









# Hicken Pain

Children Who Lost a Parent or Caregiver to COVID-19 and What the Nation Can Do to Help Them

#### SOCIAL POLICY ANALYTICS

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#### COVID COLLABORATIVE

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## Open Letter to the American People

America's COVID-19 crisis has not ended, but we have begun to count the staggering size of our loss. An outbreak beyond precedent has led to deaths on the scale of a global war. These tragedies were experienced in the isolation of pandemic precautions and hospital wards. Hundreds of thousands have died at the same time, but largely apart. An event causing mass casualties has left lonely grief.

Some of the cruelest pain has come to a group with the least capacity to understand and cope with it. More than 167,000 children—roughly one in 450 of all children in the United States—have lost at least one of their caretakers to COVID. More than 70,000 children have been deprived of a parent. Nearly the same number have lost a grandparent who lived in the home. At the extreme of this need, more than 13,000 children have lost their only in-home caregiver.

For these children, COVID has done more than hurt their lives; it has ended their world. Especially early in development, a parent or family caregiver fills a child's entire sky—providing most of his or her stability, confidence and care. The sudden, seemingly unexplainable departure of a caregiver leaves a void of affection and direction that each child will struggle to fill. And the outcome of that struggle will determine much about their future. The traumatic loss of a caregiver has been associated with depression, addiction, lower academic achievement, and higher dropout rates. It represents lost potential for individuals and our society.

COVID can strike anyone, but it concentrates its cruelty on certain groups. Because of racial inequities in American healthcare, and because people of color risked greater exposure as frontline workers, a higher proportion of minority caregivers have lost their lives. This means COVID's hidden loss falls heaviest on minority children. Non-White children lost caregiving adults up to nearly four times the rate of their White peers. Any solution we seek must accommodate this grim reality. The grief and confusion of these young people is concealed by being scattered across the country. Unless we know one of them personally, empathy requires analogy. COVID's hidden loss is the moral equivalent of children calling to us from the wreckage of a collapsed building. We must do everything necessary to rescue and comfort them.

There is no precedent for this challenge, but we have a good idea how this kind of grief can be confronted. The vast majority of these children do not require treatment in a clinical setting. But all of them require loving people in their lives who understand the depth of their loss and are dedicated to their well-being. This may come from extended family, peer support groups, grief camps, or mentoring programs. A smaller group—perhaps 5 to 10 percent of children—will experience traumatic, prolonged grief that requires clinical intervention. In every case, we need to act quickly to provide these children with the tools of resilience.

What follows is a comprehensive blueprint for outreach and care for children who have lost caregivers during the pandemic. It is a plan that requires action from all sectors across the nation in a manner that transcends politics and other divisions.

COVID-19 has challenged us as a people as seldom before. Some things we have liked about ourselves. Some things we have not. Now we have a chance to show that America is a single moral community, dedicated to the welfare of children carrying a heavy burden of pain and loss. This is an effort we can undertake as a united country. We experienced the unity of grief; now we must embrace the higher unity of hope and possibility. There can be no partisan division in caring for these children in need. We know they have hard paths ahead. But we want each of their difficult stories to be stories of recovery and healing. We want each child to know they are not alone. And we hope others will join us as we stand beside these hidden victims during the toughest days of their lives and beyond.

## **Executive Summary**

The COVID-19 pandemic has been the single deadliest acute public health crisis in American history, exceeding the death tolls of both the 1918 flu and HIV/AIDS since the 1980s. These deaths are a salient threat to the functioning of family and social networks. Among the more than 760,000 deaths from COVID-19 in the United States in the last 22 months are many parents, custodial grandparents, or other caregivers on whom more than 160,000 children had relied for financial, emotional, and developmental support. Many of these children—aged under 18—already faced significant social and economic adversity, and these devastating losses can impact their development and success for the rest of their lives.

Non-White children suffered losses up to nearly four times that of White children. While significant losses occurred in all states, half the losses were found in five states. The vast majority of these children will experience normative grief that can be managed through non-clinical, community-based interventions, such as grief camps, peer support, mentoring programs, and the Family Bereavement Program. Other children may experience traumatic, prolonged grief requiring clinical treatment. In all cases, supports and care will be needed.

Addressing the needs of these children who experienced such loss must be a high priority,

**In short**, the children most likely to lose a parent or other caregiver to COVID-19 are most likely to have faced significant previous adversities that hinder their ability to successfully adapt to new experiences of adversity or trauma. Children who have lost a co-residing parent, grandparent, or other caregiver are presently facing personal tragedies occurring in a period of national and international uncertainty, stress, and turmoil, and policymakers and other leaders face a responsibility to minimize the clinical, social, and economic impacts these children face.

and this report provides guidance to leaders in the public and private sectors. First, we estimate the number of children and teenagers under 18 years of age who have lost a parent or other co-residing caregiver to COVID-19, and then we discuss the impacts of parental and caregiving loss on children and

adolescents. Following that, we review evidence of interventions commonly used to address grief and other traumas that may be applicable in this context. Finally, we offer a set of recommendations that integrate best practices into the current policy and political realities that we face as this crisis persists; and we call on the nation to act.

#### **Key Findings**

#### ESTIMATING COVID-19-RELATED LOSS ON CHILDREN

The magnitude of the total loss of life from COVID-19 outpaces deaths in every U.S. war, and the impact of that loss on children in less than two years is profound. The numbers present a challenge to the nation.

- **Total Loss:** 167,082 children under 18—more than one out of every 450—lost a parent or other in-home caregiver to COVID-19.
- Loss of A Parent, A Grandparent Caregiver, or Their Only Caregiver: More than 72,000 children lost a parent to COVID-19 and over 67,000 lost a grandparent caregiver in the home, while more than 13,000 children lost their only in-home caregiver.
- Loss by Age: Seventy percent of caregiver loss (117,948) affected those aged 13 and younger. Fifty percent of caregiver loss (83,798) was among elementary and middle-school age children (5-13 years old) and 20 percent (34,150) was among those from birth through 4 years old. More than 29 percent (49,134) of caregiver loss affected youth who were high school age (14-17 years old).
- Loss by Race & Ethnicity: Non-White children lost caregiving adults at higher rates than their White peers. American Indian and Alaska Native and Native Hawaiian and Pacific Islander children lost caregivers at rates of nearly 4 times the rate of White children; Black and Hispanic children at nearly 2.5 times the rate of White children; and Asian children at 1.6 times that of White children.
- Loss is Concentrated, but Also Found in Every State in the Country: Five states—California, Florida, Georgia, New York, and Texas—accounted for half (50 percent) of total caregiver loss from COVID-19. Arizona, Mississippi, New Mexico, and Texas had the highest rates of caregiver loss, while Maine, New Hampshire, Vermont, and Wisconsin had the lowest rates.
- Loss by Geography, Race, and Ethnicity: The District of Columbia had the widest disparities in caregiver loss, where Black and Hispanic children's rates of caregiver loss were 11 and 18 times the rates of loss for White children, respectively. The rates of caregiver loss for American Indian and Alaska Native children were more than 10 times those of White children in Mississippi, New

Mexico, North Dakota, South Dakota, and Utah.

#### IMPACTS OF LOSS OF A PARENT OR CAREGIVER

Beyond the data are the impacts of such loss on children.

- **Grief is a normal process following loss**, though how it manifests varies as a function of the age of the child, the characteristics of the loss experience, and the quality of the supports, especially from the surviving caregiver.
- The vast majority (90 to 95 percent) of children will experience a normative course of grief that can be managed through existing familial and social supports and non-clinical community-based interventions like grief camps, peer support groups, or a mentoring program. The remaining 5 to 10 percent may experience traumatic, complicated, or prolonged grief, for which clinical therapy may be required.
- The consequences of losing a parent or other caregiver can persist through a child's lifetime. They can include depression, post-traumatic stress disorder (PTSD), anxiety, lower rates of academic attainment and higher dropout rates, higher rates of alcohol and other substance use, suicide, and reduced employment.

## ASSESSING THE EVIDENCE OF PREVALENT INTERVENTIONS FOR GRIEF AND TRAUMA

Decades of study around the interventions for grief and other traumas provide guidance on the way forward.

- **Group peer-support and grief camps** are commonly used non-clinical interventions to normalize feelings of loss and provide emotional support from peers and counselors. They reduce or prevent symptoms of anxiety and depression and decrease the likelihood of complicated grief.
- **Social and emotional learning** in schools and early childhood programs can help students and families cope with feelings of loss in contexts of positive relationships, but surveys show more work needs to be done to prepare educators and schools to help bereaved children.
- Evidence-based mentoring programs can support bereaved family members. Though evidence focused on bereaved children is lacking, trauma informed mentoring programs for youth facing a high degree of adverse childhood experiences have a robust evidence base demonstrating positive impacts on mental health, educational attainment, civic engagement, and healthy relationships with peers and adults.

- The Family Bereavement Program (FBP) provides group counseling to be eaved children and a surviving caregiver with a focus on improving the caregiver's mental health so they can better attend to the needs of those in their charge. FBP is well-developed with a robust evidence base.
- Cognitive Behavioral Therapy (CBT) is an evidence-based clinical intervention for children

experiencing more severe forms of grief, including childhood traumatic grief (CTG) or symptoms of prolonged grief disorder (PGD), with noted improvements in anxiety, depression, PTSD, and traumatic grief. Variants of trauma and grief-focused CBT have been developed over the last 15 years, and they tend to be more effective than CBT that is not specific to grief and other treatment modalities.

Approximately one out of every 450 children and adolescents under age 18 in the United States lost a caregiver to COVID-19.

#### Recommendations

Based on best evidence and practice, there are important steps that policymakers, educators, and leaders in the nonprofit and private sectors can take to help children who have lost a parent or other caregiver to COVID-19. We recommend:

- Undertaking a coordinated strategy to comprehensively identify children who have lost a parent or caretaking guardian to COVID-19 through schools, community-based organizations, primary care settings, and the use of municipal administrative records. Some of these efforts can be accomplished through executive action, and others through federal, state, and local governments and partnerships with private service providers. Federal funding may be required to facilitate action by state and local governments and non-governmental stakeholders.
- **Creating a COVID-19 Bereaved Children's Fund**, drawing lessons from those established for the families of September 11, 2001 and HIV/AIDS orphans. This fund can provide short-term financial assistance and support the mental health and other needs of COVID-19 bereaved children. Priority attention should be given to the 13,000 children who lost their only in-home caregiver.
- **Creating a public education campaign** that encourages families, youth, and children to seek help and connects them to resources in their communities and schools.

#### SCHOOL AND COMMUNITY-BASED INTERVENTIONS

- The federal government should provide funding and technical assistance through the U.S. Department of Education and the U.S. Department of Health and Human Services to expand the grief-competence of schools, community-based organizations, faith-based institutions, and other community leaders. We recommend federal policymakers provide funding and technical assistance to expand the capacity of community-based organizations to manage "light-touch" bereavement interventions like peer support and mentoring programs with the support of national-level organizations and through additional public and private funding.
- Federal policymakers should expand access to high-quality early childhood programming for COVID-bereaved children, with categorical eligibility for publicly funded programming like Head Start and Early Head Start and the waiving of parent-activity requirements and co-payments.
- School districts, states, and the federal government should support the expansion of the integration of social and emotional development and evidence-based mentoring within academic learning, including the skills of building and sustaining supportive relationships, self-awareness, self-management, resilience, collaboration, and problem-solving. States and school districts should make COVID-bereaved children a priority for social and emotional learning through the Collaborating States Initiative and Collaborating District Initiative led by the Collaborative for Academic, Social, and Emotional Learning (CASEL). Surveys show the vast majority of students, parents, teachers, and administrators support such efforts for all students and that such development is critical to enable bereaved children to cope with loss.
- National grief-focused nonprofits in coordination with community-based organizations should develop a registry of available grief services to inform referral efforts and make those widely available through communities, states, and national platforms.
- **Strengthen social service systems** providing critical resources to COVID-bereaved children and their families, which will have impacts beyond the immediate crisis.

#### **CLINICAL INTERVENTIONS**

• **Expanding access to mental healthcare in schools** through additional training plus partnerships with external mental healthcare providers.

- **Expanding access to outpatient mental healthcare** through increased co-location of services, integrated behavioral healthcare, and telehealth access. Pending rule changes from CMS, with some amendment, can drastically improve access to teletherapy.
- Reducing cost-sharing responsibilities or facilitating pro bono provision of outpatient mental healthcare associated with COVID-19-based parental loss.

#### ECONOMIC INTERVENTIONS

- **Congress should make permanent the Child Tax Credit** as revised by the American Rescue Plan, which will benefit families experiencing loss.
- The White House and Congress should provide categorical eligibility for COVID-19 bereaved children for a range of means-tested economic supports, including TANF, SNAP, Medicaid, and the recently amended Child Tax Credit.
- State, tribal, and local governments should provide pre-emptive outreach, case management, and eligibility screenings for families with a COVID-19 decedent to facilitate enrollment in protective supports and services.
- The federal government should improve outreach and accessibility for FEMA's Funeral Reimbursement Assistance program, and Social Security Death and Survivor's Benefits.

#### ADDITIONAL RESEARCH

Through funding, convening, and other supports, the federal government and foundations should facilitate research that:

- Improves the enumeration and identification of COVID-bereaved children, by race, ethnicity, income, and age, with a focus on socioeconomically vulnerable populations.
- Improves our understanding of the long-term impacts of parental and caregiver loss.
- **Supplements the field's sparse evaluation literature** by rigorously testing a range of prevention and therapy-focused grief services through randomized controlled trials when possible.
- Further documents the clinical impacts of COVID-19-induced parental bereavement on children, with a comparison to child bereavement for other causes and in other circumstances.
- Further documents state, tribal, local, and nonprofit best practices in addressing the needs of COVID-bereaved children.

