

# A NATION'S HIDDEN GRIEF

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*Addressing the Need for Bereavement  
Care in the United States of America*

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Neela Saha

Master of Public Policy Candidate

Frank Batten School of Leadership and Public Policy



NHPCO

National Hospice and Palliative  
Care Organization

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### *Dedication*

I would like to dedicate this project to Yuye Zhang for being the first person to teach me how to properly take care of my own mental health. All of the purple is just for you.



## Client Overview

The National Hospice and Palliative Care Organization (NHPCO) is a D.C.-based nonprofit representing interests of hospice and palliative care providers through legislative advocacy. NHPCO's vision is to create a world where individuals and families facing serious illness, death, and grief will experience the best that humankind can offer.

Hospice workers regularly provide counseling for grieving communities affected by mass tragedy events, in addition to services for individuals affected by life-limiting illnesses and their family members. NHPCO has advocated for the expansion of bereavement-related support and services since its inception. The COVID-19 pandemic is a mass tragedy event that has both highlighted and exacerbated the bereavement care access deficit in a never-before-seen manner. NHPCO believes this is the window of opportunity to lobby Congress to address the bereavement care access deficit on a national scale.

## Disclaimer

The author conducted this study as a part of the program of professional education at the Frank Batten School of Leadership and Public Policy, University of Virginia. This paper is submitted in partial fulfillment of the course requirements for the Master of Public Policy degree. The judgements and conclusions are solely those of the author, and not necessarily endorsed by the Batten School, by the University of Virginia, or by any other entity.

## Honor Statement

On my honor as a University of Virginia Student, I have neither given nor received unauthorized aid on this assignment.

A handwritten signature in black ink that reads "Neela Saha". The signature is written in a cursive, flowing style.

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## Acronyms

AAFP - American Academy of Family Physicians

APA – American Psychiatric Association

BIPOC – Black, Indigenous and People of Color

BLS – Bureau of Labor and Statistics

CDC – Centers for Disease Control and Prevention

DSM-5 – Diagnostic and Statistical Manual of Mental Disorders, 5<sup>th</sup> edition

FDA- Food and Drug Administration

HRSA – Health Resources & Services Administration

IRS – Internal Revenue Service

NAMI – National Alliance on Mental Illness

NHPCO – National Hospice and Palliative Care Organization

LGBTQIA+ – Lesbian, Gay, Bisexual, Transgender, Queer, Intersexual, Asexual, and/or other non-heterosexual, non-cisgender

SAMHSA – Substance Abuse and Mental Health Services Administration

USA – United States of America

VA – U.S. Department of Veterans Affairs

## Glossary

Bereavement – the experience of a loss considered significant to an individual

Uncomplicated grief - internal manifestation of loss whose symptoms lessen over time

Complicated grief - abnormally long, protracted, disabling grief

Bereaved individual – someone who has experienced a significant loss

Grieving individual – someone who is reacting to a significant loss whose symptoms may or may not manifest in an outwardly observable manner

Kinship – familial relationships such as parents, child, spouse, sibling, or grandparents

Kin - a parent, child, spouse, sibling, or grandparent

Mass Tragedy - any incident or group of related incidents that lead to multiple premature deaths in a community to such a degree that it can be considered to have negatively impacted the community as a whole

## Problem Statement

Many individuals in the USA are living with untreated complicated grief. This deficit in bereavement care access has resulted in the development/exacerbation of debilitating mental health disorders (such as substance use disorders) among individuals living with complicated grief. This bereavement care access deficit is exacerbated by mass tragedy events such as terrorism, pandemics, and natural disasters.

## Executive Summary

A significant minority of grieving individuals are still impaired by their grief more than one year after a loss. This is referred to as complicated grief and - while grieving is typically a necessary, healthy process – individuals suffering from complicated grief are at increased risk for the exacerbation/development of various mental health disorders.

There is a bereavement care access deficit in America that has been present for many years but hasn't gained much attention on the national stage until the onset of the COVID-19 pandemic. This deficit is due in large part to a shortage of mental health providers and high out-of-pocket costs related to mental health.

The bereavement care access deficit makes it difficult for people living with complicated grief to access treatment, increasing their risk of developing mental health disorders. Mass tragedies – such as the COVID-19 pandemic –exacerbate how many individuals will develop complicated grief at any given time.

In order to address the needs of individuals suffering from complicated grief as a result of mass tragedies, I evaluated five different alternatives that tackled the contributing factors to the bereavement care access deficit and the development of complicated grief:

- Alternative 1: Status quo, free bereavement counseling in Veterans' Administration
- Alternative 2: Maintain status quo funding and additional funding for a national public information campaign
- Alternative 3: Maintain status quo funding and appropriate additional funding for a national bereavement care hotline
- Alternative 4: Maintain status quo funding and appropriate additional funding for grief counselor certification for eligible mental healthcare providers
- Alternative 5: Maintain status quo funding and appropriate additional funding for the first few therapy sessions for Americans

I evaluated these alternatives in terms of cost (inclusive of the status quo cost for alternatives 2-5), effectiveness (in terms of people with alcohol and/or non-alcohol substance abuse reached), and political feasibility (in terms of total support from leaders of key committees and favoring the most bipartisan alternatives). I assessed that the overall best alternative was for alternative 5. In particular, this alternative is far superior to the status quo in terms of cost-effectiveness.

## BACKGROUND – *Complicated Grief*

The background section is separated into three sections: complicated grief, bereavement care access deficit, and mass tragedies. After discussing the impact of complicated grief to an individual, I will move into discussing the bereavement care access deficit on a national scale. Finally, I will discuss how mass tragedy events – in particular the COVID-19 pandemic – exacerbate the bereavement care access deficit. I will also summarize each of the three sections in highlights located at their conclusion.

### What is the difference between bereavement and forms of grief?

#### *Bereavement vs Grief*

According to the American Academy of Family Physicians (AAFP), there is a distinction between bereavement, uncomplicated grief, and complicated grief. While bereavement and grief are often used interchangeably by the general public, grief counselors and researchers make a distinction between them.

**Table 1**

#### *Technical Distinctions Between Bereavement and Two Categories of Grief*

Term	Definition	Duration
Bereavement	The experience of a loss considered significant to an individual	Overlaps with grief
Uncomplicated Grief	Internal manifestation of loss whose symptoms lessen over time (i.e. sadness, loneliness, crying, insomnia, lack of self-care, anger, social withdrawal)	Typically one year for adults, half a year for children
Complicated Grief	Abnormally long, protracted, disabling grief which can exacerbate existing mental health disorders or contribute to the development of new disorders	More than one year, potentially a lifetime without intervention

*Note.* This information is directly taken from the AAFP guidelines (Dudley, 2019) with the exception of the durations of uncomplicated and complicated grief which is taken from the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; APA, 2013)

Bereavement refers to the experience of a loss considered significant to an individual. A loss can also refer to the loss of a loved one's life, job, marriage, housing, and/or other aspects important to an individual's happiness. Grief is how that loss manifests internally for an individual – commonly through sadness, loneliness, anger, insomnia, and etc. These symptoms can vary in



## BACKGROUND – *Complicated Grief*

intensity and frequency and may or may not be easily recognizable to people around that individual and/or the individual themselves (Dudley, 2019). The commonality between these symptoms are that they typically impair the individual from functioning in their day-to-day life as healthily as they did prior to the loss (Dudley, 2019). This is often observable as a loss of productivity. However, sometimes a grieving individual makes extra efforts to maintain productivity, often to the detriment of their mental health (Dudley, 2019). In short, a bereaved individual refers to someone who has experienced a significant loss. A grieving individual is one who is reacting to a significant loss.

