

### Outside Witness Testimony for the Record

Submitted to Subcommittee on Labor, Health and Human Services, Education and Related Agencies U.S. Senate

Pertaining to
Centers for Disease Control and Prevention
Office of Surveillance, Epidemiology, and Laboratory Services/Division of Behavioral Health

Submitted by Joyal Mulheron, Executive Director, Evermore June 24, 2021

Chairwoman Murray, Ranking Member Blunt, and members of the Committee, thank you for the opportunity to provide testimony pertaining to fiscal year (FY) 2022 appropriations for the Centers for Disease Control and Prevention (CDC). Your leadership has resulted in major advances in the health and wellbeing of Americans, as well as ensuring that our taxpayer dollars are appropriated to our nation's most pressing health and human needs.

I submit this testimony on behalf of Evermore, a nonprofit dedicated to making the world a more livable place for bereaved families by raising awareness of the consequences and implications of bereavement for society, advancing sound research that drives policy and program investments, and advocating on behalf of bereaved families for whom very limited legal protections are available in the aftermath. The purpose of my testimony today is to alert you to an emerging public health concern--bereavement--and its impact on millions of families throughout the nation. Bereavement shares a powerful intersectionality with multiple national public health emergencies, including COVID-19, overdose, homicide, and suicide. As such, bereavement plays a key gatekeeping role in determining whether we as a nation can turn the corner on these ongoing public health crises towards national recovery and wellbeing. This watershed moment offers us a rare opportunity to effect long-needed and long-awaited systemic changes. These changes can bring together a diverse array of seemingly disconnected, separately raging crises to support our nation's grieving individuals, families, and communities; compassionately lighten the burden of bereavement that encumbers and shortens so many lives, and re-enable them to reach their full potential.

Bereavement is a pernicious social concern threatening nearly every aspect of family wellbeing and solvency for millions across the country. The unexpected death of a loved one poses a dual threat to our national well-being, as it is both among the most common major life stressors, and the single worst lifetime experience, reported by Americans in national surveys. Losing a loved

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<sup>&</sup>lt;sup>1</sup> https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4869975/

one is not only a personal tragedy, but casts a long shadow that can extend for decades as it places surviving parents, children, siblings, and spouses at significant risk for impaired health, premature death, <sup>2,3,4,5</sup> and underachievement. Some additional risks include serious mental health disorders, <sup>7,8,9</sup> teen pregnancy, violent crime involvement, youth delinquency, <sup>12,13</sup> substance abuse, <sup>14,15</sup> diminished academic attainment, diminished lifetime income, and less purpose in life, among many others.

Perhaps most concerning, our national life expectancy—an index of overall population health—has dropped by more than one full year. This last happened nearly 80 years ago following the United States' entry into World War 2. The implications of these statistics are sobering: They not only indicate that many middle-aged people of child-bearing and child-rearing years are dying, but that many children and adolescents are losing their parents, grandparents, aunts, uncles, and mentors. Recurring bereavement under tragic and often-traumatic circumstances has now become a commonplace fact of life for many US residents. Further, COVID and our other spiking epidemics have set back progress in closing the racial health disparities gap by some 20 years. Pacial inequalities in bereavement are magnified across the life course as Black Americans are more likely than White Americans to experience the death of children, spouses, siblings, and parents. Black Americans are three times as likely as White Americans to have two or more family members die by the time they reach the age of 30.21 Black children are three times as likely to lose a mother and more than twice as likely to lose a father by age 10 when compared to White children.

