighborhood untouched.

Rigorous population-level studies have found that bereaved parents,² children,³ siblings,⁴ and spouses⁵ are at significant risk of impaired health and premature death. A sampling of additional risks includes serious mental health disorders,^{6,7,8} teen pregnancy,⁹ violent crime involvement,¹⁰ youth delinquency,^{11,12} substance abuse,^{13,14,15} diminished academic attainment,¹⁶ reduced lifetime income,¹⁷ and less purpose in life,¹⁸ among many others.

In 2021, the U.S. Centers for Disease Control and Prevention (CDC) logged more deaths in a single year¹⁹ than any other point in a century of data collection. In 2022, the U.S. Census Bureau reported that nearly 75 percent of U.S. counties experienced more deaths than births from July 2020 to June 2021.²⁰ The cumulative impact of these trends has been a decrease in America's life expectancy,²¹ and perhaps more concerning, a spike in child death,²² and by extension, parental bereavement, a particularly devastating bereavement experience. In addition, maternal mortality rates increased in 2021.²³

https://www.census.gov/library/stories/2022/03/deaths-outnumbered-births-in-half-of-states-between-2020-and-2021.html #: ``:text=Half%20of%20all%20states%20and, relationship%20between%20births%20and%20deaths.

² https://pubmed.ncbi.nlm.nih.gov/12573371/

³ https://pubmed.ncbi.nlm.nih.gov/21039482/

⁴ https://pubmed.ncbi.nlm.nih.gov/28437534/

⁵ https://pubmed.ncbi.nlm.nih.gov/21858130/

⁶ https://www.nejm.org/doi/full/10.1056/NEJMoa033160

⁷ https://pubmed.ncbi.nlm.nih.gov/19155806/

⁸ https://pubmed.ncbi.nlm.nih.gov/21039482/

⁹ https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4302726/

¹⁰ https://pubmed.ncbi.nlm.nih.gov/20431471/

¹¹ https://pubmed.ncbi.nlm.nih.gov/30344839/

¹² https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4577059/

¹³ https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4037812/

¹⁴ https://bmjopen.bmj.com/content/10/6/e038826

¹⁵ https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9765932/

¹⁶ https://pubmed.ncbi.nlm.nih.gov/24616354/

¹⁷ https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3471209

¹⁸ https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2841012/

¹⁹ https://www.cdc.gov/nchs/products/databriefs/db456.htm

²¹ https://www.cdc.gov/nchs/data/vsrr/vsrr023.pdf

²² https://jamanetwork.com/journals/jama/article-abstract/2802602

²³ https://www.cdc.gov/nchs/data/hestat/maternal-mortality/2021/maternal-mortality-rates-2021.htm

Over a decade ago, notably preceding the COVID-19 pandemic, Americans reported that the unexpected death of a loved one was the most common traumatic experience, alongside being the worst experience of their lives.²⁴ There is no scientific reason to believe or measurable indicator that the bereavement experience has improved. In fact, the evidence base—that exposure to death is a serious health concern—is only continuing to grow.

Bereavement's powerful intersection with multiple national public health emergencies is largely unrecognized or unknown among federal and state leaders, although several federal agencies are beginning to take note. Over the last year, multiple federal agencies have started examining bereavement's role in the context of agency authorities. Some examples include:

- At the direction of Congress, the Agency for Healthcare Quality and Research is reviewing the feasibility of developing high-quality grief and bereavement standards.
- The Assistant Secretary for Planning and Evaluation is producing a Congressionally-directed report on grief and bereavement services.
- The Department of Education is considering amending FAFSA to measure the impact of orphanhood on higher education matriculation.
- The Federal Trade Commission is reviewing 1984's The Funeral Rule, which dictates that consumers have the right to a general price list when selecting funeral and cremation services.

As these agencies build a framework for the inclusion of bereavement in their policies, programs, and priorities, HRSA should similarly examine its opportunities to support bereaved American children and families.

As defined by Title V legislation, bereavement overlaps with several of the MCH Block Grant program priorities, such as:

- Assuring access to quality maternal and child health care services for mothers and children, especially those with low incomes or limited availability of care;
- Reducing infant mortality and incidence of preventable diseases, and generally promoting the health of children;
- Providing access to prenatal, delivery, and postnatal care to women (especially low-income and at-risk pregnant women); and
- Increasing the number of low-income children who receive regular health assessments and follow-up diagnostic and treatment services.

The importance of HRSA's leadership in supporting bereaved children and families experiencing financial hardships or who are at high risk of pregnancy, infant, and child loss cannot be overstated. Unlike the health risks resulting from tobacco or obesity, where a series of exposures over time lead incrementally to adverse health outcomes, when a child or family experiences a death event, there is a clear,

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²⁴ https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4119479/

measurable, and defined inflection point that places these individuals at increased risk of poor health, social, and economic outcomes.