In research, it is very difficult to accurately count how many people are grieving because symptoms are not necessarily identical from person to person or observable. For researchers, it is much more realistic to estimate how many people are bereaved. Therefore, grief-related research is properly referred to as bereavement research. Researchers focus on the population of bereaved individuals under the assumption that there is nearly a 100% overlap between the population of bereaved individuals and grieving individuals.

This assumption is fundamental to bereavement research and, therefore, fundamental to this paper. Furthermore, due to an absence of research on other forms of loss, loss in this paper exclusively refers to the loss of a fellow soldier (in the case of veterans) or an immediate relative (in the case of both veterans and the general public).

### *Uncomplicated Grief vs Complicated Grief*

In addition to the distinction between bereavement and grief, the distinction between uncomplicated and complicated grief is key to understanding the evaluation of the alternatives. The distinction is in both the duration and severity of symptoms. Uncomplicated grief typically lasts for a year at most, while complicated grief lasts well beyond a year. Symptoms caused by uncomplicated grief are short-term and anything that significantly inhibits an individual's day-to-day functionality resolves within a year for adults, though an individual may still feel the effects of a loss for years to come.

Symptoms caused/exacerbated by complicated grief are long-term and very often cause/exacerbate the development of mental health disorders such as major depressive disorder, dysthymia (persistent depressive disorder), suicidal ideation, posttraumatic stress disorder, separation anxiety disorder and substance abuse disorder (APA, 2013). Complicated grief disorder has been reviewed by DSM-5 work groups, who have renamed it 'Persistent complex bereavement disorder' and placed it in the chapter 'Conditions for Further Study' due to a lack of research on complicated grief as compared to other disorders recognized by DSM-5 (APA, 2013) (elaborated on in Appendix D). Its potential to exacerbate/cause other mental health disorders is well-recognized as severe (APA, 2013).

Throughout this report, when I refer to complicated grief, I am referring to persistent complex bereavement disorder as specified by the DSM-5. It's important to note that persistent

complex bereavement disorder cannot be officially diagnosed by psychologists yet. The most typical comorbid disorder with persistent complex bereavement disorder are major depressive disorder, posttraumatic stress disorder, and substance use disorder (APA, 2013). Due to this and the fact that substance use disorder being a very common reason for existing, successful federal mental health programs, I will be using substance use disorder frequently later on as part of my criteria. For a sense of scale, note that one study found, of people with serious mental health issues suffering from complicated grief, ~20% developed lifetime non-alcohol substance dependence and ~40% developed lifetime alcohol dependence (Sung, 2011).

Finally, it is important to note that is not the intention of any of these alternatives to stop Americans from grieving. Experts agree that grief is a normal, necessary process for individuals dealing with a loss (APA, 2013; Dudley, 2019). The majority of cases are uncomplicated and don't necessarily require a mental health-focused intervention (Dudley, 2019). This report is focused on intervening for the 10 to 20% of grieving individuals who are living with complicated grief because untreated complicated grief (not uncomplicated grief) leads to the exacerbation/development of various mental health disorders in the long-run, particularly when left untreated (Bonanno, 2001; Middleton, 1996).

### Why does complicated grief occur?

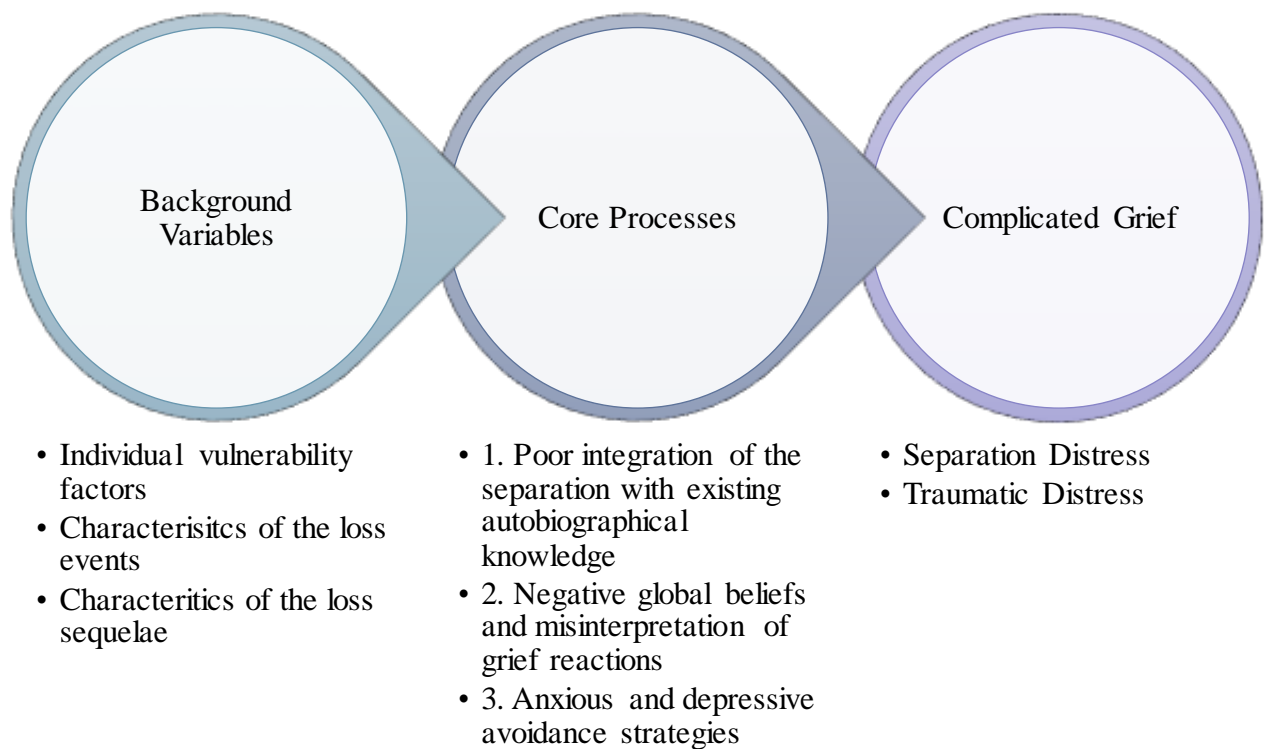
#### *The Cognitive-Behavioral Model of Complicated Grief*

As already assessed by DSM-5 workgroups, there is a lack of research on complicated grief (APA, 2013). Furthermore, precise definitions related to grief have not been consistently utilized across empirical research, making it difficult to compare studies (Stroebe, 2017). Therefore, I make every effort to rely on bereavement research using the same standard for defining complicated grief as the DSM-5 where possible.

There are two prominent theories of complicated grief: the attachment-based model and cognitive-behavioral model of complicated grief (Shear, 2007); (Boelen 2007). The latter is essentially just an updated expansion on the former.

**Figure 1**

*The Cognitive-Behavioral Model of Complicated Grief*



*Note.* This was taken from Figure 1 in Boelen's paper outlining his theory (Boelen, 2007).

Boelen's model (Figure 1) highlights the three main reasons (core processes) complicated grief occurs while acknowledging there are a variety of contributing factors (background variables) that affect the odds any given individual will develop complicated grief. In simpler terms, according to Boelen's model, an individual suffers from complicated grief occurs because:

- 1) Their brain has not accepted that the loss is irreversible and processed the meaning and implication the loss has to their life.
- 2) A lack of personal grief literacy (up-to-date, accurate knowledge about grief) and a lack of grief literacy in their society.
- 3) They have used maladaptive strategies (i.e., alcohol/drug abuse) to avoid processing the meaning and implication the loss has to their life.