## Introduction

The COVID-19 pandemic has been the single deadliest acute public health crisis in American history. As of November 15, 2021, more than 760,000 Americans have died from COVID-19 infections, exceeding U.S. mortality from both the 1918 flu epidemic and HIV/AIDS over the last 40 years.<sup>1,2</sup> These deaths are a salient threat to the functioning of family and social networks. Though largely ignored in the pandemic policy-response to date, the death of a caregiver represents a potentially catastrophic way in which COVID-19 can influence development not only during childhood but across one's life. Among these 760,000 deaths are parents, custodial grandparents, or other caregivers on whom children and adolescents relied for financial, emotional, and developmental support.<sup>3-7</sup>

A high priority for policymakers is estimating the number of children made acutely vulnerable because their caregiver died from COVID-19. The impacts of losing one or both parents—defined by the United Nations as "orphanhood" for anyone under the age of 18—are well documented.<sup>8–13</sup> These can include poor mental health, poor academic outcomes, increased rates of high school dropout, economic turmoil, and general instability in the short-term, with long-term consequences like higher rates of alcohol and other substance use disorders, worse peer relationships, and reduced employment into adulthood.<sup>10,11,14–17</sup> These adversities may be especially salient for the 26 percent of children and adolescents under 18 living with only a single parent. These households are disproportionately low-income and Black or Hispanic, meaning that economic hardships and structural racism predating the pandemic and the death of a caregiver make resilience in the wake of trauma even more challenging.<sup>18</sup>

Changes in the American household over the last 70 years require us to look beyond biological parents when considering the impacts of caregiver death on children. Nearly one-quarter of children live in a multigenerational household (one with a child, parent, and grandparent) by age five, a household structure more common among non-White children and among adults with low-educational attainment.<sup>19</sup> The consequences of a grandparent's death can resemble those of parental loss, especially when the grandparent provides nurturing and material support. More than one-third of co-residing grandparents are responsible for meeting most of their grandchildren's basic needs, and they are about 30 percent more

likely to live below the federal poverty level.<sup>20</sup> Nontraditional households extend beyond biological relatives, and a growing number of American households are "doubled up" in housing with non-family members, who may assume some caregiving role. Data from disparate Census Bureau surveys tell roughly the same story: doubled-up households are nearly twice as likely to be poor, to have less education, and to be led by a Black or Hispanic householder.<sup>21</sup>

Moreover, low-income and Black and Hispanic populations were also most at-risk of COVID-19-related mortality.<sup>22,23</sup> Many occupied low-wage essential positions that kept them in proximity to customers and coworkers throughout the pandemic.<sup>24</sup> These communities also have higher rates of comorbidities associated with COVID-19 mortality, including overweight, obesity, diabetes, hypertension, and other morbidities.<sup>25,26</sup>

In short, the children most likely to lose a parent or other caregiver to COVID-19 are most likely to have faced significant previous adversities that hinder their ability to successfully adapt to new experiences of adversity or trauma. Children who have lost a co-residing parent, grandparent, or other caregiver are presently facing personal tragedies occurring in a period of national and international uncertainty, stress, and turmoil, and policymakers and other leaders face a responsibility to minimize the clinical, social, and economic impacts these children face.

This report seeks to guide government, nonprofit, business, and philanthropic leaders to assist the most vulnerable COVID-19 survivors. First, we produce estimates of COVID-19-related loss to children for each state by age of the child and by race and ethnicity. We also highlight the additional adversities already faced by disadvantaged children, allowing policymakers and other leaders to target interventions based on social risk factors and children's developmental stage. Second, we discuss the clinical and economic consequences of COVID-19 bereavement on children and families and provide recommendations for addressing them and review the evidence for several relevant interventions. Finally, we provide recommendations for comprehensive action, for school, community-based, clinical and economic interventions, and for additional research to continue to build the evidence and innovate over time.

## Estimates of Caregiver Loss to COVID-19

We estimate childhood and youth caregiver loss from a COVID-19 infection by combining COVID-19 death counts by state, race/ethnicity, and age group with population data from the American Community Survey's 2019 Public Use Microdata Sample (PUMS), which provides representative household and person-level samples of the United States. This unique combination of data allows us to create a child-centric assessment of caregiver loss by race, ethnicity, age, and state. Additional methodological details can be found in Appendix II.

Children from racial and ethnic minority groups were, by far, **more likely to lose a caregiver** than White, non-Hispanic children. Approximately one out of every 450 children and adolescents under age 18 in the United States, 167,082 in total, lost a caregiver to COVID-19 through mid-November 2021. More than 72,000 of them suffered the death of a parent, and 13,047 lost their only at-home caregiver. More than 118,000 children losing caregivers were under the age of 14. Children from racial and ethnic minority groups were, by far, more likely to lose a caregiver than White, non-Hispanic children. More

than 100,000 non-White children lost a caregiver to COVID-19; the largest group were Hispanic children (64,163). American Indian and Alaska Native children and Hawaiian and Pacific Islander children had the highest rate of caregiver loss at nearly four times that of White children. High-population states had the highest number of children who lost a caregiver. Five states—California, Florida, Georgia, New York, and Texas—account for half (50 percent) of total caregiver loss, though Arizona and Mississippi had the highest rates of caregiver loss. Tables and maps are displayed in Appendix I.

The numbers presented throughout this section are conservative estimates, representing the lower bound of COVID-19 related caregiver bereavement. There is ample evidence of undercounting of deaths from

COVID-19 infections—this was particularly true in the early days of the pandemic when infections and deaths were heavily concentrated in urban, low-income areas with higher concentrations of racial and ethnic minorities. This means that perhaps the most vulnerable children are the ones most likely to be excluded from this estimate. Second, additional deaths are attributable to the increases in suicides and decreases in healthcare access that were compounded effects of COVID-19. Third, we do not include deaths of non-custodial parents or other caregivers who do not live with the child but whose loss may trigger the same level of grief.

#### **Familial Roles**

Our results estimate that 72,699 children lost a parent and 94,383 lost at least one other caregiver in the home. Other sorts of caregivers were frequently co-residing grandparents, and their higher rate of loss is consistent with COVID-19 mortality rates that increase with age.

More than 13,000 children lost their sole caregiver to COVID-19. While all instances of caregiver loss are a threat to a healthy child and family functioning, these children are likely at highest risk because they lack an established second caregiver while they also were likely already more socially and economically vulnerable due to other factors. This group of children warrant special attention in the policy and practice responses to COVID-19 bereavement. Differences are apparent in caregiver loss by family roles based on race and ethnicity, as described below.

#### **Disparities by Race and Ethnicity**

Non-White children had the highest rates of caregiver loss. Nationally, Non-Hispanic Black and Hispanic children lost caregivers at rates more than double those (2.4 and 2.5 times, respectively) of White children, and American Indian or Alaska Native (AI/AN) children and Native Hawaiian and Pacific Islander children had the highest rate of caregiver loss, at nearly 4 times the rate of White children. These differences are due to two factors: higher COVID-19 death rates and larger average household sizes, with co-residing grandparents or others being more common among non-White populations. These disparities are most concentrated in the youngest age cohort.

These disparities varied by state and territory. The District of Columbia had the highest rates of Black and Hispanic caregiver loss relative to their White peers—11 and 18 times higher than the rates of loss for White children, respectively. In general, states with larger American Indian populations had the highest

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risk of COVID-19 caregiver loss for AI/AN children. In Mississippi, New Mexico, North Dakota, South Dakota, and Utah, the rate of caregiver loss for AI/AN children was more than 10 times that of White children.

There were differences by race and ethnicity in family roles among lost caregivers. Black children had the highest rates of sole caregiver loss, consistent with higher rates of COVID-19 mortality and single motherhood among the Black population. AI/AN children had the highest rates of loss for all caregiver roles except sole caregiver, and Black, Hispanic, and Hawaiian and Pacific Islander children were also notably high relative to their White peers across caregiver categories. Asian children had rates similar to those for White children for most categories of caregiver loss but lost grandparents at more than double the rate.

#### Caregiver Loss by Child's Age

Older children and teens were more likely to lose a caregiver to COVID-19 infection, though considerable numbers of younger children also experienced loss. A meaningful number of children in each age group lost a caregiver to COVID-19. About 20 percent (34,150) of children with a caregiver death were in the youngest age group (birth through 4 years old), 50 percent (83,798) were elementary or middle-school age (age 5 through 13 years old), and 29 percent (49,134) were high school age (age 14 through 17 years old). While all children and adolescents warrant support when they lose a caregiver, those supports should be tailored to their developmental needs. This is especially true for young children who rely on caregivers to meet a more diverse set of needs.

Correcting for the size of each age-band, 14- through 17-year-olds were most likely to experience the loss of a caregiver, followed by 5- through 13-year-olds, and then the birth- through 4-year-olds group. This is again consistent with COVID-19 mortality rates that increase with age: older children are more likely to have older parents and grandparents as caregivers. However, we reiterate the above-described differences in child age by race: Children of color or Hispanic ethnicity who lost a caregiver, as a group, were more likely to be younger compared to White, non-Hispanic children. This underscores the increased levels of risk borne by children and adolescents from historically marginalized backgrounds.

## Parental Loss in the Contexts of Development and the COVID-19 Pandemic.<sup>1</sup>

The death of a parent or other primary caregiver is a severe, though not terribly uncommon, occurrence, and there is a large body of related research through which we can understand the impacts of a COVID-19 death on children. Approximately 5 percent of children in the United States will lose a parent or guardian by the age of 15.<sup>27</sup> This tragedy poses a threat to short and long-term outcomes for that child, warranting immediate and sustained mobilization of support to promote resilience. When a parent dies, the child is challenged in the short-term to cope with grief and the circumstances of the loss through bereavement.<sup>II</sup> The child must meet this challenge without the lost parent, who may have been a primary resource for structuring his or her experiences and co-regulating their emotions.<sup>28,29</sup> Children and families are challenged to adapt in other ways to the parent's absence in both the short and long terms. Family functioning must be preserved so that children's needs (e.g., cognitive, emotional, relational, academic) continue to be met across development.<sup>30</sup>

Despite these challenges, many children who experience the death of a parent go on to show resilience. Resilience refers to the absence of serious impairments in functioning across important areas of living. For example, resilient children are able to have positive relationships with family and friends, show good academic achievement and attainment, and have positive emotional/behavioral health and the like,

<sup>&</sup>lt;sup>1</sup> This section is based largely on research that predates the pandemic, given a lack of studies specifically about childhood bereavement of parents who died of COVID-19. We extrapolate key findings to the current situation.

<sup>&</sup>lt;sup>II</sup> In this section we use the terms 'parent' and 'primary caregiver' interchangeably for simplicity's sake; Primary caregivers do not need to be biological parents and processes of childhood bereavement and adaptation are similar or the same.

despite experiencing some event or circumstance that threatens good outcomes. Modern developmental science explains that this resilience comes about because of a combination of contextual and individual factors in children's lives.<sup>31</sup> While individual factors are important, resilience is frequently found in how children's contexts support them when it comes to responding to threats like parental death and bereavement. Resilience is most common when children's contexts recognize and respond to their developmental needs. This section discusses the dual developmental processes associated with parental death, namely managing grief and adaptation through bereavement in the short and long terms. We present normative processes associated with resilience as well as findings on maladaptive processes that portend problems.

#### **Grief and Bereavement**

Grief is a normal and usually intense emotional reaction that follows loss and the realization that the individual will need to go on without the deceased. Children of all ages experience grief and enter a process of bereavement when a parent dies, though the emotional experience and behavioral manifestations are highly individual. They also vary as a function of the circumstances of the loss, the child's age, and developmental level.<sup>32,33</sup> Many children feel depressed or anxious, and grief often resembles many aspects of clinical depression. Some may feel guilt related to the circumstances of the loss. Still others may experience anger, sometimes directed at the person who died or toward someone else. Crying is common but not universal. Children may lose interest in activities that they used to enjoy. Behavior problems are not rare. Younger children may be more likely to display anxiety symptoms, such as separation anxiety and clinging to remaining caregivers, and may repeatedly ask questions about the deceased caregiver, not understanding the permanency of death.

The death of a parent will continue to be a profound experience that affected children will revisit throughout their lifetimes, though pronounced grief is relatively temporary. In most cases, grief peaks in the first 12 to 18 months following loss, although grief tends to be phasic, meaning children and their family members may experience periods of reemergent, intense grief from time to time for months and years after the initial bereavement period.<sup>29,32</sup> During the first 12 to 24 months following the loss, successful childhood bereavement typically involves accepting the loss and experiencing the emotional distress that accompanies it, coping with changes in the environment and the child's self-perception without the lost caregiver, making meaning from the loss, and forming close relationships with other adults who can help meet the child's developmental needs.<sup>34,35</sup>

About 5 to 10 percent of bereaved children are thought to experience some clinical level of impairment.<sup>36</sup> Some experience prolonged grief that persists, often signaling some difficulty or complication in the bereavement processes. Prolonged grief predicts increased risk for later and lasting problems, such as depression, anxiety, suicide, and symptoms of post-traumatic stress disorder, though duration of symptoms might be less important in children.<sup>29</sup> Grief can also co-occur with symptoms of post-traumatic stress disorder, referred to as traumatic grief. In brief, symptoms of traumatic stress become associated with the loss, often in a way that interferes with successful coping and bereavement.<sup>37</sup> For example, children might avoid thinking or talking about the lost parent because of intense memories about the events surrounding the death. Children might also avoid contexts that remind them of the death, like school, activities, or friends of the deceased parent. Children who experience traumatic grief are at particularly high risk of persisting mental health problems and other impairments in functioning.

#### Adaptation to Parental Loss

Promoting resilience among parentally bereaved children requires attending to both the shorter-term bereavement processes around the time of the loss as well as the longer-term processes of supporting the child development without the parent.<sup>30</sup> When a parent dies, most children are cared for by their other parent or another close family member, with a small minority entering the child welfare system.<sup>38</sup> In the short term, the remaining parent or new caregiver may be experiencing their own grief, which may make it difficult to optimally respond to children's needs. Caregivers and other family members' adaption following the loss and how well families ultimately function have important implications for a child's wellbeing. Many grieving families draw on friends, extended family, religious communities, and other sources of social support, all of which are important predictors of resilience to a wide range of developmental risk factors.<sup>39</sup>

#### Long-Term Risk Indicators for Children Who Experience Parental Loss

Parental loss is associated with a higher risk of poor outcomes into adulthood. Though 90 to 95 percent of children who experience the death of a parent will not ultimately manifest problems, longitudinal studies of groups of children who experienced parental loss often find higher rates of mental health diagnoses like depression and anxiety,<sup>40–42</sup> higher rates of alcohol and substance abuse disorders,<sup>43</sup> worse peer relationships,<sup>44</sup> higher rates of suicide, and lower rates of educational attainment, adult employment, and other indicators of human capital.<sup>44–47</sup> Studies have tested for characteristics of the experience that may

help target efforts to promote resilience where they are needed most. These include different aspects of the loss itself, as well as characteristics of the child and family.

