Evermore Outside Witness Testimony for the Record
Subcommittee on Labor, Health and Human Services, Education and Related Agencies
US Senate

Testimony submission by Joyal Mulheron, Founder & Executive Director, Evermore
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Chairman Blunt, Ranking Member Murray, and members of the Committee, thank you for the opportunity to provide testimony on the fiscal year (FY) 2021 appropriations for key U.S. Department of Health & Human Service Agencies including the Administration for Children and Families (ACF), Centers for Disease Control and Prevention (CDC), Centers for Medicare & Medicaid Services (CMS), Health Resources and Services Administration (HRSA), Indian Health Service (IHS), National Institutes of Health (NIH), Office of Minority Health (OMH), Substance Abuse and Mental Health Services Administration (SAMHSA) and the Social Security Administration (SSA). 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 am submitting this testimony on behalf of Evermore, a nonprofit dedicated to making the world a more livable place for bereaved families by raising awareness, advancing research, and advocating on behalf of bereaved families and the professionals who serve them. The unexpected or untimely death of a loved one is the most common traumatic event Americans experience; many rate it as the worst event of their life. This is not surprising considering suicide, homicide, overdoses, mass casualty events, and now COVID-19. Americans are not only exposed to an alarming number of tragic and often traumatic deaths, but they are encountering a formidable array of barriers to bereavement care that compound their suffering. For too long, access to quality bereavement care has gone unrecognized by lawmakers, lacked funding, and been excluded from federal health agency priorities. Although bereaved families indeed appreciate Congressional "thoughts and prayers," we desperately need your leadership on this immediate, ongoing, and often invisible public health crisis. Epidemics of suicide, opioid overdose, and others including contagious diseases are so vast that our national life expectancy dropped for the first time in a century. Arguably, we need your leadership more than ever.

Bereavement care is an essential element to any comprehensive public health strategy. Our families require more support, practitioners require more tools and resources, and we must understand more about bereavement. Research not only saves lives, but drives innovation.

Rigorous population-level studies, examining the health behaviors and outcomes of millions of people, have concluded that bereaved parents, siblings, children and spouses are all at risk of *premature death* as a result of such loss. This is just the tip of the iceberg: bereavement is an underlying driver of the poor health undermining our nation's health care and social services systems.

Consider the following:

> Today, ten million American children are bereaved, with two million having lost a parent and a projected eight million having lost a sibling. These uniquely devastating losses alter the lifetime success of these youth. Nearly 90 percent of detained youth have experienced the death of a close loved one and 25 percent subsequently joined a gang.

> Research studies have found that “bereaved children experience lower self-esteem, reduced resilience, lower grades and more school failures, heightened risk of depression, suicide attempts, suicide, and premature death due to any cause, drug abuse, violent crime involvement, youth delinquency, and a greater number of, and more severe, psychiatric difficulties.”

If this does not cause alarm and encourage leadership, what will? These few statistics demonstrate that our nation’s federal health agencies should actively work to stem the individual and societal costs of bereavement. The cost of inaction is incalculable.

Our request, *a no-cost appropriation*, will achieve three goals: (1) continue LHHS’ leadership in advancing America’s health, (2) reveal what, if anything, is being done by our federal health agencies to advance bereavement care and (3) alert leadership that bereavement itself poses great risks to our society and should rank within future priority activities. To that end, our research indicates that some agency policies may be inflicting additional harm, including additional trauma, on the newly bereaved.

In March 2020, we worked with the U.S. House of Representatives to advance appropriations report language that would require key federal health agencies to report to Congress what activities, if any, they are conducting to advance bereavement care for Americans. This is the *first time in history* federal health agencies will be asked to report bereavement-related activities.

In an effort to ensure parity across legislative chambers, our hope is that this subcommittee will adopt the same report language that the House advanced. The House-endorsed report language is as follows:

> “*State of Bereavement Care —The Committee is aware of research indicating that individuals and families suffer severe health, social, and economic declines following the death of a loved one — be it a child, sibling, spouse, or parent. The Committee encourages OMH, ACF, CDC, CMS, HRSA, IHS, NIH, SAMHSA, and SSA to examine its involvement in activities to advance bereavement care for families, including documenting and investigating the policies or programs that help or hinder functional coping or adaptive processing and the prevalence and outcome of bereavement events (what relationships are impacted, how the loved one died and their age, risk factors and associated health events or outcomes, and biological or physiological changes in well-being).”*

Federal Agency Rationale and Context

Bereavement and its unintended outcomes are inextricably linked to many of our federal health agencies missions, priorities, and programs. Outlined below is a brief rationale as to why we suggest each of the following federal agencies; however, we are happy to provide more robust explanations upon request:

ACF - Given bereavement’s alarming prevalence and outcomes among children, understanding how ACF integrates, if at all, bereavement care into their programs is imperative. Facilitating functional coping and adaptive processing among these children following the death of a loved one may help stem or reduce other health and human services expenditures, as well as alter the trajectory, independence, and individual success of these children.