These core processes have been backed up over the years through bereavement care research. In particular, a lack of grief literacy was noted as a key reason many family members at-risk for developing complicated grief refused decent quality, affordable bereavement counseling (Ghesquiere, 2016). As noted, Boelen's paper also highlights contributing factors, but he does not expand too much on them, instead devoting most of the paper to explanations of the core

processes and the ways complicated grief manifests (which is in line with the DSM-5 criteria to diagnose persistent complex bereavement disorder). However, other papers have expanded on the contributing factors.

### *Kinship*

In at least ~25 years of bereavement research (with admittedly varying degrees of adherence to scientific principles in early years), kinship has consistently been highlighted as the biggest contributing factor to complicated grief of the factors studied (Cleiren, 1993; Fernández-Alcántara, 2017). In particular, kinship has been highlighted as more important than multiple background variables related to individual vulnerability factors (i.e., gender) and characteristics of loss events (time and manner of death), explaining 19% of the variance of complicated grief intensity by itself (Fernández-Alcántara, 2017). Other predictors when combined explained 13% of the variance, indicating that kinship was the most important contributing factor by a wide margin (Fernández-Alcántara, 2017). The general trend is the closer the relation, the more difficult the loss. Kinship is almost always narrowed down to the loss of a child, spouse/partner, sibling, parent, or grandparent.

#### Background - *Complicated Grief* Section Highlights

- A significant minority of grieving individuals develop complicated grief one year after a loss, which can cause/exacerbate many serious mental health disorders. The most critical risk factor is if one lost close kin.
- Bereavement research theorizes that an inability to accept the irreversibility of the loss, a lack of grief literacy, and using maladaptive strategies are the core processes behind complicated grief. These can contribute to a reluctance to seek/accept help – in particular, a lack of grief literacy.

## What is the evidence for a bereavement care access deficit?

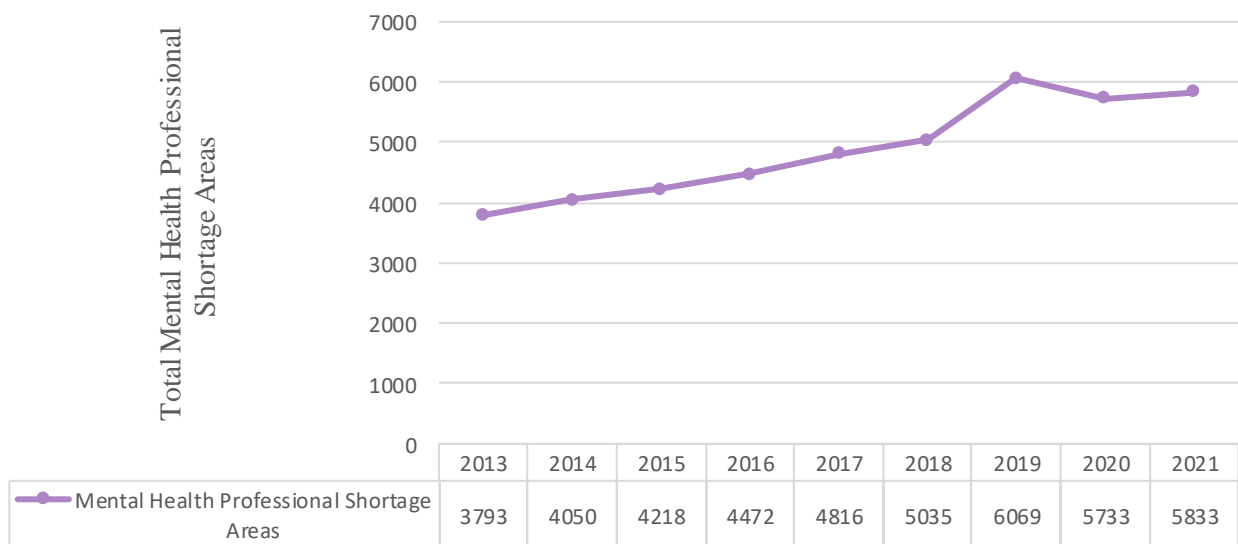
So, after knowing what complicated grief is and how it can affect an individual, the natural question is how does this play out on a national scale. Namely – how many individuals are living with complicated grief and what is the state of bereavement care access in the USA.

At any given time, ~28% people are estimated to be grieving at any given time in the USA prior to the COVID-19 pandemic (Parkes, 1998). Remembering that 10 to 20% of people who are grieving deal with complicated grief, this means approximately 2.8% to 5.6% of people are living with complicated grief in the USA (Bonanno, 2001; Middleton, 1996). This is consistent with the estimate provided in the DSM-5 entry for persistent complex bereavement disorder (APA, 2013). Given the total US population of 328,239,523 people in the most recent census, that means ~9.2 million to ~18 million individuals are living with complicated grief in any given year (United States Census Bureau, 2019). This is all without accounting for the influence of shocks such as mass tragedy events with national implications (i.e., the COVID-19 pandemic). The impact of such events will be discussed later.

## Mental Health Provider Shortages

**Figure 2**

*Mental Health Professional Shortage Areas from Fiscal Year 2013 to Fiscal Year 2019*



*Note.* Each year refers to a fiscal year. The data for all fiscal years besides that of 2020 came from the Health Resources & Services Administration (HRSA) website (HRSA, 2019; HRSA, 2021). The data for 2020 came from the Kaiser Family Foundation website because the fiscal year 2020 factsheet has not been uploaded yet (Kaiser Family Foundation, 2020). For the year 2021, data collection the current value represents the total shortage areas as of the second quarter

## BACKGROUND – *Bereavement Care Access Deficit*

While I could not find data for trends in bereavement care access overtime as it relates to people living with complicated grief, I was able to find data regarding the state of mental health care in the USA overall (presented in Figure 2). This is relevant for bereavement care since most AAFP bereavement care recommendations include a therapeutic component (Dudley, 2019). Overall, the total amount of mental health professional shortage areas has steadily increased overtime besides a decrease between 2019 and 2020. While this may seem positive, the Kaiser Family Foundation estimated that nationally, the total need met was only ~27% in 2020 (Kaiser Family Foundation, 2020).

*“I estimate at least ~6.7 to ~13 million people living with complicated grief live in areas with serious mental healthcare professional shortages at any given time.”*

The total population living in a mental health professional shortage area in 2020 was ~120 million, over one third of the total population of the USA (Kaiser Family Foundation, 2020; United States Census Bureau, 2019). Furthermore, though the counting for 2021 is not yet complete, the total shortage area designations at the total population living in those areas (now ~122 million) is higher than in 2020 (HRSA, 2021). Assuming that people living with complicated grief currently have no particular advantage in accessing healthcare (and I have nothing to suggest otherwise), I estimate at least ~6.7 to ~13 million people living with complicated grief live in areas with serious mental healthcare professional shortages at any given time (Kaiser Family Foundation, 2020; United States Census Bureau, 2019).

### *Excessive Out-of-Pocket Costs*

Another critical component of access is cost. In 2015, the National Alliance on Mental Illness (NAMI) report on mental healthcare affordability found that about one out of four respondents with insurance could not find an in-network outpatient mental health care provider in their area (NAMI, 2016). Because of this, when they were able to find a mental health provider, their out-of-pocket costs were higher for seeing mental health professionals than for primary care providers and medical specialists (NAMI, 2016). Fifteen percent of respondents seeing an outpatient mental health therapist had out-of-pocket costs exceeding \$200, exceeding that of primary care providers and medical specialists (NAMI, 2016). Supporting this, a 2014 study found that “acceptance rates for all types of insurance were significantly lower for psychiatrists than for physicians of other specialties” (Bishop, 2014).