#### YOUNG CHILDREN MAY BE AT HIGHER RISK.

Parental loss is especially pernicious during early childhood (infancy, toddlerhood, and preschoolaged). Studies based on samples limited to middle childhood and adolescence tend to find no differences in child outcomes based on the age of the child when the death occurred.<sup>44</sup> Parental loss, however, during early life (birth to age 5 years) appears to put children at higher risk for later poor mental health and academic outcomes compared to older children who experience parental loss and among younger middle-childhood aged children.<sup>40,48,49,50</sup> This is consistent with rapid developmental change and plasticity in early childhood. Major stressful disruptions during this period can be especially detrimental to the child's developing physiology and cognitive and social/emotional skills if they are not protected by the presence of one or more warm, consistent, and nurturing caregivers.<sup>51</sup>

#### CAUSE AND SUDDENNESS OF THE PARENTAL DEATH.

Mental health and other problems are more likely when childhood parental loss is caused by an external factor, such as an accident, disaster, homicide, or suicide.<sup>40,52,53</sup> These deaths are usually sudden and unexpected. Sudden deaths are more likely to involve trauma and generally permit less time for social supports and

#### **Childhood resilience**

following parental death during COVID-19 will be especially challenged because already-disadvantaged families are more likely to be affected. COVID-19 is disproportionately impacting groups that are less likely to be well-equipped to successfully cope because of longstanding societal disinvestment.

other protective factors to mobilize in anticipation. In contrast, deaths due to illness are more likely to involve a longer period of treatment and, sometimes, hospice during which children, families, and broader social support systems can anticipate the loss and prepare to cope.

#### MATERNAL VERSUS PATERNAL DEATH.

The literature paints an inconsistent picture about whether the death of a mother or father has a distinguishable impact. Some studies find a stronger relation between some mental health problems and maternal death,<sup>54</sup> others show a stronger influence of paternal death,<sup>12</sup> and still others find no difference.<sup>40</sup> Nevertheless, it is critical to note that maternal death may increase the risk of child welfare involvement, especially in some cases for young children.<sup>40</sup> Meanwhile, paternal death may more greatly reduce socioeconomic resources in many families and may be more likely to be a sudden death.<sup>55,56</sup> It is likely that the specific contexts and sequelae of the maternal or paternal deaths are influential. Future research may help disentangle the relative impacts of maternal versus paternal loss.

#### CASCADING NEGATIVE EVENTS.

Developmental science and related fields recognize that adverse experiences tend to accumulate in children's lives, often in non-random ways.<sup>16</sup> Children who experience parental loss may be more likely to encounter subsequent hardships as a result which, in turn, further reduce the likelihood of resilience.<sup>52,57</sup> For example, the loss of a family breadwinner often results in reduced family income. Children sometimes are forced to move residences or may enter the child welfare system in families with fewer socioeconomic resources, previously single-parent households, or in cases where both parents have died. These moves may disconnect some children from teachers, coaches, and other mentors who are powerful resources for children who experience adversity. These additional losses of close relationships, familiar contexts, and routines cascade from the initial parental loss and represent additional challenges when it comes to supporting children's needs and promoting resilience.

#### SUBSEQUENT POSITIVE PARENTING.

Children who received more child-focused, warm, and consistent parenting from the remaining caregiver are more likely to show resilience. Oftentimes the remaining parent is challenged by their own processes of bereavement, grief, and trauma from the loss of a partner and/or co-parent. Parents differ on how much they are able to support and respond to the needs of their children. Positive or child-centered parenting is warm, involves consistent discipline, and is attuned and responsive to the needs of the child. Positive parenting and maintaining positive family routines are associated with fewer mental health symptoms for the child and other correlates of good

functioning.<sup>58,59</sup> These parenting behaviors promote child resilience and positive development through responding to the child's needs while also reducing the likelihood of the child experiencing cascades of additional negative events.<sup>60</sup> Meanwhile, diminished parental functioning and mental health problems are associated with worse child outcomes, presumably in part due to difficulties in providing warm, consistent, child-centered parenting.<sup>44</sup> Evidence-based therapies for parentally bereaved children include components to directly support caregivers in their role as a parent, helping them assist the child in discussing the loss and their feelings as part of their bereavement.<sup>33,61,62</sup>

#### PREEXISTING INEQUITY.

Families where a parent dies are more likely to have experienced other disadvantages compared to other families. For example, affected families are more likely to be experiencing poverty,<sup>9</sup> less likely to have mothers with very high academic attainment, less likely to have fathers in professional jobs, and more likely to have paternal unemployment than intact families.<sup>46</sup> Children who struggle following parental loss are also more likely to have a preexisting mental health diagnosis and/or exposure to trauma, which at least partially accounts for any effect of the loss on later problems.<sup>43</sup> These findings are consistent with a developmental view of risk and resilience: better-resourced children and families with histories of competence are generally more likely to show resilience to new adversities, like parental death, as they tend to have more internal and contextual resources at their disposal. Families who experienced preexisting inequity will be less likely to successfully adapt to adversity, resulting in a higher likelihood of problems.<sup>63</sup>

#### AVAILABILITY OF OTHER SUPPORT SYSTEMS.

As alluded to in the above sections, children and families typically rely on extended social support systems during bereavement, including extended family members, friends, neighbors, faith communities, and teachers, to name a few. Memorialization rituals and traditions help encourage this sort of support, such as funeral rites. Social support is a powerful resource for children who experience the death of a parent and is associated with fewer long-term mental health problems and better functioning.<sup>39</sup> The death of the parent, however, and any resulting cascade of other negative events, can also threaten important social network connections, resulting in an erosion of social support for the child and remaining family members that increases the likelihood of long-term child impairment.<sup>56</sup>

## Applying Existing Findings to Childhood Parental Death During the COVID-19 Pandemic

The experiences of parental death during the pandemic are likely different from experiences of parental death on which much of the childhood bereavement research is based. We consider these differences below, underscoring that there are currently no rigorous findings on childhood bereavement during the COVID-19 pandemic on which to confirm our expectations.

#### PREEXISTING SOCIOECONOMIC AND PSYCHOSOCIAL INEQUITY WILL FURTHER IMPEDE FAMILY AND CHILD RESILIENCE.

COVID-19 infections and deaths in the U.S. have been disproportionately borne by persons from racial or ethnic minority groups.<sup>64</sup> Where socioeconomic data are available, COVID-19 disease burden and mortality have been greater among lower-income groups.<sup>65</sup> Furthermore, the pandemic has had massive economic impacts and caused high rates of unemployment.<sup>66</sup> As seen in our estimates, these factors mean that children and families who experience parental death are more likely to be from socioeconomically disadvantaged groups.

Childhood resilience following parental death during COVID-19 will be especially challenged because already-disadvantaged families are more likely to be affected. COVID-19 is disproportionately impacting groups that are less likely to be well-equipped to successfully cope because of longstanding societal disinvestment. Put simply, resilience occurs when children amass resources that can be used to successfully cope with adversity, such as parental death. Socioeconomic resources can be important, especially to the degree that basic needs are being met and surviving caregivers are able to avoid financial stress that might interfere with parenting, for example. In addition, developmental histories marked by long-standing track records of competence equip children and families with psychosocial skills, like better child self-regulation and more flexible parenting strategies, that can be deployed to cope with new adversities, in this case aiding in bereavement and avoiding cascades of additional negative events.<sup>63</sup> Both sorts of resources are less likely among groups that have experienced systemic disadvantage throughout their development.

#### CASCADES OF NEGATIVE EVENTS ARE ESPECIALLY LIKELY.

Before the pandemic, parental death was related to an increased likelihood that the child and family would experience subsequent hardships as a result. Often these are characterized in the literature as related to socioeconomic factors, such as a reduction in income, a necessary residential move, or lost health insurance.<sup>67</sup> Widespread economic fallout from the pandemic may exacerbate these sorts of negative cascades, especially among families who are already in financial crisis. The timing or extent of these cascades, however, may be initially unclear as a number of

emergency policies have been enacted and supports put in place targeting basic needs. For example, increased efforts to distribute food, increases in food subsidies, eviction and foreclosure moratoria, and the provision of the new child tax credit may be preventing or delaying components of these cascades of negative events in the short term. If or when these protections are removed, it is likely that children experiencing grief and bereavement will be affected, thereby causing harm and reducing the likelihood of resilience.

#### While the context of

the pandemic is unique, studies of children across a range of adversities, even if severe, affirm that resilience is surprisingly common and arises from ordinary processes in the lives of most children, especially warm, consistent relationships with remaining caregivers and other important adults.

#### EXTERNAL SOURCES OF SOCIAL SUPPORT WILL BE CHALLENGED.

Social distancing, restrictions on gatherings, and the interruption of routine supports (e.g., inperson school) associated with the pandemic likely make it more difficult for children and families to engage important social supports. Past research underscored that both the parental death and subsequent cascades of negative events were linked to an erosion of social support that, in turn, were linked to worse outcomes for the child.<sup>56</sup> Pandemic-related restrictions likely exacerbate this process, making it less likely that children and families will be able to easily access social support.

#### TRAUMATIC GRIEF MIGHT BE MORE COMMON THAN BEFORE THE PANDEMIC, BUT THIS IS UNCLEAR.

Grief that includes symptoms of traumatic stress is more difficult to address and is more likely to result in persistent mental health problems, especially in children.<sup>37,68</sup> Traumatic grief is more common in sudden deaths, usually the result of accidents, suicides, disasters, and other mass

trauma events, which also prevent support systems from mobilizing in anticipation of the death, as is more common in deaths caused by illness.<sup>29</sup> While COVID-19 deaths are due to an illness, COVID-19 patients who die are typically in the hospital for barely a week before they pass. This suggests that responses to COVID deaths may be more typical of sudden deaths than those of chronic illness like cancer.

### RESILIENCE WILL BE COMMON AND WILL LARGELY REST ON FAMILY FUNCTIONING.

Despite the multifaceted challenges and ways that parental death threatens good outcomes, most children show resilience. The caregiving context is perhaps the most important contributor to childhood bereavement and adaptation. Remaining parents who are able to adequately manage their own grief and attend to the child's needs, such as through positive parenting, conveying accurate information, and maintaining healthy family routines, are much more likely to bring about resilience.<sup>29,69-71</sup> During COVID-19, parents were additionally challenged by reduced opportunities for social support, reduced or absent routine supports for children (e.g., in-person school and early child care and education programs), increased likelihood of financial crisis, and other pandemic-related factors, all which can immensely increase parents' stress and make positive parenting and healthy family functioning difficult. While the context of the pandemic is unique, studies of children across a range of adversities, even if severe, affirm that resilience is surprisingly common and arises from ordinary processes in the lives of most children, especially warm, consistent relationships with remaining caregivers and other important adults.<sup>72</sup> Resilience will be evident for many children affected by parental death during the COVID-19 pandemic. Promoting resilience for even more of these children requires supporting families.

## Reviewing the Evidence for Preventive and Clinical Interventions

For the 90 to 95 percent of children who experience normative and short-term grief, ordinary supports, including positive parenting, supportive teachers, mentors, peers, and, for some, specialized-but-notclinical services like grief camps and peer-support groups, may be enough to bring about resilience. The remaining 5 to 10 percent of children will experience complicated grief and will be much more likely to show more severe impairments.

The variability in grief eliminates the possibility of a one-size fits-all approach to addressing COVIDrelated bereavement among children, and interventions must be targeted appropriately. Offering a lighttouch service to children with severe needs will leave them vulnerable to severe negative outcomes, while more intensive and expensive interventions to those who need no more than comfort and coping skills may leave that need unfulfilled while wasting scarce therapeutic resources. Here, we review the evidence for common interventions for children who have experienced grief and other traumas.

#### **Grief Camps**

Grief camps are a common short-term intervention for bereaved children. They generally last from a weekend to a week and focus on normalizing death, grief, and responses to grief, in the context of everyday life in the hopes of removing feelings of isolation and angst that come from losing a loved one. Grief camps tend to incorporate outdoor recreational activities like rope courses and rock climbing and artistic endeavors like poetry and painting with peer and counselor-led group discussions about their loved one and their death. Some employ Substance Abuse and Mental Health Services Administration (SAMHSA)-described, trauma-informed therapy, and Cognitive Behavioral Therapy (CBT) techniques for brief periods. Mixing play with difficult discussions about loss and death allows children to have positive

experiences and approach their grief from a place of comfort and security. These camps are designed to be short-term ways to help children develop coping skills, promote resilience, and prepare children to continue their positive development. Some camps involve a surviving parent, though most focus exclusively on the child.<sup>73-76</sup>

Relevant research is largely focused on short-term indicators of psychological and social well-being rather than broader and downstream metrics of more interest to policymakers but offer meaningful insight into that limited set of outcomes. Camps enable children to better articulate their feelings of loss and grief and think of their feelings as "normal." Participants widely felt that they learned healthy grieving and coping skills and gained a sense of autonomy often lost during grief.<sup>73,77</sup> They are also associated with reductions in Childhood Traumatic Grief (CTG) and Post-Traumatic Stress Disorder (PTSD).<sup>75</sup> One camp found a significant decrease in anxiety and improvement in self-concept, a characteristic that is often correlated with self-efficacy, agency, and autonomy. Another found improvements in a child's peer relationships, social and behavioral well-being, and, most directly, indicators of prolonged grief.<sup>78</sup>

Group aspects of the camps are critical to program efficacy. Group therapy and collaborative activities are crucial to forming relationships and normalizing grief, and participants reported that they were critical in helping them "get over (their) anger" because they were "not the only one going through losing somebody."<sup>74</sup> Seeing how other children grieve and hearing other children's stories of grief in moderated, structured settings allow them to learn new coping mechanisms and reinforce the normalcy of their experience.

Some camps involve parents, which can improve communication between the child and parent in a way that enhances coping and the child's ability to speak about their loss.<sup>74,77</sup> This supports findings from the Family Bereavement Program (FBP), discussed below, which found that many of the program's positive impacts in children were mediated by the program's association with improved parenting and better parent-child communication.<sup>61</sup>

Bereavement camps, as any intervention, have limitations. First, we are not aware of notable impacts on depression or on a well-validated measure of varied emotional and behavioral problems, though families note that they found value in the learned coping skills and understanding of death.<sup>79</sup> To the extent there was parental dissatisfaction, it largely stems from a mismatch between the limits of a group camp setting and the needs of the family. In some cases, it was parents themselves having difficulties coping, which the

camps were not meant to address. In others, the child exhibited significant mental health concerns prior to program enrollment, and the parent had hoped that the camp would address this higher-level problem.<sup>76</sup>

#### Mentoring

Mentoring is a widely used and flexible intervention applicable to traumatized or vulnerable children in a wide breadth of contexts, and is perhaps best known as the program model for Big Brothers Big Sisters of America (BBBSA).<sup>80-83</sup> They provide positive relationships and role models to youth in need of additional support from a caring adult, and have more than 5,000 programs across the country.<sup>84,85</sup>

Though a host of mentoring organizations specialize in trauma informed mentoring, Tuesday's Children emerged as a leader in applying that model to bereavement in the face of tragedy, providing mentoring to children of those who perished on 9/11. They have since expanded their work to the children of victims of terrorism, military action, and disasters. There is a wide body of evidence and a diverse set of mentoring models attuned for young people facing various degrees of trauma and loss. Trauma-informed mentoring is especially beneficial for grief-stricken children and adolescents who need support through new relationships with trained and supported adults. The developmental literature emphasizes the importance of these sorts of relationships with mentors outside of the immediate family, especially for children and adolescents who feel abandoned or alone following experiences of loss. A good mentor may be supportive—helping a mentee establish more adaptive perspectives and behaviors.<sup>81</sup>

Studies of mentoring interventions have found that enrolled adolescents were less likely to begin using drugs or alcohol or hit others. They also saw improved attitudes toward school and school attendance, and better relationships with peers and family. On average, caregivers of enrolled children noted positive and persistent changes in children's behaviors.<sup>80,81,86–88</sup> Young people who had mentors report setting higher educational goals and are more likely to attend college than those without mentors; they are also more likely to report engaging in productive and beneficial activities than youth without a mentor.<sup>88</sup> Beyond the nonprofits in which mentoring programs are usually housed, rigorous evaluations have also tested the model in school settings. Though the program improved academic achievement in year 1, those gains were not sustained in the year-2 follow-up and the program did not produce positive outcomes across other domains like problem behaviors or peer relationships.<sup>87</sup> This is a reason for investment in longer-term relationships, especially in response to traumatic loss.