CDC - CDC's National Center for Health Statistics (NCHS) collects mortality events, but not who survives them or what outcomes survivors' experience. Bereavement itself is an "injurious" event threatening family health, wellbeing, and economic solvency. Scientific evidence finds that bereaved parents, as a result of their loss, experience cardiac events, immune dysfunction, depressive symptoms, poorer well-being, less purpose in life, more health complications, marital disruption, psychiatric hospitalization, a slight increase in cancer incidence as well as premature death for mothers and fathers as early as age 40.

CDC is one the nation's most trusted sources of data and evidence on population and public health. Given 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 top priority for CDC. The country needs consistent and reliable data on the prevalence and sequelae of bereavement on which to formulate sound policy and practice. These data will also be important as the CDC begins plans for the next decade of Healthy People 2030.

CMS - As the purveyor of Medicare and Medicaid benefits, it touches the lives of millions of Americans at high-risk of experiencing bereavement. Although bereavement counseling is a required Medicare benefit for up to one year of hospice participants, it is not eligible for stand-alone reimbursement. Reimbursement rates are not linked to counseling quality, and researchers have found that there are few, if any, financial incentives for hospice to ensure quality care. These constitute real barriers to bereaved families' ability to function and cope with a death. As the primary funder of hospice benefits, CMS should ensure that the quality of services rendered meet sound professional standards, including incorporating standard quality assurance and improvement practices and a research evidence base. With $1.2 trillion taxpayer investment, it is imperative that we understand CMS benefit coverage, quality, uptake, and reimbursement rationale.

HRSA - HRSA's core demographics, footprint and the health risk profiles of its participants, make it a prime candidate for helping us to understand bereavement offerings and how their programs help (or hinder) an individuals' ability to cope and productively return to the workforce.

IHS - Millions of American Indians and Alaska Natives (AI/NA) experience both a higher portion of disease prevalence and a reduced life expectancy, when compared to their fellow Americans. As a result, AI/AN experience death at younger ages, thus compounding their social and health hardships. Requesting current bereavement-related activities will help elucidate to what extent, if any, IHS is facilitating functional coping and adaptive processing among this high-risk population.

NIH - In 2016, NIH aligned mortality and prevalence data to its spending categories to link its research priorities and our nation's public health needs. Because NIH extracts data from CDC and NCHS (and CDC does not collect those bereaved by mortality events) bereavement does not rank in NIH's 292 top disease conditions or research priorities. However, with a $33 billion budget authority, undoubtedly NIH is conducting useful research as it relates, directly or indirectly, on bereavement care, function, coping, statistics or outcomes. The potency of bereavement as a highly prevalent and impactful stressor capable of altering lifelong developmental trajectories underscores how critical these endeavors are to shaping programs, resources, and driving innovation to meet our pressing public health needs.

OMH - Black Americans are at higher risk of losing a child, spouse, sibling or parent throughout the lifespan when compared to their white counterparts. As a result of these unique stressors, black Americans face greater adversity and cumulative disadvantage. OMH should play a leadership role in understanding bereavement's implications to advance the wellbeing of minority Americans and reduce gaps in health disparities and inequities.

SAMHSA - Substance abuse and mental health distress play a central role in an individual's ability to cope, productively contribute to the workforce and maintain stability following the death of a loved one. Although it has made major strides in addressing childhood trauma, today, none of SAMHSA's five hotlines or three directories of services include care for the bereaved. SAMHSA should examine its current offerings and determine how bereavement integrates into their existing priorities and programs.

SSA - SSA offers programs to the bereaved, but many of them are not being utilized or have not been updated for decades. Consider, only 45 percent of bereaved children access Social Security benefits following the death of a parent, thus leaving them at greater risk of poverty, academic failures and use of other social programs. Further, the lump sum death benefit (LSDB) program offers $255 to bereaved individuals to help subsidize the high cost of funerals (estimates range from $7,000 to $12,000). LSBD has not been updated since 1954. SSA's programs, data and policies warrant examination.

Thank you for the opportunity to present this testimony on behalf of bereaved Americans.