## BACKGROUND – *Bereavement Care Access Deficit*

One study found that only 52% of family members were assessed to be at high risk for developing complicated grief utilized hospice bereavement counseling even though the counseling was assessed to be affordable and of decent quality (Ghesquiere, 2016). Using this, I will assume 52% of people dealing with complicated grief at any given time would be interested in bereavement care – so, around ~4.8 million to ~9.3 million people (Kaiser Family Foundation, 2020; United States Census Bureau, 2019). Assuming everyone has insurance coverage, potentially ~1.2 million to ~2.3 million people with complicated grief have difficulty finding an in-network outpatient mental healthcare provider (Kaiser Family Foundation, 2020; United States Census Bureau, 2019; Ghesquiere, 2016). There's no guarantee that mental healthcare will be affordable for those who find an in-network outpatient mental healthcare provider.

*“Potentially ~1.2 million to ~2.3 million people with complicated grief have difficulty finding an in-network outpatient mental healthcare provider.”*

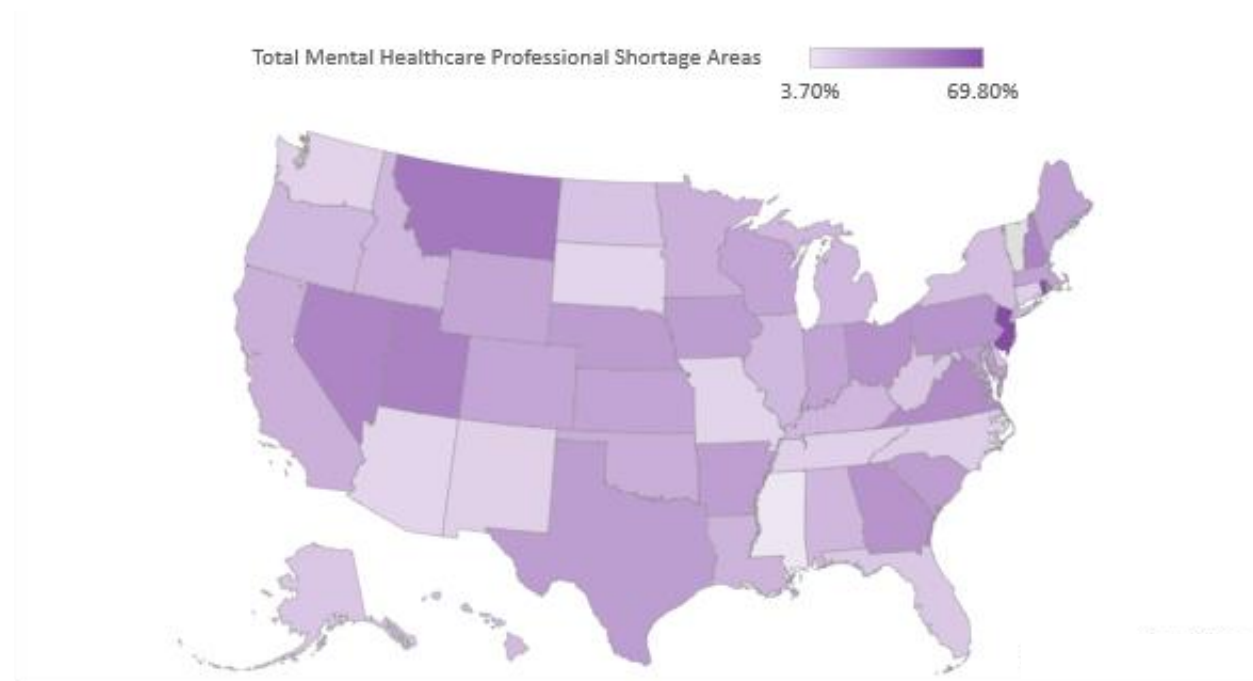
### Is everyone affected equally by the bereavement care access deficit?

In short, no, bereavement care access is incredibly inequitable across a variety of dimensions. In this section, I will discuss disparities as they relate to geographic location and ethnicity/race.

#### *Geographic Location*

**Figure 3**

*State by State Comparison of Percent of Mental Healthcare Need Met*



*Note.* The data for this graph is taken from the fiscal year 2021 second quarter estimates on the HRSA website and the Kaiser Family Foundation (HRSA, 2021; Kaiser Family Foundation, 2020). I could not find data to calculate percent need met for Vermont.



## BACKGROUND – *Bereavement Care Access Deficit*

There isn't a single state that doesn't have a mental health professional shortage area, so this is an issue throughout the nation (HRSA, 2021). It is also clear that some states have much larger shortages than others. The state with the highest number of mental healthcare professional shortage areas is California while the state with the least is Delaware (HRSA, 2021). The percent of need met was highest in New Jersey (69.8%) and lowest in Missouri (3.7%). However, besides New Jersey (69.80%), Rhode Island (69.50%), and Montana (51%), there was not a single state where the percent of need met exceeded 50% (Kaiser Family Foundation, 2020). In the grand majority of states, anywhere from 60% to 80% of the population would not be able to have their mental healthcare needs met in their locality (Kaiser Family Foundation, 2020).

In terms of the rural versus non-rural, there are almost double the amount of rural health professional shortage areas as there are non-rural health professional shortage areas (HRSA, 2021). Rural health shortages primarily occur in rural health clinics (approximately 36% of cases), federally qualified health centers (approximately 27% of cases), and tribal health organizations/other organizations dedicated to Native Americans (approximately 20% of cases) (HRSA, 2021). This indicates overall access issues related to facilities running at over-capacity and unable to meet the psychiatric needs of their communities.

### *Ethnicity/Race*

In particular, tribal health organizations make up an alarming amount of rural health professional shortage areas given that Native Americans only make up 1.3% of the total US population, indicating Native Americans likely face disproportionately high bereavement care access issues (United States Census Bureau, 2019). Organizations dedicated to serving Native American healthcare needs also make up ~ 8% of non-rural health professional shortage areas which, while not as drastic as the inequity in rural areas, is still disproportionate when considering how many Native Americans make up the total US population.

In addition to disparities in Native American access, a study funded by the US Department of Health and Human Services found disparities in Black-white and Latino-white mental health care expenditures for those paying high out-of-pocket costs relative to other Americans (Lê Cook, 2014). Black-white disparities were highest among the privately insured while Latino-white disparities were highest among the publicly insured (Lê Cook, 2014). The more educated an individual – Latino or Black -, the lower the disparities, but disparities were present regardless (Lê Cook, 2014). Overall, racial inequities persist for Black and Latino individuals – no matter their income, education level, and insurance type – that result in them expending disproportionate amounts of money for mental healthcare.