Mentoring programs are more likely to be effective when mentees are more vulnerable, meaning that they have faced significant levels of challenges.<sup>80,81</sup> This may be part of the reason that mentoring programs have been used widely, with demonstrated efficacy, for children of incarcerated parents.<sup>83,89</sup> The acute challenges imposed by the death of a parent or guardian suggest that mentoring may have a similar role to play for the decedents of victims of COVID-19. They are also more effective when services are tailored to the specific vulnerabilities of the targeted youth.<sup>83</sup>

Evaluations of mentoring programs largely exclude policy relevant variables, limiting our ability to assess their effectiveness in many domains of interest. There is also limited relevant cost-benefit analysis. In one study of BBBSA, the program largely broke even and had a \$2,822 net positive return per mentee when the only costs assessed were public dollars.<sup>90</sup> Because the analysis excluded many policy-relevant outcomes with costs associated with them—like public assistance, criminal justice involvement, and substance use disorders—it likely understates program-related financial benefits in the form of defrayed service expenses.

A mentoring program's impact is largely contingent on the quality of the match between mentor and mentee.<sup>82,86,89</sup> Mentor-mentee relationships are most effective with increases in length of relationship, frequency of phone contact, and the mentee's perception of the closeness with their mentor.<sup>81,91,92</sup> Youth whose match lasted for longer than one year had increased self-worth, perceived social acceptance, perceived academic competence, a better relationship with their parent, and decreases in substance use, compared to youth with shorter, or less substantive relationships.

The evidence-based Elements of Effective Practice for Mentoring and the parallel National Quality Mentoring System outline the practices that produce high quality matches. These include screening, training, match support, and closure. Matches are most likely to be successful when mentors are emotionally committed to the mentee and see themselves as instruments of change. Beyond the motivations of the mentor, the quality of the pairing is also vitally important. Programs that place an emphasis on systematically matching youth and mentors have larger impacts than those that did not, and the evidence says that these matches should be built around shared life experiences and ambitions, not exclusively or primarily on commonly held demographic characteristics.<sup>86</sup>

Two other program elements beyond high-quality matches are key to program success. The first is care in program implementation, with emphases on mentor screening, established expectations and guidelines,

professional support, and adaptation. The second element focuses on external partnerships. Some youth will have needs too complex to be addressed through a relatively light solution like a mentorship program.<sup>93,94</sup> Having a network of clinical providers capable of managing those needs can improve program success. There are also efficiency gains when partnerships with clinical providers facilitate the sharing of resources for training and screening mentors. These partnerships may also empower mentors, by providing readily available resources to which to refer mentees who have needs beyond their capability.<sup>88</sup>

#### **Peer Support Programs**

Peer support services have a long history, most notably in mental illness and substance abuse, and are increasingly common as a form of grief therapy. Like mentorship programs, evidence suggests that peer support programs are most efficacious when peers share similar backgrounds, interests, and life circumstances.<sup>95</sup> And, similar to mentorship programs, there is little research of peer support programs' impact on bereavement, though that body of literature is growing.

A systematic review of bereavement-focused peer support programs found robust evidence for the interventions' effectiveness.<sup>95</sup> Recipients of peer support show lower levels of anxiety, avoidance, and depression, and higher levels of grief resolution. Evidence suggests that these benefits exist whether the support is provided through in-person or online interactions, increasing opportunities for well-matched peer supports. Two studies have tested the model's efficacy on youth bereavement. One observational study found that informal peer support resulted in lower depression, better academic and employment functioning, and greater engagement in life generally.<sup>37</sup> In a separate qualitative study, teenagers reported that their peer support group was the most helpful, especially because families were distraught or dealing with the logistics of their parent's death.<sup>96</sup>

Peer support lends itself especially well to particularly difficult or sensitive deaths. Suicide survivors received the most beneficial support from others who experienced the suicide of a loved one. There is

stigma around COVID-19 deaths because of the politicization of public health interventions and restrictions, now including vaccination. Survivors— especially ones who disagree with their deceased loved ones' COVID prevention decisions—may be hesitant to seek support from a general peer support group due to feelings of social stigma.<sup>95,97</sup>

Matching through shared experiences is the core of some support programs in place for bereaved children and families. Two notable examples are the <u>Tragedy</u> <u>Assistance Program for Survivors</u> (TAPS)<sup>98</sup> and an emerging pilot from the <u>Children's Brain Tumor</u> The variability in grief eliminates the possibility of a one-size fits-all approach to addressing COVID-related bereavement among children, and interventions must be targeted appropriately.

<u>Foundation's</u> (CBTF). TAPS provides one-on-one mentoring support to family members of a deceased member of the military, and CBTF runs a Bereaved Sibling Mentor Program for children who had a sibling die from a brain or spinal cord tumor. Both seek to create matches that maximize the overlap in life experiences between the mentor and the mentee. CBTF's program does that, in large part, by focusing on a specific set of cancers. In turn, TAPS attempts to keep matches within the same branch of the military because of the unique experiences of each service.

#### **Family Bereavement Program**

The <u>Family Bereavement Program</u> (FBP) is a bereavement program for children and their caretakers from Arizona State University rooted in a developmental perspective, seeking to enhance protective factors that promote resilience while alleviating risk factors that threaten long-term child development. Unlike other prevention programs that focus primarily on the child, the FBP is explicitly focused on providing care to both the child and their parent or other caregiver because it recognizes the importance of strong parent-child relationships in promoting resilience. The FBP's caregiver and child/adolescent programs consist of 12 group sessions plus two individual sessions for families' specific needs. The program aims to facilitate positive caregiver-child relationships, positive coping self-esteem, and adaptive coping skills and sessions led by masters-level counselors.<sup>99</sup>

The Family Bereavement Program, due to its roots within a university, has a more complete grief-focused evaluation record than any other intervention we examined. More so than the mentorship and grief camp evaluations, the FBP examines psychological and policy-relevant outcomes and finds that impacts are largely positive and long-lasting. Children who went through the program have lower rates of problematic grief, social detachment, and insecurity six years after their participation in FBP. Academically, children with fewer behavioral problems had increased educational expectations, and younger children saw improvements in their GPA.<sup>99-102</sup>

Much of the program's success can be attributed to its effect on surviving caregivers. In one study, effective parenting mediated the effect of the program on GPA for families with younger children, and FBP's improvement in effective parenting led to reduced internalizing and externalizing problems at the six-year follow-up. In general, caregivers of resilient children reported themselves as having fewer mental health problems than the caregivers of children more impacted by a parent's death.<sup>100,103</sup>

The FBP is, of course, not the only program serving a caregiver alongside a bereaved child. *Pathfinders*, for example, is a 10-week therapist-led prevention program run by Judi's House, a bereavement center in Colorado, that centers theory and strengths-based practices in its approach.<sup>104</sup>

#### Therapy—Cognitive Behavioral Therapy (CBT)

For 90 to 95 percent of COVID-bereaved children, preventative, non-clinical measures like grief camps, mentoring, peer supports, and the Family Bereavement Program, should be sufficient to stave off traumatic or prolonged grief. For the remaining 5 to 10 percent who require the most intensive services, psychotherapy is generally the indicated treatment for those that fall into that category.<sup>105</sup>

This support can come in several forms, but the relevant literature overwhelmingly suggests Cognitive Behavioral Therapy (CBT), and variants of CBT focused on trauma and grief, as the preferred treatment modalities for treating either complicated or traumatic grief. CBT is a three to six month talk therapy led by a psychologist, psychiatrist, or licensed social worker to interrupt automatic thoughts and activities to replace them with intentional and mindful ones.<sup>106</sup> By learning how cognitive processes lead to emotions and behaviors, traumatized individuals can interrupt negative thought processes and replace them with more productive ones.

CBT, across its subtypes, has been found to be more effective at reducing Post-Traumatic Stress Disorder, Childhood Traumatic Grief (CTG), and Prolonged Grief Disorder (PGD) compared to other support therapies. Trauma-Focused (TF) CBT is perhaps the most researched and standardized intervention applicable to this challenge—dating back to the 1990s, it has been established as a reliable tool to reduce PTSD, depression, and anxiety symptoms among children who have suffered a range of traumas.<sup>107</sup> A trial of its use in helping individuals suffering from complicated grief showed improved outcomes at three and six months, including significant reductions in anxiety and PTSD. Notably, one trial of an adaption of the CBT program showed that school-based programs with components similar to TF-CBT can be implemented in a school setting, which may make this hard-to-find and often expensive intervention available to students who might otherwise be unable to access it.<sup>108</sup>

Other forms of CBT are especially focused on dealing with death. CBT Grief-Help is a manualized individual treatment for PGD in bereaved children and adolescents and is meant to be combined with parental counseling.<sup>109</sup> A randomized controlled trial found that it reduced depression significantly more than supportive counseling alone. In addition, several versions of CBT-CTG (Childhood Traumatic Grief) have found both statistically and clinically significant reductions in PTSD, depression, CTG, and several other standardized measures of complicated grief.<sup>107</sup> Additional work has found exposure therapy to be a potentially helpful boost for CBT interventions, finding that it reduced complicated grief, PGD, depression, and functional impairment significantly more than traditional CBT alone or supportive therapy.<sup>110,111</sup>

## Recommendations: Addressing the Clinical and Economic Needs of COVID-Bereaved Children

#### Identifying Children Who Lost a Parent to COVID-19

We recommend undertaking a coordinated strategy to comprehensively identify children who have lost a parent or other caretaking guardian to COVID-19. Identifying COVID-19 bereaved children is the first step in providing any type of support. To date, no comprehensive or systematic effort to identify these families or children has taken place, though smaller efforts have sought to identify children or families of specific COVID-19 decedents. One example is the Brave of Heart Foundation, providing up to \$75,000 for families of healthcare workers and others who worked in healthcare settings who died because of COVID-19. They have the advantage of working with specific employers to identify family members of employees who died from COVID-19, yet much of their work has required time-intensive and unscalable efforts like calling funeral homes and reviewing obituaries.

In general, though, children and families of COVID-19 decedents are only identified as they seek services. This, like any count or outreach effort predicated entirely upon service utilization, is certain to undercount and underserve COVID-bereaved children. Below, we provide specific recommendations for a multipronged approach to comprehensively identify COVID-19 parentally bereaved children.

#### UNIVERSAL SCREENING IN SCHOOL AND PEDIATRIC HEALTHCARE SETTINGS

Universal screeners are ideal for identifying rare events like COVID-related caregiver loss. We recommend a White House Executive Order to provide for screening in public and publicly subsidized schools, early

childhood education, and healthcare settings, along with public-private partnerships to facilitate screenings in other circumstances.

Schools are a common source of social needs screenings because they are a nearly universal touch point for school-aged children and because they can provide many services on-site or through partnerships. School systems already screen for household income for the U.S. Department of Agriculture's National School Lunch Program, homelessness, and physical health challenges at the beginning of each school year. The U.S. Department of Education can provide universal screenings in all public schools and Head Start and other pre-K programming run through Local Education Agencies (LEAs). The U.S. Department of Health and Human Services can make the same provisions for screenings through non-LEA Head Start programs, as well as early childhood education programs receiving federal child-care subsidies.

Though screening for social determinants of health is not universal in healthcare settings, the practice has been endorsed by the American Academy of Pediatrics and has become standard in many healthcare systems. A well-documented example is the U.S. Department of Veterans Affairs' (VA) routine screening of housing instability and homelessness among outpatients. From 2012 to 2014, the two-question screener for housing instability and homelessness was administered to 5.8 million veterans and identified 1.7 percent who were homeless but not yet receiving VA homeless services.<sup>112</sup>

The Center for Medicare and Medicaid Services can provide for these screenings at all Federal Qualified Healthcare Center's (FQHC's). The private and philanthropic sectors have a large role to play here. Providers of electronic health records—notably EPIC—can include screening questions as a standard package on the EHR systems it sells to healthcare systems. In addition, widespread adoption by major healthcare systems could provide near-universal coverage, as consolidation of the healthcare system means that larger systems have more reach than they once did.

#### Administrative Data

We recommend that state, tribal, and local governments use administrative records to identify family members of COVID-19 decedents. The federal government can facilitate this effort through funding, technical assistance, and data availability.

Death data maintained by public health agencies can be matched to birth certificates, child education records that include guardianship, or records of government assistance, including SNAP, Medicaid, TANF, homelessness, and others containing information about all household members. Similar efforts have been undertaken in other contexts. Allegheny County, which includes Pittsburgh, used its well-established integrated data system to identify children whose parents died because of opioid use. County health officials found 664 deceased parents on the birth certificates of 989 children under the age of 18, 25 percent of whom were younger than 5 years old.<sup>113</sup>

Municipalities with robust integrated data systems or histories of data sharing are likely first places to explore using such an approach. Matching COVID-19 death records with social services and education systems would be particularly useful for identifying areas of high concentration of children with the greatest economic and clinical needs. In these instances, careful consideration would need to be given to any universal or special privacy protections that are relevant to each class of data (e.g., public versus private records; Privacy law of 1972; HIPAA, FERPA or CR 42 part 2 regulations, etc.), which may be based in either state or federal law, and any restrictions related to specific proposed uses without individuals' consent (e.g., research versus direct contact uses).

Administrative data maintained by private entities can also be used to identify parentally bereaved children. Health insurance companies have access to medical records that include diagnoses and cause of death, and family members enrolled in the same insurance plan as a decedent could be identified with relative ease. Life insurance providers, though they lack diagnosis and cause of death information, have beneficiary information and could systematically identify children of a parent who died of COVID-19.