To that end, it is important to understand the context of death experiences for children and families. Consider, for example, sudden unexpected infant death investigations (SUIDI),²⁵ under the jurisdiction of fetal and infant mortality review (FIMR) panels. Nationally, there are an estimated 3,400 sudden unexpected infant deaths (SUIDs) each year, mostly resulting from co-sleeping arrangements that result in the accidental suffocation of the infant.²⁶ According to some research, minimal reductions in SUIDs have been achieved in the last two decades.²⁷

CDC's best practice for death investigations encourages death scene investigators to have the newly bereaved family reenact the death event with a fabric baby doll within hours of the death itself, while being photographed by police and death scene investigators, often while Child Protective Services is summoned if there are additional children in the house.

CDC's SUIDI manual states,

"Most death investigators agree that attempting to reintroduce and reposition a decedent's body into a scene for photographic reasons would not be a wise decision. However, the doll reenactment does just that with surprisingly positive results for both the investigator conducting the reenactment and the family member or caregiver performing the reenactment." ²⁸

We submit that "surprisingly positive results" for the family are questionable, as we cannot substantiate in the scientific literature that doll reenactments provide a therapeutic benefit for families. Indeed, in our conversations with families, we have not identified one family that felt the reenactment helped them to better process or cope with the trauma of losing their beloved child or had any positive impact on their health or well-being.

Conversely, some stakeholders state that families can decline reenactments since they are voluntary in nature. However, in our experience, families report that declining reenactments only amplifies law enforcement suspicion and has resulted in the confiscation of all media, including photos, videos, computers, and other memorabilia, of their deceased children. In some cases, these items are returned months or more than a year later when families are cleared of any wrongdoing. According to the National Academies of Medicine, formerly known as the Institute for Medicine, the death of a child is one of the greatest and most enduring stresses a person can experience.²⁹ In this instance, the United States government requests that a newly bereaved parent reenacts the death event, and if they decline,

https://publications.aap.org/pediatrics/article-abstract/139/6/e20163844/38709/Racial-and-Ethnic-Trends-in-Suddlen-Unexpected?redirectedFrom=fulltext

²⁵ https://www.cdc.gov/sids/TrainingMaterial.htm

²⁶ https://injepijournal.biomedcentral.com/articles/10.1186/s40621-022-00377-7

²⁷

²⁸ https://www.cdc.gov/sids/pdf/suidmanual/Chapter7 tag508.pdf

²⁹ https://pubmed.ncbi.nlm.nih.gov/25057608/

law enforcement confiscates memorabilia compounding the hardships families encounter during a time of intense grief.

Further complicating matters are the social barriers—real or perceived—between law enforcement and historically marginalized populations, which are amplified for SUIDs as Black and Brown populations, who experience SUIDs at a higher rate, and in some cases a much higher rate, than non-Hispanic whites.³⁰ In Chicago, for example, one study found that non-Hispanic Black infants experienced SUIDs at 12.735 times the rate as non-Hispanic white infants.³¹

Some death investigators argue doll reenactments are required to identify infanticide; however, infanticide ranks as the 13th leading cause of death among infants, which disproportionately occurs in the first 24 hours of life.³² To be clear, infant homicide is unacceptable, and should be prosecuted to the fullest extent of the law. We submit, however, that a harm reduction strategy should be offered to reduce the number of families asked to reenact death events, thereby reducing additional trauma and discriminatory practices, particularly among Black and Brown families.

HRSA's MCH Block Grant program has an opportunity to reduce, if not eliminate, additional traumas experienced by newly bereaved families and offer supportive grief and bereavement services in the aftermath.

Immediately and perhaps simply, bereavement should be added to the definition of "preventive and primary care services" for the MCH Block Grant program, thus giving states the opportunity and flexibility to offer services, tailor programs, and test interventions for their unique constituencies.

However, bereavement cannot simply be added as an afterthought to HRSA's programming decisions for the MCH Block Grant program. A measured and deliberate process should be launched to determine how and where bereavement would become integrated into the MCH Block Grant. This deliberation should include HRSA staff, state coordinators, policy experts, and other key stakeholders.

Just as death is mentioned more than 150 times in pending state guidance, so too should the aftermath of death—bereavement—become integrated into the MCH Block Grant program, thus serving our nation's children and families.

³⁰ https://injepijournal.biomedcentral.com/articles/10.1186/s40621-022-00377-7

³¹ Ibid.

³² https://www.cdc.gov/mmwr/volumes/69/wr/mm6939a1.htm

HRSA has an unparalleled opportunity to act and serve our nation's grieving children and families; we hope you agree.

Thank you for the opportunity to submit these comments.

Sincerely,

Joyal Mulheron

Evermore, Executive Director

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