To facilitate and inform future policymaking and national investments, as well as develop an evidenced-based bereavement care response system, Evermore encourages a budget increase of \$2.5 million in CDC's Office of Surveillance, Epidemiology, and Laboratory Services/Division of Behavioral Health to collect bereavement prevalence and incidence data via its Behavioral Risk Factor Surveillance Survey (BRFSS). BRFSS is the nation's premier survey tool collecting data

<sup>&</sup>lt;sup>2</sup> https://pubmed.ncbi.nlm.nih.gov/21039482/

<sup>&</sup>lt;sup>3</sup> https://pubmed.ncbi.nlm.nih.gov/28437534/

<sup>&</sup>lt;sup>4</sup> https://pubmed.ncbi.nlm.nih.gov/12573371/

<sup>&</sup>lt;sup>5</sup> https://pubmed.ncbi.nlm.nih.gov/21858130/

<sup>&</sup>lt;sup>6</sup> https://live-evermore.org/wp-content/uploads/2020/11/Evermore-Bereavement-Facts-and-Figures-2020.pdf

<sup>&</sup>lt;sup>7</sup> https://www.nejm.org/doi/full/10.1056/NEJMoa033160

<sup>&</sup>lt;sup>8</sup> https://pubmed.ncbi.nlm.nih.gov/19155806/

<sup>&</sup>lt;sup>9</sup> https://pubmed.ncbi.nlm.nih.gov/21039482/

<sup>10</sup> https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4302726/

<sup>&</sup>lt;sup>11</sup> https://pubmed.ncbi.nlm.nih.gov/20431471/

<sup>12</sup> https://pubmed.ncbi.nlm.nih.gov/30344839/

<sup>13</sup> https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4577059/

<sup>&</sup>lt;sup>14</sup> https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4037812/

<sup>15</sup> https://bmjopen.bmj.com/content/10/6/e038826

<sup>&</sup>lt;sup>16</sup> https://pubmed.ncbi.nlm.nih.gov/24616354/

<sup>17</sup> https://papers.ssrn.com/sol3/papers.cfm?abstract\_id=3471209

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

<sup>&</sup>lt;sup>19</sup> https://www.bmj.com/content/bmj/373/bmj.n1343.full.pdf

<sup>&</sup>lt;sup>20</sup> https://pubmed.ncbi.nlm.nih.gov/28115712/

<sup>&</sup>lt;sup>21</sup> Ibid.

<sup>&</sup>lt;sup>22</sup> Ibid.

from 400,000 adults living in the 50 states, the District of Columbia, and three U.S. territories. It is the largest continuously-conducted health survey in the world.

The CDC is one the nation's most-trusted sources of data and evidence on population and public health. Our nation requires consistent and reliable data on the prevalence and sequelae of bereavement on which to formulate sound policy and practice.

Today, the CDC collects mortality data, but not data pertaining to the bereaved families who survive these death events, and what the ramifications are. With five million individuals losing a loved one to COVID-19,<sup>23</sup> including an estimated 46,000 children who lost a parent,<sup>24</sup> the need for sound data collection to frame a federal response has never been greater. Indeed, we have relied on private researchers--including Ashton Verdery, Ph.D. of The Pennsylvania State University and Emily Smith-Greenaway of the University of Southern California--to provide these estimation models because the federal government does not measure bereavement exposure.

By extension, bereavement prevalence and incidence for homicide, suicide or overdose are currently unavailable, leaving us with no accurate means of capturing its impact (perhaps better designated as *shockwaves*) on individuals, families, and communities. This is a major missed opportunity for our social and health systems to surveil, monitor, and learn from our national epidemics and mount an effective response. Adding bereavement exposure to BRFSS would provide key demographic data, trends by race and geography, resulting in both a better understanding of the scope of the problem and informing future policymaking and program priorities and investments.

In 2019, Toni Miles, M.D., Ph.D. of the University of Georgia piloted three bereavement exposure questions in Georgia's BRFSS module, prior to the COVID-19 epidemic (see Figure 1). Her work found that 45 percent of Georgia BRFSS respondents were bereaved in the previous two years. Extrapolating this figure to the overall state population, she estimates that 3.7 million Georgian adults were recently bereaved. Her work also estimates that approximately 400,000 Georgia adults had two or more close family members die. African American adults are at particular risk, with 58 percent reporting a loss. Those in their prime working years are affected, with 48 percent of adults ages 35-64 experiencing a loss. *Preliminary* evidence indicates that bereavement exposure may undermine capacity to work; 53 percent of those newly out of work had experienced a family death.<sup>25</sup>

## Three Proposed Bereavement Exposure Questions for BRFSS

Interviewer: I'd like to ask you some questions about friends or family who have passed away in recent years.