#### HEALTHCARE SYSTEMS TREATING COVID-19 PATIENTS

Hospital social workers in communication with COVID-19 patients and their families are positioned to gather information about dependents. This information can be collected by social workers from patients directly (while capable of communicating) or from their family members
either pre- or post-mortem. Collecting these data before or immediately proximal to a patient's death may be more likely to have higher capture rates than sweeping, population-level screening tools already discussed. There are, however, notable constraints, including understaffed hospitals, limitations of existing EHR systems, and potential reluctance among overwhelmed family members.

## CAMPAIGN TO ENROLL AND IDENTIFY COVID-19 PARENTALLY BEREAVED YOUTH AND CHILDREN

A broad, mass media campaign could encourage families to identify themselves as survivors of COVID-19. This could include television, social media, billboard, and radio advertising. It would need to be paired with an offer of services or other support to incentivize participation and would—even more than other strategies—require verification of COVID-19 bereavement status.

## VERIFICATION OF COVID-19 RELATED BEREAVEMENT

Any program that provides assistance on the basis of COVID-19 caregiver bereavement should take steps to verify eligibility. This requires eligibility of two relevant criteria:

- The applicant lost a parent or other caretaker; and
- The deceased caretaker died due to COVID-19 infection.

One notable concern is that many COVID-19 fatalities from the pandemic's early months do not list COVID-19 as the cause of death. The Federal Emergency Management Agency has developed <u>relevant guidance</u> for applicants to its funeral reimbursement program which should similarly be incorporated into any program assisting this population.

#### AGGREGATING IDENTIFICATION INFORMATION

We recommend the development of a database that aggregates data from each of the above sources to facilitate a comprehensive and cohesive effort to enumerate and serve children and their families. The federal government has, in recent years and especially during the Biden administration, made notable efforts to collect and aggregate data from local and private sources. The U.S. Department of Veterans Affairs, for example, <u>allows uploads</u> of individual-level homeless service records from local agencies to better identify Veterans. A separate effort from the Census Bureau matched local social service data with federal tax and social service records to

better understand income and benefits use among homeless adults.<sup>114</sup> Any use of identified administrative data for operational purposes must be done with consideration for relevant privacy laws.

## Screening for Complicated or Traumatic Grief

We recommend broad screening for level of need as the critical next step for identifying youth in need of services, and we recommend that this screening occur in routine settings like schools and pediatric care in which we suggest initial identification. In-school assessments can be conducted by school-based resource workers, mental health practitioners, or through partnering external providers. Primary care clinics and community-based organizations can rely on in-house expertise or partner with local public and private mental health agencies as necessary. We suggest screening for complicated, traumatic, or prolonged grief, as well as PTSD, another potential reaction among many bereaved children.

Previously validated screening tools and procedures include:

- The Pandemic Grief Scale;<sup>115</sup>
- The Persistent Complex Bereavement Disorder Checklist;<sup>116</sup>
- The UCLA-Posttraumatic Stress and UCLA-Grief Screening Scales;<sup>117</sup>
- The Grief Screening Scale;<sup>118</sup>
- The UCLA Trauma-Grief Screening Interview;<sup>119</sup> and
- The UCLA PTSD Reaction Index.<sup>120</sup>

Beyond standardized screening procedures, community leaders in regular contact with children also need to remain vigilant. Local governments and grief-focused philanthropies should facilitate trainings and make them aware of training materials developed by the National Child Traumatic Stress Network (NCTSN), among others, understanding childhood traumatic grief, noting warning signs and methods of assessing minors for traumatic or prolonged grief in schools and medical settings. These strategies can also be applied to leaders and staff of community-based organizations and religious institutions.<sup>121</sup>

## Enhancing Community-Based Support for COVID-19 Bereaved Children

In this section, we recommend a series of initiatives to support existing community-based resources critical for supporting the more than 167,000 children who lost a caregiver to COVID-19. As noted,

the majority of COVID-19 bereaved youth will need no more than existing care networks, perhaps supplemented by nonprofit or school-based resources, to avoid problematic grief.

### EQUIP SOCIAL FIRST RESPONDERS TO IDENTIFY GRIEF

Social first responders—trusted adults in schools, religious institutions, athletic leagues, and other community-embedded organizations—already in children's lives should be leveraged to identify and respond to grief.<sup>122</sup> These adults, however, are not usually trained in identifying problematic grief and are generally unfamiliar with services that may be available. We suggest a two-pronged approach to helping equip these adults with information and skills to support children through bereavement.

First, we recommend information campaigns to educate adults in identifying grief and fundamental ways to offer basic emotional support to children in need. The National Child Traumatic Stress Network has a compendium of resources. Local governments can be effective partners in furthering these campaigns because they are trusted resources, are sensitive to local concerns, and routinely contract with small community-based organizations and national athletic programs like Police Athletic Leagues, Little League Federations, early childhood facilities, and networks of faith-based institutions to recruit staff and volunteers to participate in these trainings. In addition, the NCTSN and New York Life have a history of providing these trainings to relevant groups, and we suggest leveraging their experience and resources.

**Second, we recommend wide distribution of grief resource directories.** Practitioners with whom we spoke suggested that youth-facing adults had a significant gap in knowledge of bereavement options. Curated lists of bereavement organizations already exist, including ones from <u>eLuna</u>, the <u>Dougy Center</u>, and the <u>National Alliance for Grieving Children</u>, and these should be integrated into the referral and resource lists of schools and community-based organizations.

## INCREASE THE CAPACITY OF COMMUNITY-BASED ORGANIZATIONS TO PROVIDE APPROPRIATE SERVICES

We recommend providing funding and technical assistance to community-embedded organizations to add or enhance their grief-focused programming. Clinicians and advocates with whom we spoke noted the shortage of community-based infrastructure dedicated to grief services. The solution is not to create a new infrastructure, but to harness the breadth and credibility of nonprofit community-based organizations, religious institutions, social service centers, early childhood programs, schools, and other settings embedded within communities most affected by COVID-19 deaths.

Identifying COVID-19 bereaved children is the first step in providing any type of support. This recommendation includes two components. One is to increase funding to the many existing bereavement centers that already focus on and facilitate peer support and grief-related services. The second is to create the capacity to provide grief-services at other community-embedded organizations, and <u>Tuesday's Children</u> provides a model for doing this. This national organization funds community-embedded nonprofit organizations to integrate bereavement services like youth mentoring and peer support into their existing offerings. Their model may be additionally relevant because it is focused on survivors of decedents in military, terrorism, or other mass-death events, and there may be lessons learned for setting eligibility criteria for programs focused on COVID-19 bereaved youth.

### CARE FOR CHILDREN WHO LOST THEIR ONLY CAREGIVER

We estimate that 13,047 children lost their only at-home caregiver to COVID-19. In addition, there are some children who may have two adults at home that appear as caregivers, but perhaps only one of them is competent to care for a minor. In both cases, a local child welfare system will be involved in finding alternate housing arrangements for the bereaved youth.

We recommend that child welfare agencies charged with finding a new caregiving arrangement for a COVID-19 bereaved child have free or subsidized access to tools that facilitate access to data systems and resources that make such connections. Family Finding, used by many child welfare agencies to access federal and state databases that can identify a child's relatives, is a prevailing option. In addition, we recommend integration of other services to engender supportive and mentoring relationships between the child and caring adults in their lives.<sup>123</sup>

#### STRENGTHEN MAINSTREAM SOCIAL SERVICE SYSTEMS

We recommend making systematic and strategic investments to reinforce and strengthen mainstream social service systems. COVID-related parental loss, combined with the economic and social stresses of the pandemic generally, are putting additional strain on already under resourced social service systems. These include child welfare systems, homeless service and affordable housing providers, and public assistance systems like SNAP, cash assistance, and Medicaid. Current investments in these systems can ensure that vulnerable families have access to the resources they need to pay rent, buy food, and care for their health in this moment of acute need. This support must include resources for the front-line workers in these systems, who face the lion's share of the additional work and the secondary trauma inflicted by these tragic circumstances. Done right, these investments will outlast the current circumstances, and provide support for the millions of vulnerable children who will continue to need help even after the pandemic is behind us.

### THE CASE FOR MENTORING

# We recommend the development of a federally funded mentorship program to ensure that **COVID-bereaved children have access to caring adults.** This should be facilitated through:

- Legislation providing mentoring resources for programs serving COVID-19 bereaved youth; this can be provided through additional support for the existing federal resource, the National Mentoring Resource Center operated by the Office of Juvenile Justice and Delinquency Prevention (OJJDP);
- Leveraging the infrastructure, experience, and coordination of the existing mentoring field leadership of MENTOR, which operates the National Mentoring Resource Center, their Research Board, scaled direct service providers like Big Brothers Big Sisters of America, and those with specific expertise in bereavement mentoring like Tuesday's Children; and
- Leveraging the infrastructure and experience of existing mentorship and peer-to-peer services focused on bereavement, like the Tragedy Assistance Program for Survivors (TAPS) and the Dougy Center.

Mentoring programs likely have the largest infrastructure of any intervention we reviewed. As noted earlier, they already receive nearly \$100 million per year in federal funding, and they have a field-level national organization in MENTOR that exists to advocate, coordinate, and provide training, guidance, and other infrastructure to local mentoring programs. Mentor matching, training processes, and the resources needed to support and enhance mentor-mentee relationships have long been studied and systematized. Many of those regimens are publicly available from BBBSA itself or similar agencies. In its role as a non-direct service field leader, MENTOR could serve as an umbrella organization that coordinates multiple entities, trainings, and other infrastructure, relieving local nonprofits of that burden. Additionally, mentorship programs can be placed in partnerships with schools, leveraging their large infrastructure and normative existence in the lives of youth, and such arrangements should be explored here.

Mentoring programs have also been the beneficiary of federal and private funding targeted toward improving outcomes for particularly disadvantaged or vulnerable groups. The federal government currently provides \$97 million for mentoring at-risk youth through the Office of Juvenile Justice and Delinquency Prevention, including children of incarcerated parents, with an expected increase to \$120 million in 2022.<sup>84,124</sup> Additionally, this funding provides the federally subsidized training infrastructure of the National Mentoring Resource Center. In addition, Congress had introduced legislation called the Foster Youth Mentoring Act, a bipartisan bill "centered on expanding resources available to mentoring programs and organizations that serve young people in the child welfare system."<sup>125</sup>

Given the federal government's history of federal funding for mentoring programs, we recommend legislation providing grant funding to programs serving youth who lost a parent or other caregiver to COVID-19. Given the country's focus on mitigating the repercussions of the COVID-19 pandemic and the universal interest in protecting vulnerable youth, we believe that this can galvanize support among advocacy and service groups like the National Mentoring Partnership and Big Brothers Big Sisters of America, plus—and crucially—bipartisan support in Congress. Absent a federal initiative, we recommend a philanthropic effort to expand mentoring programs in the areas hit hardest by COVID-19.

We recommend that a national program operate through or in partnership with an entity like MENTOR, which has the national experience, evidence-based grounding and coordinating and training infrastructure to successfully bring these programs to fruition. Given the specificity of managing grief, especially for children, we also recommend leveraging the expertise of an established peer-support organization or program, like the Dougy Center or the Tragedy Assistance Program for Survivors (TAPS). Funding alone is insufficient to establish and maintain new mentorship programs at community-based organizations. The relevant literature is clear on the importance of following best practices in implementation and the significant overhead and support necessary for mentorship programs to succeed—an endeavor not achievable by the small, community-embedded and -based organizations that would be responsible for direct program management.

### ENSURE ACCESS TO MATERNAL AND CHILD

We recommend facilitating prenatal, perinatal, and postpartum support for pregnant mothers who lost a partner to COVID-19, with categorical eligibility for Medicaid-covered prenatal care. In addition, we recommend screening and response-plans for caregiver depression and complicated, traumatic, or prolonged grief in pediatric primary care to ensure that caregivers receive the support they need for their young children. Birth outcomes and early development are influenced by maternal experiences beginning, at least, during pregnancy.<sup>126</sup> Furthermore, parental depression and other mental health issues have been shown to impact parenting quality and child outcomes.

In addition, it is a priority to engage COVID-bereaved children in high-quality early care and education programs promoting early development and resilience. These can include home visiting programs, center-based or home-based early care and education programs for young children (from birth to kindergarten), as well as pre-school programs for children aged 3 to 5 years old. All early childhood programs look to provide a context that is responsive to the needs of young children and promote healthy early development. More comprehensive programs, such as Head Start and Early Head Start, also include family workers who collaborate with families to get basic needs met, often through helping the family connect to other health and human service programs for which they qualify. Many program models involve caregiver engagement to support positive parenting.

Head Start curricula that are especially attentive and responsive to children's diverse developmental needs, specifically social and emotional learning, are likely well-positioned to be vital supports for children in processing their experiences of grief in the early childhood program and also for surviving parents to promote their wellbeing and help ensure that children receive positive parenting to effectively process grief at home, as well.<sup>127,128</sup> Furthermore, Early

Intervention programs are specialized services for children with special needs that warrant a higher level of service. It is important that these programs are knowledgeable about grief and bereavement processes for young children and for caregivers.

The heavy role of federal and state agencies in early childhood education offers opportunities to intervene for orphaned children. Early Head Start and Head Start are administered federally through the Office of Head Start in the Administration for Children and Families. Home visiting is supported through the Maternal, Infant, and Early Childhood Home Visiting (MIECHV) Program under Maternal and Child Health in the Health Resources and Services Administration. Meanwhile, states can receive funds through the Child Care and Development Block Grant program administered by the Office of Child Care. Early Intervention, however, is administered by the U.S. Department of Education. Coordinating efforts to assist each of these components in supporting young children will need to span multiple agencies.

## ENSURE ACCESS TO HIGH-QUALITY EARLY CHILDHOOD PROGRAMS

We recommend categorical eligibility for children and families who lost a caregiver to COVID-19 to enroll in Early Head Start, Head Start, and other public early childhood, home visiting, and care programs. Beyond facilitating access, these programs have the benefit of being bound by federal and state certification and curricular rules, meaning that professional development for providers in grief and grief-relevant programming can be strongly encouraged or mandated. We also recognize that these programs are not universally available—in fact, rates of early childhood programming are negatively correlated with COVID-19 death rates. We therefore recommend providing categorical eligibility for early childhood programming subsidies for COVID-bereaved children.

We recommend that new early childhood and education programs be attentive to the sudden shifts in family circumstances associated with caregiver loss and waive all family copays and employment-related parent-activity requirements. The Build Back Better (BBB) Framework includes subsidized early childhood education (ECE) for children from birth to 3 years old and universal high-quality preschool. While the final language of the bill continues to be in flux at the time of writing, the BBB Framework is projecting that federal programs will expand the availability of new high quality ECE providers, expand existing federal programs like Head Start and Early Head Start, and provide a subsidy to limit the cost of ECE for families with an infant or toddler based on family income. Any new program should include professional development requirements for staff that involve social and emotional learning, especially supporting normative grief processes in children and surviving caregivers as well as manifestations of complicated grief that would warrant referral to mental health services.