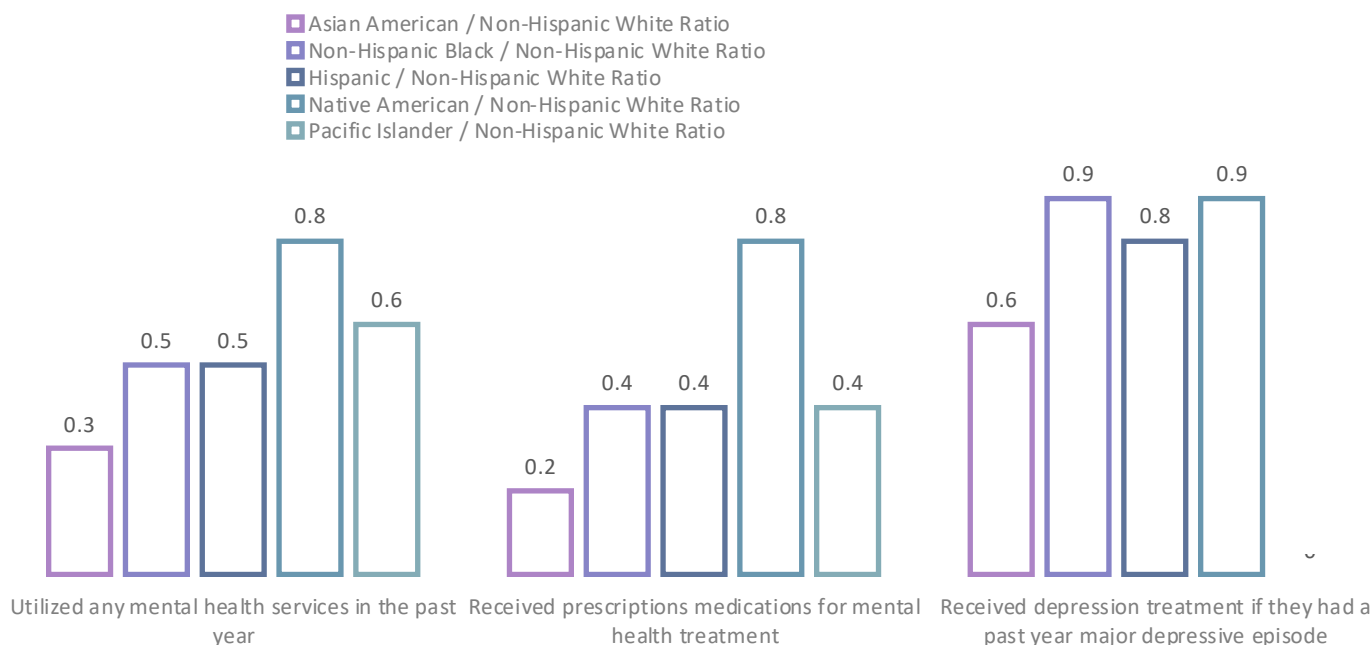
Lê Cook expanded on his previous study to include Asians as well and found significant Asian-White disparities as well (Lê Cook, 2017). In fact, he found significant Asian-White, Black-White, and Hispanic-White disparities in all three of his measures of annual access in 2004 and 2011: utilization of any mental health care, outpatient care, and psychotropic medication. In fact, he found the lowest overall utilization of any mental healthcare among Asians as compared to Hispanics, Blacks, and Whites (Hispanics and Black had roughly the same utilization).



## BACKGROUND – Bereavement Care Access Deficit

**Figure 4**

*Access to Mental Healthcare According to the Office of Minority Health*



*Note.* Data is taken directly from the U.S. Department of Health and Human Services' Office of Minority Health (Office of Minority Health, 2018). Data for the Pacific Islander / Non Hispanic-White ratio in response to the measure of depression treatment was missing. All data is limited to adults over age 18.

In Figure 4, the closer a ratio is to 1, the less the disparity compared to non-Hispanic whites for a given measure. Disparities exist across all measures. Consistent with Lê Cook's findings when examining disparities in 2004 and 2011, Hispanics and non-Hispanic black individuals still face similar levels of disparities in terms of overall utilization and Asians by far utilized mental health services the least. For the last measure regarding major depression, a caveat to interpreting those numbers positively is that it would depend on the assumption that BIPOC and non-Hispanic white adults report major depressive episodes at equivalent rates (which I have not found supporting evidence for). Also, different communities have different degrees of mental healthcare need across a variety of criteria listed in the DSM-5 (Office of Minority Health, 2018). Even in cases where utilization, prescriptions medication receipt, and depression treatment are close to equivalent for BIPOC and non-Hispanic white, this does not mean disparities in terms of mental healthcare need met and/or mental healthcare expenditure don't also exist.

### Why has this not been solved?

In the 1970s, sociologists and psychologists became interested in studying grief. There were a number of missteps along the way that have since been corrected in bereavement research – however these findings haven't spread to the public. For example, people still often cite the five stage model developed by Elizabeth Kubler-Ross, unaware that the Yale bereavement study's evidence – the first empirical examination of the model – did not support it (Maciejewski, 2007). There still is not enough research to make persistent complex bereavement disorder and official DSM-5 diagnosis.

There is also a lack of substantial research on complicated grief as it relates to various BIPOC groups. In a recently published literature review of bereavement research, almost every study examined either didn't report statistics related to race/ethnicity or had a higher percentage of white people participating than there are white-identifying people in the country (Mason, 2020; United States Census Bureau, 2019). Manifestations of grief differ across communities, so it is unclear exactly how much bereavement research is applicable to minorities until more inclusive research is conducted (APA, 2013). The lack of substantial research related to various groups facing inequalities also means that, while I would ideally like to evaluate all my alternatives by their potential to reduce various inequities, I don't have the data to back up such an evaluation.

Furthermore, bereavement only seems to capture the national consciousness during mass tragedy events that have national implication. Following the September, 11 2001 terrorist attacks, many employers adopted leave policies (Ward, 2020). National discourse revolved more on workplace leave and funeral attendance than on processing grief and trauma – to this day, Oregon is the only state that has passed a law requiring employers to provide bereavement leave (Ward, 2020). Google trends show that the term 'complicated grief' has slowly started to gain traction, but has yet to be a widely-known term (Google, 2021).

Ultimately, the public is only just starting to understand grief and bereavement care has just started to catch national (or even state-level) attention due to the COVID-19 pandemic. It has not been solved because it is only now that people advocating for bereavement care have truly begun to understand complicated grief and effective ways to help individuals living with it. In addition, it has not been solved because there has not been enough significant, sustained public attention on bereavement as it relates to labor laws, much less mental health components of grief which requires a much higher level of grief literacy to adequately discuss, until potentially now (Resnick, 2021).

## BACKGROUND – *Bereavement Care Access Deficit*

### Background – *Bereavement Care Access Deficit* Section Highlights

- A lack of mental healthcare providers and the high cost of seeing a provider contribute to a national bereavement care access deficit.
- This deficit does not affect everyone equally, though it is present in every state in varying but significant levels. Bereavement care research related to inequities is sparse.
- Bereavement care has not been adequately addressed at federal or state levels in terms of labor laws, much less in terms of mental health support, because bereavement has only started to attract significant, sustained public attention recently.

### How do mass tragedies affect the bereavement care access deficit?

Mass tragedies refers to any incident or group of related incidents that lead to multiple premature deaths in a community to such a degree that it can be considered to have negatively impacted the community as a whole. To be considered a mass tragedy at either the federal or state level, two conditions must be fulfilled:

- The President of the USA must have made a major disaster declaration or an emergency declaration as per the Stafford Act (Stafford Disaster Relief and Emergency Assistance Act, 1988) given the tragedy occurred after the Stafford Act was passed.
- Multiple premature deaths have occurred. A death is considered premature if the individual dies earlier than their life expectancy.
  - Life expectancy typically takes into account age, medically-relevant history, gender, and country of residence.

Common examples of mass tragedies include (but are not limited to) floods, wildfires, terrorist attacks, hurricanes, epidemics and earthquakes. A sitting President has never made a major disaster/emergency declaration for mass shootings that are not considered to be the work of non-US based terrorist organizations. Therefore, while mass shootings often result in multiple premature deaths that affect a community as a whole, are not considered a mass tragedy at the federal or state level under this definition.