- 1. Have you experienced the death of a family member or close friend in the years 2018 or 2019?
- 2. How many losses did you experience during that time?

<sup>&</sup>lt;sup>23</sup> https://www.pnas.org/content/117/30/17695

<sup>&</sup>lt;sup>24</sup> https://jamanetwork.com/journals/jamapediatrics/fullarticle/2778229

<sup>&</sup>lt;sup>25</sup> Personal email communication with Dr. Toni Miles, June 24, 2021.

\_\_\_ losses Don't know Refused

3. For each loss, please tell me if he or she was a spouse, friend or a family member. INTERVIEWER NOTE: With family members please indicate relationship; Mother, Father, Sister, Brother.

Figure 1. Bereavement questions piloted in Georgia's 2019 BRFSS. These questions are being proposed for inclusion in the 2022 CDC BRFSS.

Dr. Miles and her team found that persons who experienced any family loss in the past two years were at a heightened risk of reporting poor health, as well as physical and mental health problems over the past two weeks within taking the survey. Persons experiencing three or more losses were at the greatest risk of multiple health concerns, ranging from obesity to binge drinking, relative to those with no losses.

## **Appropriations Request**

An increase of \$2.5M to support the addition of an optional module to determine incidence and prevalence of bereavement exposure in CDC's annual BRFSS for all 50 states and U.S. territories. Module offering would commence in 2022.

In addition, we are requesting 1) the creation of a publicly available dataset featuring bereavement for use by behavioral health analysts and 2) a special highlight section in CDC's Health US, 2022, an annual snapshot of population health in the U.S.

#### Bill Language requested:

Of the funds made available under this heading, \$2,500,000 shall be directed to the inclusion of three bereavement measures in the BRFSS.

## Report Language requested:

The death of a loved one impacts millions of American residents leading to poor health, social and economic outcomes. This agreement includes \$2.50 million for the Office of Surveillance, Epidemiology, and Laboratory Services to better understand the scope of bereavement exposure by including three new items to the Behavioral Risk Factor Surveillance Survey. Measures should be previously tested and fielded in at least one statewide survey. This data set should be available publicly to encourage and inform additional extramural research activities. This agreement encourages CDC to include a special highlight section in its Health US, 2022.

Figure 2. Appropriations request, bill and report language.

# **Additional Justification for Requests**

1) Publicly-available bereavement dataset. We request the creation of a publicly available bereavement dataset enabling social and health scientists to extrapolate risk factors and potential implications for U.S.-based populations. Researchers will be able to examine interrelationships between exposure and outcomes, ask new research questions and begin to integrate this data into their existing research endeavors intended to help

- individuals reach their fullest potential. To that end, these data may influence CDC's Healthy People 2030 goals.
- 2) CDC's Health US, 2022. We request a special highlight section in CDC's 2022 health status report to the nation, *Health, United States*. This report presents key highlights and findings from federal health data systems.

#### Conclusion

To date, there is no national dataset capturing bereavement prevalence and incidence as our nation is facing unprecedented loss. Unequivocally, COVID-19 has reshaped our national landscape and is a seminal moment detailing how lack of quality bereavement care taxes individuals, families and the nation. Bereavement and its unintended outcomes are inextricably linked to many of our federal health agencies missions, priorities, and programs.

With more than millions of individuals in the United States suffering the loss of a loved one to COVID-19 and countless others who have lost a loved one to suicide, homicide, overdose, and chronic diseases like cancer and Alzheimer's disease, combined with the growing evidence base about the profound long-lasting effects of bereavement on individuals and community health, bereavement (as a marker of risk) and quality bereavement care should be a priority for CDC and the federal government. Bereavement exposure and by extension its care is an essential element to any comprehensive public health strategy.

Thank you for the opportunity to present this testimony on behalf of millions of bereaved Americans and thank you for your continued leadership.

Sincerely,

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