Furthermore, new federal early childhood care and education subsidies should provide greater support to families who experienced the recent loss of a caregiver. Requirements that determine income in the past year are inappropriate for these families as they will not reasonably estimate current household income going forward for many. As a result, any co-payments should be waived for these families for at least 12 months. Otherwise, many families will be uncertain whether care will be unaffordable, exceeding the 7 percent of household income that the framework is meant to guarantee.

Finally, all programs, including Head Start, should waive required parent-activities related to employment and employment seeking for at least 12 months for families who recently lost a caregiver. Many of these families will be renegotiating family roles, with surviving caregivers often challenged to take on more caregiving responsibilities while also becoming more responsible for earning income. These efforts will be complicated by the caregivers' own grief, and even normative grief can interfere. Requirements that caregivers be employed or seeking employment are not meant to add burdens to families while they are renegotiating roles following loss.

## **Clinical Care for COVID-Bereaved Children**

About 5 to 10 percent of children will face problematic grief and need more intensive services than those discussed above. Here, we offer a set of recommendations to increase the supply and accessibility of grief-centered mental health services. These include:

- Expanding opportunities for training in grief-focused therapies to mental healthcare providers;
- Increasing access to and affordability of mental health for COVID-bereaved children; and
- Increasing the capacity for mental health provision in schools and creating partnerships between schools and mental health practitioners.

We note two significant problems in caring for the children who lost a parent or caregiver and face prolonged or complicated grief. First, "social first responders"—teachers, religious leaders,

pediatricians, youth athletic league coaches, and social service staff who interact with community members regularly—are not generally trained to identify and understand grief and grief-related issues. Data are lacking, though a survey of teachers and other school staff found that 15 percent felt "very

comfortable" addressing students' emotional needs that have been "caused or intensified by the" pandemic and fewer than a quarter (24 percent) felt "very comfortable supporting a student who lost someone close to them. Despite this lack of training, 87 percent said that at least one student each year typically needs their support due to the loss of a loved one, a number certain to have risen in the midst of the COVID-19 pandemic.<sup>129</sup>

Five states—California, Florida, Georgia, New York, and Texas—account for 50 percent of total caregiver loss.

Second, there are notable shortfalls in the pediatric mental healthcare infrastructure, meaning that for many children experiencing complicated grief, critical resources are simply unavailable. One-third of Americans live in designated mental health professional shortage areas (MHPSAs), and these gaps are concentrated in the rural and low-income urban areas hit hardest by COVID-19.<sup>130</sup> In schools, the most convenient location to identify and serve bereaved youth, school-based mental health professionals are woefully under-resourced. The ratio of students to school psychologists is 1,211:1, which is more than double the National Association of School Psychologists' recommended ratio of 500:1. Only three states meet the recommended 250:1 ratio of students to school counselors.<sup>131,132</sup>

Additionally, there is a mismatch in the racial and ethnic composition of the survivors of COVID-19 deaths and the mental health professionals tasked to serve them. While Black and Hispanic populations are at the highest risk for COVID-19 mortality, 86 percent of psychologists and 65 percent of social workers are White.<sup>133,134</sup> As cultural competence emerges as a critical component of overall clinical effectiveness, this will confound efforts to engage and retain racial and ethnic minority children in sorely needed therapy.

Two factors compound these challenges for COVID-bereaved children. First, only a small percentage of mental health professionals are trained in grief-focused modalities. Only 8 percent of MHPs in a recent survey had taken any course in grief interventions, and fewer than 20 percent noted that their universities even offered related courses.<sup>135</sup> Additionally, the pandemic has exploded the need for pediatric mental

healthcare, stretching an already sparse resource. This has prompted pediatric health and mental health-focused groups to declare a "National State of Emergency in Children's Mental Health."<sup>136</sup>

### **INCREASE ACCESS TO MENTAL HEALTHCARE**

## Train Existing Providers in Grief-Focused Therapies

We recommend incentivizing existing mental health providers to become competent in grieffocused therapies through short-term and readily available training. We are aware of:

- A <u>web-based course</u> in Trauma-Focused CBT and its adaptation for Childhood Traumatic Grief (CTG) developed by the National Trauma Child Traumatic Stress Network (NCTSN) with academic and healthcare partners; and
- <u>One or two-day workshops</u> in therapies for Prolonged Grief Disorder through Columbia University's Center for Prolonged Grief.

We recommend that mental health licensing bodies like the Council on Social Work Education (CSWE) incentivize trainings by providing course subsidies and Continuing Education (CE) credits. We know that these organizations may lack the resources to provide financial incentives on such a broad scale and suggest that one or more foundations establish a "COVID-19 Grief Training Fund" to meet this need.

## <u>Telehealth</u>

# We recommend improving access to mental health telemedicine by increasing broadband accessibility and eliminating cost-sharing payments for COVID-bereaved children.

Telehealth has rapidly gained popularity during the COVID-19 pandemic as families, and most mental healthcare interventions are amenable to delivery through telehealth. Thus, telehealth increases access to niche interventions like grief-related services not available in many parts of the country.

It is not, however, an immediate panacea. For one, there are longstanding disparities in telehealth use by income and race that have widened over the last two years.<sup>137</sup> Second, rural and low-income urban communities hit hardest by COVID-19 are the ones least likely to have reliable home broadband internet access due to cost, gaps in infrastructure, or digital discrimination. Third,

mental health services—even those provided over video or phone—can be expensive, and many insurance companies have not reimbursed telehealth services at the same rates as in-person care.

Federal policymakers are making efforts to close these gaps. The recently passed Infrastructure Investment and Jobs Act includes \$65 billion for enhancing broadband accessibility, including:

- \$42 billion to expand broadband infrastructure;
- \$14.2 billion for a \$30 per month subsidy for low-income households to afford broadband internet (this reduces the current subsidy by \$20 per month, but expands program eligibility); and
- \$2.75 billion to end digital discrimination.<sup>138</sup>

In addition, the Center for Medicare and Medicaid Services (CMS) is taking steps to expand the mental health services available via telehealth. It is implementing provisions in the 2021 Consolidated Appropriations Act—which included the third round of federal stimulus payments—to remove geographic restrictions in telehealth and to allow patients to access telehealth services offered from any location.<sup>139,140</sup> In addition, it is proposing to allow Medicare to pay for telehealth mental health visits for rural and vulnerable populations when those services are provided by Rural Health Clinics and Federally Qualified Health Centers. This would include telephone calls and other audio-only services, which would be particularly helpful for people in rural areas without sufficient broadband infrastructure, individuals who may not be able to afford broadband, and people enrolled in Medicare who do not use or are otherwise incapable of using video services.

We support these steps and suggest expanding them to people on Medicaid, and we encourage legislative action to require these provisions for private insurers as well.

## Expansion of Co-Located and Integrated Mental Healthcare

We recommend incentives to providers offering mental health services co-located with or integrated into primary care services. Families are more likely to engage providers when they can be accessed in a single, convenient location. They are more likely to trust and accept help from a range of associated disciplines (e.g., mental healthcare; social services) that they might otherwise avoid due to stigma or inaccessibility. Incorporating mental healthcare providers and human service into co-located spaces could assist families who would benefit from these services to address complicated grief.

In integrated primary care, the pediatrician, mental healthcare provider, social worker, and other disciplines work together as a coordinated care team, sharing information and formulating a cohesive approach that draws on their different expertise. Integrated care models often involve the convenience and trust that comes with co-located services with the added benefit of close coordination between providers. Ensuring that mental healthcare and human service workers are integrated with pediatrics, and that those providers are knowledgeable about childhood grief, holds potential for underserved communities with high rates of COVID-related mortality.

### Reduce Costs for Mental Healthcare

Even where there is access to mental healthcare, cost is another common barrier. COVID-19 decedents and their families are more likely to be low-income and are less likely to have health insurance than others.<sup>141</sup> Even among families with insurance, there has been a trend toward increased copayments and deductibles for mental health services.<sup>142</sup> In addition, many mental healthcare providers do not accept Medicaid or even private insurance, further reducing access to the low-income populations who have the greatest needs.

We recommend efforts to reduce or eliminate the costs of grief-related mental healthcare for children, youth, and their caretakers who lost a loved one to COVID-19. This can be operationalized in one (or more) of the following ways:

- Reimbursement of copayments and deductibles through the COVID-19 Bereaved-Children Fund;
- Private and public insurers waiving patient cost-sharing responsibilities; or
- Therapists forgiving or refunding copayments or deductibles or offering pro bono inperson and/or telehealth services.

### Leverage Schools

We recommend the provision of federal funding and technical assistance to Local Education Agencies to increase the capacity of school systems to respond to this crisis. We note several options for doing so. First, train teachers in basic information about childhood grief, including recognizing and responding when a student is grieving. Several programs and curricula already exist. The National Child Traumatic Stress Network, for example, has a comprehensive array of online workshops and materials that would provide teachers and school administration with a basic competence in dealing with grief.

We also suggest leveraging New York Life's Grief Sensitive Schools Initiative (GSSI). Through the program, school staff are trained by grief-focused mental health professionals to better understand and address the needs of students who have lost a loved one. At least five personnel from a school are trained, and they provide materials and workshops to their colleagues. GSSI offers a \$500 grant to "improve grief support and resources" to incentivize participation.<sup>143</sup>

Second, supplement mental health resources by increasing staff competence and creating pathways to new capacity. Incentivize partnerships with external therapists and healthcare organizations that can provide grief-focused mental health services. Mental health professionals can engage students and families through their partnership with the schools. Notably, because these services would be arranged through the school and because outside services are being sought due to capacity and competence deficits within the school system, these arrangements should be made through contracts between schools and districts and mental health professionals, with no cost-sharing burden falling onto the students or their families.

Finally, leverage on-line and in-person trainings for grief-specific therapies, as noted earlier in this section.

## Addressing the Economic Needs of Children who Lost a Parent or Caregiver to COVID-19

Any meaningful intervention to address COVID-19 related caregiver loss must acknowledge that affected households are disproportionately low-income and susceptible to sudden income loss, and many need imminent economic support.

Programs serving this population must ensure streamlined enrollment and participation, avoiding the problems evident in some other programs unveiled during the COVID-19 era, such as COVID-19-focused eviction prevention funds. While we address specific programs below, **we recommend establishing** 

#### HIDDEN PAIN

presumptive eligibility for families who lost a caregiver to COVID-19 for existing support programs, such as the Earned-Income Tax Credit, Child Tax Credit payments established by the American Rescue Plan, the Supplemental Nutrition Assistance Program, Temporary Assistance for Needy Families, Medicaid, and subsidized early childhood programs such as Early Head Start and Head Start. This presumptive eligibility acknowledges that families who lost a parent to COVID-19 had disproportionately lower incomes prior to the loss and were more likely to have only a single person working.

There also should be a concerted effort to inform families of programs that they become eligible for following death of an adult family member. This effort should be proactive and include any programs that involve categorical eligibility specifically for this group as well as existing programs that the family may now be eligible for based on changes in income. Outreach efforts could include general information campaigns, targeted stakeholder communications (e.g., to health systems and other human service providers), and specific collaboration on process with other federal and state programs that enroll children and families.

## PROVIDE SHORT-TERM FINANCIAL ASSISTANCE BY EXPANDING FEMA'S FUNERAL REIMBURSEMENT PROGRAM

We recommend an expansion of FEMA's funeral reimbursement program. The Federal Emergency Management Agency has been authorized to reimburse up to \$2 billion for funeral-related expenses for COVID-19 decedents. We recommend expansion of this program coupled with community-based outreach efforts to increase awareness and facilitate enrollment.

More than half of allotted program funds have been spent on fewer than half of COVID-decedents as case and death counts grow nearly unabated, and the program will hit its \$2 billion ceiling well before all COVID-19 funeral expenses are covered. This is especially important as those most vulnerable and hesitant families who are unaware of or do not fully understand the program or application may seek assistance later than others and, perhaps, do so after allocated funds have already been spent.

While more than 760,000 Americans have died because of COVID-19, only 321,191 applications for funeral-related relief have been filed. In addition, only 61 percent of completed applications have been granted, varying from 43 percent in Alaska to 73 percent in Connecticut and South

Dakota.<sup>144</sup> We cannot offer any definitive determination regarding the reasons for these low uptake and acceptance rates. Conversations with practitioner stakeholders suggest that some families may have sufficient resources that the effort needed to apply is not worth the amount of

money available. However, many families in need of these resources simply may not be aware of them, and the arduous application may discourage many who do not understand the application process. In addition, many families with immigrants—documented and undocumented—may be hesitant to apply for fear of additional scrutiny and deportation.

To improve participation, hospital administrators and funeral directors should all be familiar with FEMA's Funeral Assistance The ratio of students to school psychologists is 1,211:1, which is more than double the National Association of School Psychologists' recommended ratio of 500:1.

Program and encourage families who lost a loved one to COVID-19 (or whose death was likely to be due to COVID-19) to take advantage of these resources. The National Funeral Directors Association has a section of its website devoted to the program and created a toolkit for funeral directors, including sample letters and other information to share with families who may have lost a loved one to COVID-19.<sup>145</sup> This is a good first step but is unlikely to reach many families in need of the available funding.

We also suggest FEMA create materials for community-based organizations and offer virtual, recorded trainings for these organizations to help community members apply for these funds. The local organizations, often embedded in vulnerable communities, are so often critical to building trust between governments and constituencies leery of government assistance or interference. Leveraging their role could expand the pool of applications. Allowing them to submit paperwork on behalf of applicants, like Affordable Care Act healthcare navigators or tax-filing accountants, could further alleviate some of the burdens on families dealing with struggles on many fronts after confronting the death of a loved one. This could also lower the rate of failed applications (currently greater than one-third) which take up valuable FEMA resources from the 5,000 contracted agents' management of 25,000 calls per day.<sup>146</sup>

## CREATE THE "COVID-19 BEREAVED CHILDREN'S FUND" TO PROVIDE SHORT-TERM FINANCIAL ASSISTANCE AND GRIEF-RELATED MENTAL HEALTHCARE

We recommend the creation of a publicly funded COVID-Bereaved Children Fund to address the financial and mental health needs facing the more than 167,000 children who lost a parent or other caregiver to COVID-19. We recommend \$2-3 billion in support for this Fund.

The scale of need arising from this crisis is beyond the scope of nearly any private funder, and such a fund would be in-line with public responses to other tragedies and public health crises. We recommend that the COVID Bereaved-Children Fund provide \$10,000 in one-time payments for each COVID-19 bereaved child, plus cover the cost-sharing responsibilities of their grief-related mental health services. These grants would alleviate some immediate financial worry for bereaved children and their families, which is especially important given the preexisting economic vulnerabilities facing many COVID-19 victims and the fact that many families lost a primary earner.