Using the Convoy Model of Social Relations, I estimate that for every death, one to five people with kinship relations are bereaved (Antonucci, 2004). I have found no evidence to support the idea that this estimate should be higher for any type of mass tragedy event (besides the COVID-19 pandemic) (Ashton, 2020). However, mass tragedies can result in a higher portion of those one to five people developing complicated grief.

A person is considered at increased risk for developing complicated grief if the nature of the death was premature/unexpected and the death occurs simultaneously with other forms of loss (i.e. housing and job security) (APA, 2013; Boelen, 2007). These are both characteristics of the grand majority of mass tragedy events. In particular for terrorism, these deaths are considered traumatic (a result of homicide/suicide) which is such a significant risk factor in the development/exacerbation of mental health disorders that the DSM-5 criteria request diagnoses specify if the nature of the bereavement is traumatic (APA, 2013).

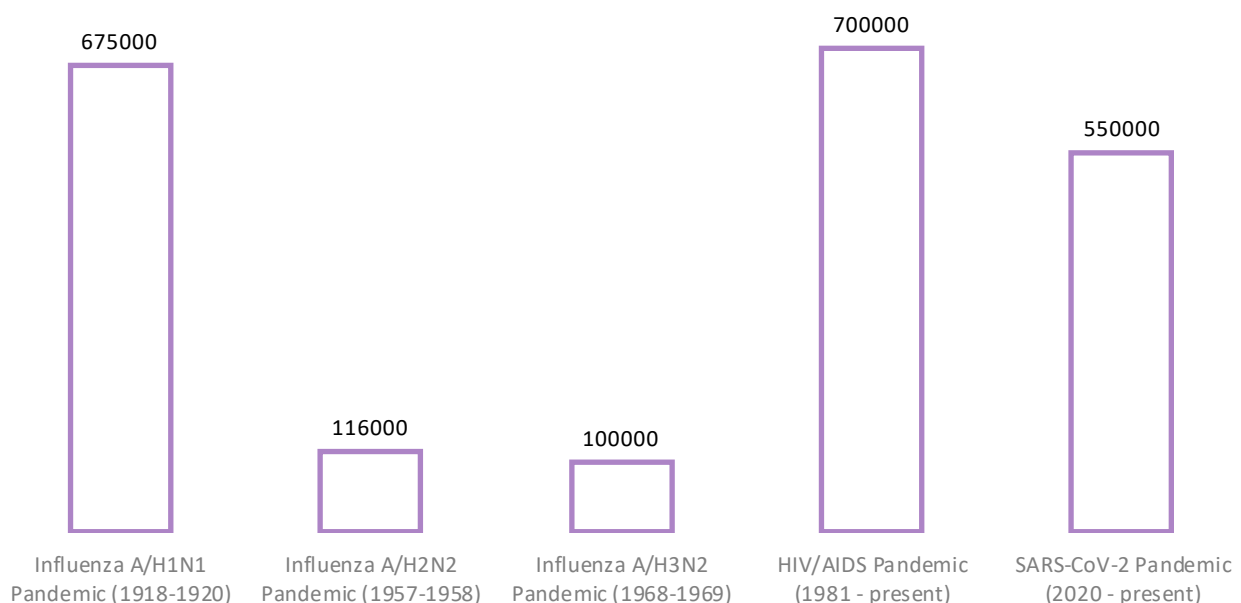
For scale, most non-epidemic mass tragedies result in at most a couple thousand deaths and it is the exception rather than the norm for a mass tragedy to be that deadly. The deadliest non-epidemic mass tragedy of all time was the 1900 Galveston hurricane which caused an estimated 6,000 to 8,000 deaths (National Park Service, 2019). Since the passage of the Stafford Act, the deadliest non-epidemic mass tragedy was the September 11, 2001 terrorist attacks, which killed

nearly 3,000 people (US Department of Defense, 2020). I estimate that around 3,000 to 15,000 people grieved the death of close kin as a result of the September 11, 2001 attacks. Because a higher proportion of people grieving develop complicated grief when dealing with a mass tragedy event, I estimate that 20% (as opposed to 10%) of people developed complicated grief – 600 to 3,000 people (Bonanno, 2001; Middleton, 1996; US Department of Defense, 2020). Using a similar method for the Galveston hurricane, I estimate between 6,000 to 40,000 people grieved the death of close kin and of those, 1,200 to 8,000 developed complicated grief (Bonanno, 2001; Middleton, 1996; National Park Service, 2019). The next section discusses epidemics.

### How has COVID-19 changed the bereavement care landscape?

**Figure 5**

*Comparison of Total US Deaths Caused by Epidemics that Have Caused Over 100,000 Deaths*



*Note.* Pandemics are a type of epidemic. The information for all pandemics besides HIV are from the CDC, the first citation for COVID and the second citation for all others (CDC, 2020; CDC, 2018). The information for HIV/AIDS is from the Kaiser Family Foundation (Kaiser Family Foundation, 2019). Pandemics are labeled by virus name rather than their common name given the racist implications of the majority of the common names, particularly towards Asians.

## BACKGROUND – *Mass Tragedies*

Figure 5 compares the total US deaths caused by epidemics which have caused over 100,000 deaths. There have only been two other pandemics in history that have caused close to as many deaths as the COVID-19 pandemic (labeled SARS-CoV-2 in Figure 6) in history and only one of them did so in a similarly small time frame – the Influenza A/H1N1 Pandemic that occurred close to a century ago. As of now, epidemics are the only type of mass tragedy that can be estimated to result in millions of people grieving the loss of kin.

Unlike any other mass tragedy event in history, more people grieve the loss of close kin per death than normal – to be more precise, nine people grieve per COVID-19 death (Ashton, 2020). That means that currently ~ 5 million people are grieving the loss of kin and, of those, approximately 1 million (using a 20% rate for complicated grief) will deal with complicated grief (Bonanno, 2001; Middleton, 1996; Ashton, 2020). Taken together, this all means the COVID-19 pandemics a uniquely impactful mass tragedy event which has exacerbated the overall need for bereavement care in a short time frame in a manner that has not been seen for at least a century .

In addition to how the COVID-19 pandemic has exacerbated the need for bereavement care, we are just starting to learn about the mental health implications for people who survive a COVID-19 diagnosis. A study published last Tuesday found that, in a sample of over 200,000 COVID-19 survivors, approximately one out of three received a diagnosis of a neurological or mental health-related illness within six months of coming down with COVID-19 (Taquet, 2021). The rate increased based on severity of symptoms. This study still needs to withstand replication with a larger sample size to be considered accurate. Assuming it is, this would mean at least ~10.3 million of the ~31 million who have been diagnosed with COVID-19 will suffer from diagnosably severe neurological or mental health related symptoms (CDC, 2021; Taquet, 2021). The COVID-19 pandemic has changed the landscape for mental health and bereavement care in ways that will be felt for many years to come. This is why, when evaluating alternatives, I focus on the COVID-19 pandemic where appropriate in recognition of its outsized impact.

### Background – *Mass Tragedy Events* Section Highlights

- Non-epidemic mass tragedies do not significantly increase the total amount of grieving individuals, but they do increase the proportion of those individuals who will deal with complicated grief.
- The COVID-19 pandemic has altered the bereavement care landscape for years to come in a way no other mass tragedy event has done for at least a century.
- Approximately 1 million people are currently suffering from complicated grief as a result of COVID-19.

# FINANCIAL COST TO SOCIETY

**Figure 6**

*Calculation Steps for the Cost to GDP Growth due to COVID-related bereavement leave*



*Notes.* All statistics included are from federal data sources, except for the inflation calculator.