Such an approach is also supported by research on unconditional cash transfers, which notes an array of benefits to children and their families receiving such financial assistance. In addition, by reimbursing the patient-borne expenses of grief-related mental healthcare, the Fund would ensure access to care for those who need it. This is especially important given that COVID-bereaved children are the most likely to face cost barriers to receiving these services.

We further recommend that a private fund offer the same resources to children who lost a caregiver but are ineligible to receive funding from the U.S. government. Supplemental private funds to address an acute crisis or notable subpopulation are not uncommon. Among other examples, the private Twin Towers Fund provided over \$200 million to the families of first responders who died on September 11th.<sup>147</sup>

## CONNECT CHILDREN AND THEIR FAMILIES TO INCOME AND OTHER SUPPORTS

As sources of income diminished due to COVID-19 deaths, particularly for low-income households, we expect that many households will become newly eligible for public benefits like Supplemental Nutrition Assistance Program (SNAP), Temporary Assistance for Needy Families (TANF), Medicaid, Affordable Care Act subsidies, early childhood care and education programs

(e.g., Early Head Start; Head Start), and that some families already receiving those benefits will be eligible for an increased assistance. In addition, many will also become eligible for tax benefits like the Earned Income Tax Credit and the Child Tax Credit.

However, many families may not be aware of the benefits for which they are eligible. Only 82 percent of people eligible for SNAP actually receive the program's benefits.<sup>148</sup> The turmoil associated with a parent's death likely means that families are less likely to immediately seek out, understand, or enroll in public assistance programs, especially as many necessitate arduous inperson appointments and documentation requirements.

We recommend that the relevant departments of local governments undertake extensive outreach to families of COVID-19 decedents to assess program eligibility for these support programs. This can be better targeted by matching COVID-19 deaths with social service or wage data from a local or state finance or labor agency or the IRS. A less arduous effort would involve working with health systems, community-based organizations, churches, early childhood programs, and K-12 schools, or public awareness campaigns through billboards and other advertising.

The same concern—that eligible populations may forego benefits—is true for Social Security death and monthly survivor benefits, which can go to a spouse or, in the event the decedent is unmarried, their children. Confusion and lack of awareness around the program have led many survivors to leave this entitlement untouched. To ameliorate this gap, we recommend matching COVID-19 death records from state or local health departments with the Social Security Administration, which can then send communications to the families of decedents explaining the program, their eligibility, and their anticipated benefit.

## MAKE THE NEW CHILD TAX CREDIT PERMANENT

The American Rescue Plan's amended and expanded Child Tax Credit has had a significant positive impact on the lives of low-income Americans, and we recommend making it permanent. It has allowed families of 27 million children who previously received either no credit or only a partial credit because their incomes were too low to claim the full credit. It also increased the value of the credit from \$2,000 to \$3,000 per child, or \$3,600 for children aged five and younger.

Finally, it changed the timing of disbursements from one lump sum per year to monthly installments.

Because distribution of the new tax credit only began in July of 2021, estimates of its impact are preliminary, but they are promising. Data from the Census Bureau's Household Pulse Survey suggest a marked decrease in food insecurity. About 3.3 million fewer households report having insufficient food in their home, a nearly one-third decrease from pre-July levels.<sup>149</sup> Moreover, Parolin and colleagues estimate that these payments alone kept 3 million children out of poverty in July, 2021, reducing the childhood poverty rate from 15.8 percent in June to 11.9 percent in July.<sup>150</sup> Both estimates showed significant impacts across racial and ethnic groups, with Zippel showing the largest decreases among food insecurity in Black and Hispanic families with children.

These expanded and monthly payments are only in place for the 2021 tax year, meaning we may revert to pre-July levels of food insecurity and child poverty in a few short months. As noted earlier, COVID-19 deaths are disproportionately found in low-income households most directly benefitting from these changes, and we strongly recommend that Congress make these changes permanent.

# Need for Additional Research

Our work revealed a general lack of information regarding the scope and impacts of parental loss to COVID-19. Here, we outline a set of inquiries critical to better understanding the current and future human costs of these tragic circumstances.

## BETTER LOCAL ENUMERATION OF COVID-19 RELATED CAREGIVER LOSS

All current estimates of COVID-19 caregiver loss are based on aggregated data and extrapolations. Despite their value, they

- Contain some level of inherent uncertainty;
- Are limited in their ability to describe these individuals based on demographics, geographic location, service needs; and
- Are unable to identify individuals who lost a parent or caregiver to COVID-19, meaning they cannot be used for program outreach or enrollment.

We therefore propose using state, tribal, and local administrative data to examine prevalence of COVID-19 bereavement among children. As Allegheny County did for opioid deaths, COVID-19 death records can be matched with birth records. Separately or in addition, death records can be matched with social service records to better understand the extent of parental loss among children in households receiving public assistance like TANF, SNAP, or Medicaid or those involved in the homelessness or child welfare systems. This would provide insight into the most socially and economically vulnerable COVID-19 survivors in a way that is not possible through any other method.

## DOCUMENTING POLICY-LEVEL IMPACTS OF COVID-19 PARENTAL BEREAVEMENT ON CHILDREN

Families that lose a parent are at risk for cascades of negative events related to lost family income and other lost socioeconomic resources, yet these impacts are poorly documented in the bereavement literature. A series of short- and long-term research on this topic, both generally and specific to COVID-19 parental bereavement, is important for providing policymakers and practitioners with insight into the long-term effects of parental bereavement generally and specifically for children who lost a parent to COVID-19. Such research could inform interventions related to eviction prevention, homelessness and housing program utilization, cash assistance, and the child welfare system.

## CONTINUE TO DEVELOP THE EVIDENCE-BASE OF INTERVENTIONS FOR BEREAVED CHILDREN

There is relatively scant literature assessing the effectiveness of the range of interventions addressing grief of parental bereavement, even though the phenomenon is relatively common. It is unclear which grief-related programs address long-term and policy-relevant outcomes, and the evidence supporting mentoring largely comes from non-bereavement literature. It is therefore necessary to fund rigorous trials of community-based and clinical interventions to prevent and alleviate complicated and prolonged grief responses to parental bereavement.

## DOCUMENTING THE CLINICAL IMPACTS OF COVID-19 PARENTAL BEREAVEMENT ON CHILDREN

Our review found no research documenting levels of impacts of parental bereavement related to the pandemic on measures of anxiety, complicated grief, depression, PTSD, or other clinical conditions associated with loss. The more than 760,000 deaths and counting are occurring from a cause and in a moment unlike any others, and it is reasonable to hypothesize that the impacts on those left behind may differ as well. We suggest research employing qualitative interviews and validated surveys of relevant clinical measures to assess these impacts relative to other parental deaths during the pandemic era as well as parental deaths prior to 2020 to better understand the unique impacts of a COVID-death.

#### **EXAMINING THE RESPONSE**

Responses to the COVID-19 pandemic have varied widely across states and localities. While significant academic and journalistic research has gone into understanding their relative impacts on COVID-19 infections and deaths, there is little if anything devoted to how municipalities are caring for surviving family members and other affected community members. A series of case studies highlighting best practices would provide guidance for municipalities, social service providers, and funders looking to improve well-being for those most affected by the pandemic.

## FACILITATING THIS RESEARCH

Without intervention, this research will neither emerge nor be conducted in a coordinated way that facilitates maximal learning and information sharing to improve policy and practice for COVID-bereaved children. Funders and other facilitators of policy and practice, including governments, academic and quasi-academic organizations, advocacy groups, and social service providers must work in concert to facilitate this research. Examples of this work could include:

- Providing funding for these and other COVID-19 parental bereavement research projects;
- Funding and hosting convenings that allow information sharing between researchers, policymakers, and practitioners; and
- Creating special issues of peer-reviewed journals devoted to the topic.

## Conclusion

At least 167,082 children under 18 years old—about 1 in 450—have suffered the death of a parent or other at-home caregiver to COVID-19 through mid-November 2021, and that number continues to grow. More than 72,000 lost a parent, and more than 13,000 lost their sole at-home caregiver. Higher mortality rates and larger household sizes among communities of color, combined with legacies of disinvestment, have led to consistently disadvantaged communities experiencing COVID-19 related orphanhood at the highest rates. We are requiring these children and families to bear the heaviest burden of the pandemic, despite permitting them the fewest resources with which to carry on. Caregiver death can contribute to negative psychological, economic, and social outcomes, especially for families from these under resourced communities, and failure to mitigate these consequences is a missed opportunity to promote success for more than 167,000 children. They have lost the most important people in their lives: their sources of care, comfort, love, and economic support. A lost parent cannot be replaced, but, in this moment, we have the opportunity and obligation to help families fill children's lives with love and support nevertheless. And we call upon the nation to act in this time of great need.

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## Appendix I: Tables and Figures

| Table 1: Summary Statistics         |         |                  |
|-------------------------------------|---------|------------------|
|                                     | #       | Rate per 100,000 |
| Total # losing caregiver            | 167,082 | 230              |
| Total # losing parent               | 72,699  | 100              |
| Total losing a primary caregiver    | 80,848  | 111              |
| Total # losing grandparent          | 67,591  | 93               |
| Total # losing sole caregiver       | 13,047  | 18               |
| Race                                |         |                  |
| Non-Hispanic Black                  | 32,287  | 334              |
| Non-Hispanic White                  | 51,413  | 141              |
| Hispanic                            | 64,163  | 350              |
| Asian                               | 7,974   | 228              |
| Native Hawaiian or Pacific Islander | 776     | 518              |
| American Indian or Alaska Native    | 3,946   | 537              |
| By Age                              |         |                  |
| 0-4                                 | 34,150  | 154              |
| 5-13                                | 83,798  | 197              |
| 14-17                               | 49,134  | 257              |

I. We do not provide separate estimates for those categorized as "Other race' or 'Multiracial' because we are unable to meaningfully parse those groups, though they are included in total results.
| Table 2: COVID-19 Caregiver Loss by Race and Age |        |        |        |         |  |  |  |  |
|--|--------|--------|--------|---------|--|--|--|--|
|  | 0-4    | 14-17  | 5-13   | Total   |  |  |  |  |
| Asian  | 1,524  | 2,328  | 4,121  | 7,974   |  |  |  |  |
| Non-Hispanic Black                               | 6,788  | 9,240  | 16,260 | 32,287  |  |  |  |  |
| Hawaiian or Pacific Islander                     | 216    | 199    | 361    | 776     |  |  |  |  |
| Hispanic   | 14,094 | 17,833 | 32,236 | 64,163  |  |  |  |  |
| American Indian or Alaska Native                 | 848    | 1,060  | 2,038  | 3,946   |  |  |  |  |
| Non-Hispanic White                               | 9,214  | 16,772 | 25,428 | 51,413  |  |  |  |  |
| TOTAL  | 34,150 | 49,134 | 83,798 | 167,082 |  |  |  |  |