Figure 6 demonstrates how I calculated the amount of GDP growth lost in 2021 dollars due to people with complicated grief taking paid leave – approximately \$300 million dollars. Because I am not sure how to approximate it, this estimate doesn't account for loss of productivity while working. Because of that, I consider this a very conservative estimate of the loss to GDP growth as a result of people suffering from COVID-related complicated grief. The main point of this calculation is to demonstrate that the complicated grief of a minority of USA residents has implications that affect the nation as a whole.

# ALTERNATIVES

## *Alternative 1: Status Quo*

Currently, SAMHSA does not operate any bereavement mental health programs. The VA offers bereavement counseling at 300 centers across the country at little to no cost for eligible members. Around 1.8 million veterans received treatment at centers in FY 2019 costing around \$8.7 billion (nominal to 2018) when subtracting out the cost of the suicide prevention program (“FY 2021 Budget Submission”). Recommending the status quo would mean recommending that the VA continues to receive funding for veteran bereavement counseling, but SAMHSA does not receive any additional money to set up programs to address the bereavement care access deficit.

## *Alternative 2: National Public Information Campaign*

This alternative would tackle grief literacy, not just that of people living with complicated grief, but also grief literacy in their communities. The goal of this campaign would be to ensure people understand:

- the difference between complicated and uncomplicated grieving patterns
- the signs that they or a loved one is experiencing complicated grief.
- how to access resources to assist in dealing with complicated grief
- types of maladaptive strategies
- how the expression of grief can differ for various minority groups and by gender

Education programs to target grief literacy fall directly in line with AAFP recommendations (Dudley, 2019). Recommending this alternative would mean recommending the VA continues to receive funding for veteran bereavement counseling and that Congress appropriates money to SAMHSA to set up a national public information campaign about bereavement.

The modality by which information is disseminated will determine who is reached. For example, Food & Drug Administration (FDA) programs (which are some of the most well-researched and effective public health education campaigns) targeting adults make use of digital paid advertising, radio ads, and billboards. Meanwhile, FDA programs targeting youth rely more heavily on social media, website development, and television ads. The pandemic has resulted in a spotlight on bereavement as it relates to the elderly and the youth. Given that the pandemic has reduced how much people travel for the immediate future, a national public campaign would initially focus on digital paid advertising, television/radio ads, and social media. This campaign should generally be modeled after the ‘Every Try Counts’ FDA campaign (FDA, 2020). As travel picks up, billboards would be set up in an effort to reach all age groups. In addition, information can be disseminated through school systems and retirement communities.



## ALTERNATIVES

### *Alternative 3: National Bereavement Care Hotline*

This alternative would tackle the shortage of mental health providers by ensuring any individual with a telephone can talk to a grief literate individual to help them process their grief. This would not be a replacement for counseling and callers would be encouraged to reach out to a mental health provider if the operator assesses an individual is living with complicated grief and would likely benefit from further support. Recommending this alternative would mean recommending that the VA continues to receive funding for veteran bereavement counseling and that Congress appropriates money to SAMHSA to setup a National Bereavement Care Hotline extension to the National Suicide Hotline (and modeled after the National Suicide Hotline).

The National Suicide Hotline regularly takes calls from individuals who are not suicidal, but still showing many symptoms in line with complicated grief. Because there would be overlap between the population the National Suicide Hotline serves and the population that a National Bereavement Care Hotline would serve, the National Bereavement Care Hotline would be incorporated into the infrastructure of the National Suicide Hotline – however, the National Bereavement Care Hotline would still have its own dedicated call-in number and redirect anyone who calls in displaying suicidal thoughts to the National Suicide Hotline. One big concern with this alternative is that the American public will likely not see the benefits of this hotline when others such as the National Suicide Hotline exist. Another concern is that people would attempt to use this hotline to substitute for therapy.

### *Alternative 4: Grief Counselor Certification for Eligible Mental Healthcare Providers*

This alternative would tackle the shortage of mental health providers. A number of individuals in the community – due to their profession – are eligible for grief counselor certification. This includes clergy, mental health / substance abuse social workers, and mental health/substance abuse counselors. Studies show that therapy specific to complicated grief is far more effective than regular interpersonal therapy (which is still effective, but not as effective) and antidepressants in treated complicated grief (Shear, 2016). Therefore, providing funding for certification – eligible individuals to receive grief counselor certification would enable them to provide effective, complicated grief-targeted counseling to individuals living with complicated grief. Recommending this alternative would mean recommending that the VA continue to receive funding for veteran bereavement counseling and that Congress appropriates money to SAMHSA to set up a grant program to reimburse certification – eligible individuals for the cost of completing certification.

### *Alternative 5: Therapy Funding for Americans Suffering from Complicated Grief related to a Mass Tragedy Event*

This alternative would tackle the high out-of-pocket costs associated with seeing a psychologist/psychiatrist by providing money to refund individuals who are likely to be suffering from complicated grief for the costs of attending five therapy sessions with someone licensed to provide bereavement counseling. Five was chosen because that is the average amount of times a given individual attends therapy (Hansen, 2006). A maximum of \$200 per session (\$1000 total maximum) will be covered as that would fully cover the out-of-pocket therapy costs of 83% of people looking for outpatient therapy (NAMI, 2016). In order to ensure this program specifically targets those who are suffering from complicated grief, only individuals who can provide proof of the death of kin due to a mass tragedy event will be eligible for the support. In addition, because complicated grief can only begin to be assessed at the one year mark, individuals will not be eligible for the refund until the fiscal year after the fiscal year within which their close kin passed away. Recommending this alternative would mean recommending that the VA continue to receive funding for veteran bereavement and counseling and that Congress the VA continue to receive funding for veteran bereavement and counseling and that Congress appropriate money to SAMHSA to set up a grant program for the purpose of refunding individuals who have lost close kin due to a mass tragedy events.

## EVALUATIVE CRITERIA

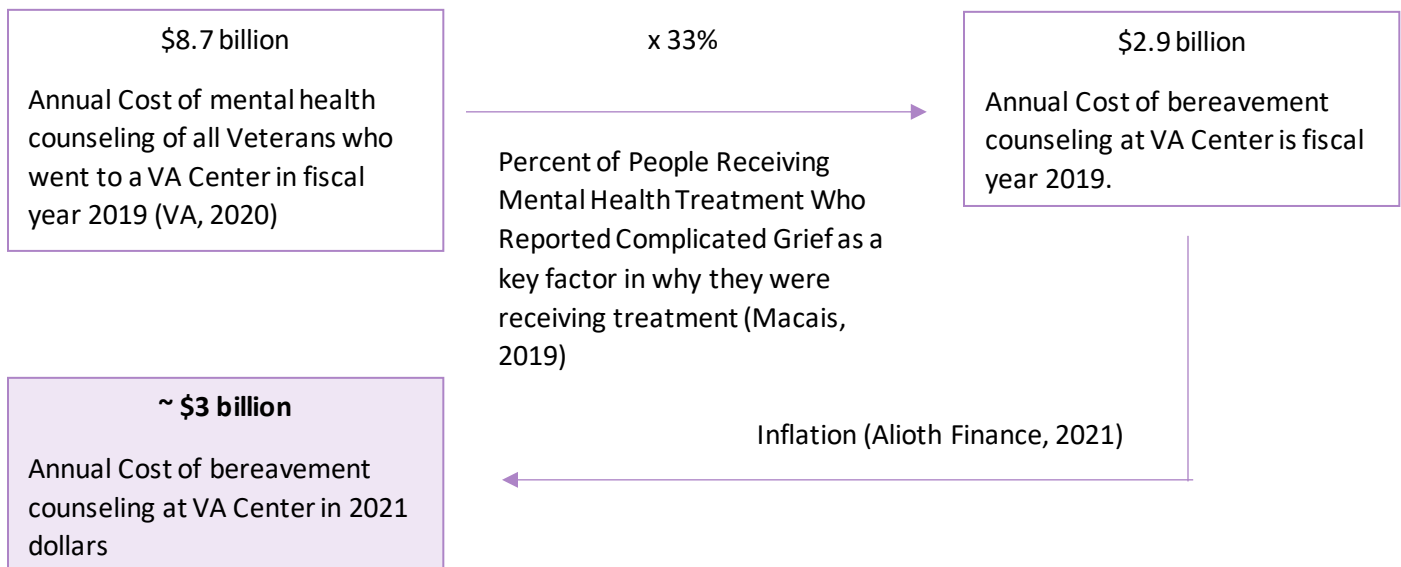
There are three major categories of evaluative criteria: cost, effectiveness, and political feasibility. Effectiveness and criteria are further broken down into two different components each. More detailed breakdowns related to effectiveness and criteria can be found in the appendices. In addition, I will discuss how I calculated out the total scores for each alternative.