| Table 3: Num         | ber and Rate of CO  | OVID-19 Bereaved      | d Childre      | en, by Stat                 | e and R   | ace          |          |                              |              |                    |             |              |                            |
|----------------------|---------------------|-----------------------|----------------|-----------------------------|-----------|--------------|----------|------------------------------|--------------|--------------------|-------------|--------------|----------------------------|
| State                | Asian               | Non-Hispanic<br>Black |                | Hawaiian c<br>Pacific Islan | or<br>der | Hispanic     |          | American Inc<br>or Alaska Na | lian<br>tive | Non-Hispa<br>White | nic         | Total        |                            |
|                      | # Rate (per 100k)   | # Rate (per           | 100k)          | # Rate (p                   | er 100k)  | # Rate (p    | er 100k) | # Rate (p                    | ver 100k)    | # Rate (           | per 100k)   | # Rate (j    | 9er 100k)                  |
| Alabama              | 22 145              | 1,296                 | 410            | 1                           | 170       | 229          | 266      | ហ                            | 95           | 1,560              | 250         | 3,233        | 298                        |
| Alaska               | 2 28                | 0                     | ω              | 0                           | 0         | ហ            | 28       | 126                          | 359          | 54                 | 62          | 199          | 112                        |
| Arizona              | 124 276             | 220                   | 288            | 10                          | 282       | 3,209        | 450      | 1,142                        | 1,217        | 1,018              | 161         | 5,980        | 366                        |
| Arkansas             | 39 342              | 401                   | 335            | 55                          | 1,224     | 231          | 270      | 2                            | 82           | 688                | 203         | 1,676        | 241                        |
| California           | 2,303 226           | 1,351                 | 314            | 198                         | 647       | 19,282       | 424      | 133                          | 185          | 2,772              | 123         | 26,891       | 304                        |
| Colorado             | 76 213              | 92                    | 177            | 0                           | 41        | 098          | 224      | 45                           | 335          | 575                | 82          | 1,723        | 138                        |
| Connecticut          | 70 209              | 260                   | 317            | 0 0                         | ං ෆ්      | 320          | 176      | οω                           | t 119        | 395                | 102         | 1,097        | ,<br>,<br>,<br>,<br>,<br>, |
| District of Columbia | 0 16                | 265                   | 400            | 0 0                         | 0 0       | 137          | 634      | 0 0                          | 32 0         | 11                 | а<br>6      | 426          | 334                        |
| Florida              | 276 271             | 3,861                 | 483            | 00                          | 224       | 4,089        | 303      | 25                           | 202          | 3,744              | 217         | 12,533       | 297                        |
| Georgia              | 189 206             | 2,701                 | 328            | 4                           | 171       | 910          | 251      | 12                           | 104          | 2,343              | 218         | 6,391        | 256                        |
| Hawaii               | 106 140             | 0                     |                | 147                         | 358       | 50           | 101      |                              | 79           | 14                 | 32          | 438          | 146                        |
| ldaho                | з 63                | 7                     | 139            | 0                           | 16        | 178          | 226      | 22                           | 346          | 453                | ដែច         | 683          | 152                        |
| Illinois             | 258 188             | 1,047                 | 254            | J                           | 772       | 1,903        | 277      | б                            | 56           | 1,281              | 68          | 4,657        | 166                        |
| Indiana              | 17 17/18            | 285                   | 224            | 0 N                         | 3/4       | 895          | 807      | 4 u                          | 107          | 1,403              | 871.        | 2,300        | 01                         |
| Kansas               | 23 123              | 78                    | 185            | 0                           | 7         | 207          | 162      | σι (                         | 148          | 507                | 109         | 866          | 124                        |
| Kentucky             | 43 225              | 176                   | 200            | -                           | 276       | 137          | 222      | -                            | 66           | 1,328              | 170         | 1,760        | 177                        |
| Louisiana            | 25 141              | 1,527                 | 392            |                             | 156       | 165          | 211      | o 12                         | 146          | 1,067              | 194         | 2,887        | 266                        |
| Maine                | 1 2/                | 1050                  | 14             | 2                           | 101       | ee 4         | 53       | o c                          | , t          | 521<br>III         | 1<br>1<br>1 | 750          | ο<br>1<br>2                |
| Massachusetts        | 150 165             | 487                   | 436            | +                           | 107       | 379          | 148      | 2 0                          | 54 7         | 971                | 121         | 2,097        | 156                        |
| Michigan             | 82 122              | 1,006                 | 302            | -1                          | 195       | 371          | 208      | 26                           | 248          | 1,598              | 112         | 3,202        | 150                        |
| Minnesota            | 295 415             | 330                   | 265            | 2                           | 215       | 124          | 110      | 64                           | 287          | 429                | 48          | 1,342        | 103                        |
| Mississippi          | 9 121               | 1,354                 | 464            | 1 0                         | 150       | 112          | 368      | 109                          | 2,931        | 954                | 279         | 2,576        | 370                        |
| Montana              | 30 133<br>3 154     | 490<br>3              | 121            | ο σ                         | 0         | 205          | 192      | 206                          | 835          | 1,395              | 136         | 2,233<br>496 | 220                        |
| Nebraska             | 3 28                | 43                    | 156            | 0                           |           | 127          | 153      | 2                            | 31           | 253                | 78          | 434          | 92                         |
| Nevada               | 232 511             | 242                   | 335            | 54                          | 1,103     | 686          | 355      | 20                           | 183          | 498                | 210         | 2,177        | 316                        |
| New Hampshire        | 1 17                | 0                     | 2              | -                           | 285       | ω            | 18       | 0                            | 10           | 104                | 48          | 111          | 43                         |
| New Jersey           | 413 237<br>6 93     | 1,171                 | 489            | 4 C                         | 664<br>0  | 2,268<br>650 | 424      | 4                            | 1449         | 1,499              | 171         | 1609         | 292                        |
| New York             | 1,486 486           | 3,290                 | 566            | 1                           | 40        | 4,681        | 474      | 36                           | 272          | 2,659              | 139         | 12,784       | 320                        |
| North Carolina       | 72 111              | 1,200                 | 235            | -1                          | 50        | 621          | 165      | 44                           | 134          | 1,534              | 130         | 3,626        | 158                        |
| North Dakota         | 1 31                | 0                     |                | . 0                         | 33        | ភ            | 170      | 141                          | 668          | 84                 | 62          | 252          | 142                        |
| Ohio                 | 90 165              | 691                   | 192            | )                           | 132       | 204          | 128      | 2 2                          | 42           | 2,337              | 128         | 3,484        | 136                        |
| Oregon               | 44 <u>290</u>       | 240                   | 345            | 2 2                         | 1/2<br>77 | 440<br>247   | 133      | 05<br>6/£                    | 41/<br>226   | 951<br>490         | 061         | 2,237        | 107                        |
| Pennsylvania         | 150 166             | 972                   | 298            | ω                           | 325       | 069          | 212      | 4                            | 48           | 2,190              | 127         | 4,206        | 161                        |
| Rhode Island         | 3 63                | 22                    | 155            | 0                           | 0         | 42           | 79       | 0                            | 0            | 192                | 167         | 278          | 138                        |
| South Carolina       | 27 132              | 1,105                 | 350            | _                           | 21        | 230          | 224      | 2                            | 55           | 1,071              | 177         | 2,534        | 229                        |
| South Dakota         | -<br>               | )<br>)<br>)<br>,      | 9              | 1 0                         | 0         | 7            | 65       | 249                          | 833          | 96                 | 62          | 359          | 168                        |
| Tevas                | עכ<br>187 בא<br>187 | 2 623                 | 340            | J 4                         | 737       | 16 713       | 460      | Δ.2 σ                        | 160<br>160   | 2,3U3<br>ק 179     | 231         | 05920        | 272                        |
| Utah                 | 19 173              | 4                     | ω <sup>0</sup> | 140                         | 1,741     | 330          | 200      | 120                          | 1,209        | 637                | 94          | 1,323        | 143                        |
| Vermont              | 0                   | 0                     | 2              | 0                           | 0         | 0            | 4        | 0                            | 77           | 18                 | 18          | 20           | 7                          |
| Virginia             | 160 143             | 796                   | 217            | 2                           | 208       | 457          | 177      | 2                            | 46           | 978                | 100         | 2,541        | 137                        |
| Washington           | 154 130             | 85                    | 119            | 82                          | 665       | 537          | 153      | 80                           | 291          | 719                | 78          | 1,808        | 109                        |
| West Virginia        | ω<br>(01 ε          | 5                     | 103            | . 0                         | 2 0       | 9            | 97       | 80                           | 0            | 623                | 196         | 666          | 186                        |
| Wyoming              | 0 48                | 0 4                   | 33             | 7                           | 421       | 203          | 108      | 23                           | 517          | 54 I<br>77         | 51          | 1,140<br>135 | 101                        |
| y y y y y y y        |                     | c                     | U N            | -                           | 1,023     | <u> </u>     | 00       | 20                           | 5            | 11                 | ò           | 20           | 0                          |

| Table 4: Counts and Rate of COVID-Bereaved Children, by Age and State |
|---|
|   |

|                      |       | 0-4                  |        | 5-13          | -     | 14-17         | Тс      | otal          |
|----------------------|-------|----------------------|--------|---------------|-------|---------------|---------|---------------|
| State                | #     | C →<br>Rate per 100k | #      | Rate per 100k | #     | Rate per 100k | #       | Rate per 100k |
| Alabama              | 634   | 222                  | 1593   | 290           | 1006  | 404           | 3 233   | 298           |
| Alaska               | 50    | 101                  | 95     | 10.3          | .,000 | 152           | 199     | 112           |
| Arizona              | 1253  | 295                  | 3 020  | 361           | 1707  | 458           | 5 980   | 366           |
| Arkansas             | 314   | 170                  | 797    | 227           | 564   | 352           | 1.676   | 241           |
| California           | 5.936 | 251                  | 13.566 | 303           | 7.389 | 367           | 26.891  | 304           |
| Colorado             | 300   | 92                   | 876    | 139           | 547   | 187           | 1723    | 138           |
| Connecticut          | 194   | 108                  | 526    | 143           | 377   | 210           | 1.097   | 151           |
| Delaware             | 46    | 86                   | 127    | 127           | 75    | 152           | 248     | 122           |
| District of Columbia | 106   | 231                  | 225    | 373           | 96    | 448           | 426     | 334           |
| Florida              | 2 596 | 230                  | 6 280  | 295           | 3 657 | 380           | 12 533  | 297           |
| Georgia              | 1.221 | 192                  | 3.224  | 250           | 1.946 | 339           | 6.391   | 256           |
| Hawaii               | .,    | 112                  | 227    | 149           | 115   | 187           | 438     | 146           |
| Idaho                | 104   | 90                   | 364    | 159           | 215   | 206           | 683     | 152           |
| Illinois             | 921   | 125                  | 2 351  | 166           | 1386  | 211           | 4 657   | 166           |
| Indiana              | 493   | 119                  | 1107   | 139           | 701   | 197           | 2,300   | 147           |
| lowa                 | 108   | 57                   | 351    | 94            | 198   | 127           | 657     | 91            |
| Kansas               | 14.4  | 78                   | 449    | 126           | 273   | 174           | 866     | 124           |
| Kentucky             | 323   | 120                  | 876    | 175           | 561   | 247           | 1760    | 177           |
| Louisiana            | 572   | 195                  | 1471   | 267           | 844   | 353           | 2 887   | 266           |
| Maine                | 15    | 24                   | 59     | 48            | 51    | 85            | 125     | 51            |
| Maryland             | 504   | 141                  | 1338   | 200           | 718   | 238           | 2 560   | 193           |
| Massachusetts        | 435   | 123                  | 932    | 140           | 730   | 200           | 2,000   | 156           |
| Michigan             | 589   | 105                  | 1608   | 110           | 1005  | 201           | 3 202   | 150           |
| Minnesota            | 223   | 64                   | 697    | 106           | 422   | 143           | 1342    | 103           |
| Mississinni          | 490   | 274                  | 1363   | 381           | 723   | 452           | 2 576   | 370           |
| Missouri             | 430   | 122                  | 1,903  | 158           | 699   | 228           | 2,370   | 164           |
| Montana              | 87    | 1/6                  | 230    | 202           | 180   | 3/1           | 196     | 220           |
| Nebraska             | 70    | 55                   | 230    | 90            | 14.4  | 14.4          | 430     | 92            |
| Nevada               | 459   | 248                  | 1129   | 323           | 589   | 380           | 2 177   | 316           |
| New Hampshire        | 19    | 30                   | 53     | 41            | 38    | 60            | 2,177   | 43            |
| New Jersey           | 1181  | 234                  | 2 851  | 292           | 1596  | 359           | 5.627   | 292           |
| New Mexico           | 312   | 234                  | 860    | 349           | 437   | 396           | 1609    | 341           |
| New York             | 3 002 | 270                  | 6 206  | 315           | 3 576 | 391           | 12 784  | 320           |
| North Carolina       | 681   | 115                  | 1886   | 162           | 1059  | 200           | 3 6 2 6 | 158           |
| North Dakota         | 50    | 93                   | 130    | 156           | 62    | 186           | 252     | 14.2          |
| Ohio                 | 639   | 94                   | 1727   | 133           | 1 118 | 190           | 3 4 8 4 | 136           |
| Oklahoma             | 372   | 149                  | 1 184  | 238           | 681   | 338           | 2 237   | 236           |
| Oregon               | 159   | 71                   | 465    | 105           | 297   | 151           | 921     | 107           |
| Pennsylvania         | 756   | 111                  | 2 157  | 162           | 1293  | 215           | 4 206   | 161           |
| Rhode Island         | 51    | 94                   | 135    | 139           | 92    | 181           | 278     | 138           |
| South Carolina       | 487   | 168                  | 1256   | 223           | 791   | 313           | 2 5 3 4 | 229           |
| South Dakota         | 83    | 144                  | 178    | 162           | 98    | 212           | 359     | 168           |
| Tennessee            | 777   | 192                  | 1971   | 256           | 1148  | 347           | 3 895   | 258           |
| Texas                | 5383  | 272                  | 12 778 | 342           | 7469  | 447           | 25.630  | 230           |
| Utah                 | 292   | 119                  | 605    | 126           | 426   | 214           | 1323    | 143           |
| Vermont              | 232   |                      | 9      | 16            | 8     | 214           | 20      | 17            |
| Virginia             | 505   | 102                  | 1269   | 135           | 767   | 185           | 25      | 127           |
| Washington           | 338   | 75                   | 922    | 109           | 549   | 150           | 1808    | 109           |
| West Virginia        | 114   | 125                  | 340    | 184           | 212   | 262           | 666     | 186           |
| Wisconsin            | 200   | 62                   | 540    | 26            | 212   | 135           | 1145    | ۵۱<br>۵۱      |
| Wyoming              | 200   | 71                   | 61     | 84            | 51    | 177           | 135     | 101           |
| ,                    |       |                      | 51     | 54            | 51    | .,,           | .55     | 101           |

## Children with Caregiver Loss Due to COVID-19, by State and Age

TOTAL NUMBER OF CHILDREN





### Children with Caregiver Loss Due to COVID-19, by State and Race





# Appendix II: Methods

#### DATA SOURCES

We used the Census Bureau's American Community Survey (ACS) Public Use Microdata Sample (PUMS) for the survey year of 2019 to calculate the number of households, and to assess the characteristics of households, including the relationships of household members, whether and how many children younger than 18 years of age live in the household. Populations of each race/ethnicity and age group at the national and state levels were also calculated using PUMS. COVID-19 deaths for each race/ethnicity and age group were obtained from the National Center for Health Statistics.

#### **DEFINING CAREGIVERS**

PUMS dataset was used to define caregivers. Both primary and secondary caregivers were identified. In households that reported the presence of a child (< 18 years of age), parents were considered primary caregivers. Other adult members of the household were considered secondary caregivers. In households where a grandparent and a grandchild resided and no parent was present, the grandparent was considered a primary caregiver. If a parent was present, the grandparents and other household members were considered secondary caregivers.

#### DEFINING DEATH COUNTS

Total COVID-19 deaths were for the current period of pandemic (from January 1, 2020 to mid-November 2021—updated as of November 17, 2021) by state, age group and race/ethnicity as reported on a current flow of mortality data in the National Vital Statistics System.

#### CALCULATION OF THE PROBABILITY (DEATH RATE) OF LOSING CAREGIVERS

Counts of COVID-19 deaths were then used to calculate the probability associated with COVID-19 mortality for each segment of the population (age group, by race/ethnicity, by state). COVID-19 death rates were calculated by dividing the number of deaths for each segment of the population (i.e., for each age group, by race/ethnicity, by state) by the corresponding estimated number of population (as the weighted sample) from PUMS. People living in group settings (including prisons, student dormitories, etc.) were excluded from the subsequent analytic PUMS dataset. For each household reporting the presence of a child (<18 years of age), first, a total household probability of death was calculated by summing the death rates of all caregivers. Because the death of the child excludes the child from the

#### HIDDEN PAIN

calculation of loss of caregivers and bereavement, the average mortality rate of the child in the household was subtracted from this total household mortality rate. To further avoid overcounting the loss of caregivers through multiple deaths, the probability of deaths of multiple caregivers in the same household was subtracted from the total household death rate.

#### CALCULATION OF THE NUMBER OF COVID-19 BEREAVED CHILDREN

The number of COVID-19 bereaved children was calculated by multiplying the probability of losing caregiver(s) in the households of children of each state, race/ethnicity, and age group by the corresponding weighted sample size. This resulted in a child centric measure of COVID-19 bereavement, in that bereavement was calculated in relation to the demographic attributes of the children.

#### LIMITATIONS

There are, of course, limitations to this study. First, there is inherent uncertainty in estimates derived from survey data and extrapolation and though we did our best to minimize that uncertainty, it is still present. Second, while race and ethnicity categorizations between CDC (death estimates) and the ACS (population records) are congruent, how individuals are categorized into those races may be differ. Third, the CDC notes that underreporting of deaths for people of Hispanic origin and those of non-Hispanic American Indian or Alaska Native and non-Hispanic Asian or Pacific Islander race, meaning both that these statistics should be interpreted cautiously and that our estimates of bereavement for these groups are likely to be understated. Fourth, we use 2019 population data from the American Community Survey Public Use Microdata Sample, as the 2020 data (which the Census Bureau will note as experimental) have not yet been released.

# Hidden Pain

Children Who Lost a Parent or Caregiver to COVID-19 and What the Nation Can Do to Help Them

**DECEMBER 2021** 











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