### Cost

For each alternative, the cost criterion was trying to answer the question: How much money would SAMHSA and the VA combined need appropriated from Congress to implement this alternative for one year? First, the status quo cost was calculated.

**Figure 7**











*Alternative 1 Cost Criterion Formula: Money Needed By VA*



*Note.* This figure breaks down how cost was calculated for alternative 1.

Figure 7 breaks down the cost of the status quo annually - \$3 billion. For Alternatives 2-5, this cost is incorporated into the calculations. The final raw scores are all annual and in 2021 dollars.

**Table 2***Total Cost Calculations for Alternatives 1-5*

<b>Alternative</b>	<b>Annual Cost of Maintaining Status Quo</b>	<b>Annual Incremental Cost of Alternative</b>	<b>Total Cost of Alternative</b>
<b>Alternative 1 (Status Quo)</b>	\$3 billion 	\$0 	<b>\$3 billion</b>
<b>Alternative 2</b>	\$3 billion 	\$33 million 	<b>\$3.033 billion</b>
<b>Alternative 3</b>	\$3 billion 	\$13 million 	<b>\$3.013 billion</b>
<b>Alternative 4</b>	\$3 billion 	\$65 million 	<b>\$3.065 billion</b>
<b>Alternative 5</b>	\$3 billion 	\$1 billion 	<b>\$4 billion</b>

*Note.* This table separates out the incremental costs of Alternative 2-5 and the cost of the status quo. The specifics of how each total cost was calculated are located in Appendix C.

For each of these alternatives, the annual incremental cost (the cost of the alternative without including the status quo cost) ranged from \$13 million to \$1 billion. I decided to include the cost of the status quo into the total cost because the federal government would consider how much they are already spending on bereavement annually when deciding if they want to appropriate additional money annually rather than just the incremental cost, since none of these alternatives advocate for cutting or reducing the VA's counseling program.

For alternative 2, the incremental cost was equivalent to the annual cost of the 'Every Try Counts' FDA public information campaign (FDA, 2020). For alternative 3, the incremental cost was equivalent to the annual cost of running the National Suicide Hotline (FDA, 2020). For alternative 4, the incremental cost was calculated first by projecting the total clergy, mental health / substance abuse social workers, and mental health/substance abuse counselors who would need to be certified to meet the need for bereavement-specific counseling. This was multiplied by the cost of grief counselor certification and recertification (a two-year process), and then annualized by dividing by two.

For alternative 5, I calculated the total amount of people who are currently experiencing (or are projected to develop) complicated grief as a result of COVID deaths as of March 18, 2021. I then multiplied this by \$1000 (the maximum amount any individual can request under this alternative). In order to realistically estimate the cost for alternative 5 in the short-term, it is necessary to account for the extraordinary impact of COVID-19 which far exceeds the total death toll of other mass tragedies. In the future, barring any mass tragedies on the scale of COVID-19, the annual incremental cost of alternative 5 would likely be much cheaper.

# EVALUATIVE CRITERIA

## Effectiveness

I was interested in effectiveness as it relates to people experiencing complicated grief and substance use disorder (broken down into alcohol substance use and non-alcohol substance use) due to the fact that substance use is a hallmark of particularly severe complicated grief. Furthermore, compared to other mental health disorders, I found that data related to substance use was more readily available and of higher quality.

Exposure to resources is defined as a singular interaction with a mental health professional/responder and/or singular interaction with a public information campaign. The median number of psychotherapy sessions is 5, so the effect size of therapy will be 5x that of exposure to resources in section V (Connolly-Gibbons, 2012). This section is elaborated on in Appendix A.

### *People With Complicated Grief and Alcohol Substance Use Disorder Reached*

This criterion tries to answer the question: How many people dealing with complicated grief and alcohol substance use disorder would be reached due to the implementation of this alternative?

For Alternative 1, I estimated how many veterans were dealing with complicated grief directly from the total number of veterans that go to VA centers for mental health treatment. From there, I utilized the fact that ~20% of people with serious mental health issues suffering from complicated grief will develop non-alcohol substance use to get an estimate of the total amount of people dealing with non-alcohol substance abuse the VA reaches annually (Sung, 2011). I also used the 5x therapy multiplier here.

For Alternatives 2 and 3, I estimated how many non-veterans (assuming veterans would choose to use the status quo, though they are not precluded from using any of the potential SAMHSA grant programs) dealing with complicated grief and non-alcohol substance use were reached based on how many people were reached in the programs the alternatives were based on (in the cases of alternatives 2 and 3). I utilized the fact that ~40% of people who are grieving suffer from complicated grief and the fact that ~28% of people in any general population are grieving at any given time (Parkes, 1998; Bonanno, 2001; Middleton, 1996). Then, I added in alternative 1's value to get total people reached.

For Alternative 4, I estimated how many non-veterans would be reached by multiplying the total certificate-eligible individuals who should be certified by 26 clients (the average amount a substance dependence counselor sees in 2 years) (Knight, 2008). I also included the 5x therapy multiplier here. Then, I added in alternative 1's value to get total people reached.

For Alternative 5, I estimated how many non-veterans would be reached based on the percent of people dealing with complicated grief as a result of the COVID-19 pandemic. I utilized the 5x therapy effect. Then, I added in alternative 1's value to get total people reached.

## EVALUATIVE CRITERIA

### *People With Complicated Grief and Non-Alcohol Substance Use Reached*

This criterion tries to answer the question: How many people dealing with complicated grief and non-alcohol substance use would be reached due to the implementation of this alternative? I basically did the same thing as with non-alcohol substance use except that I utilized the fact that ~20% of people with serious mental health issues.

**Table 3**

*Total People Reached for Alternatives 1-5*

Alternative	1	2	3	4	5
<b>People dealing with Alcohol Dependence &amp; Complicated Grief Reached</b>	1.20 million	1.26 million	1.21 million	2 million	2.93 million
<b>People dealing with Non-Alcohol Substance Dependence &amp; Complicated Grief Reached</b>	600,000	630,000	605,000	1 million	1.46 million

*Note.* This table reports the total people dealing with certain mental health issues reached with each alternative.

If an alternative was not projected to reach more people than the status quo, its values in Table 3 would be equivalent to those for Alternative 1. Each alternative with some incremental cost beyond the status quo cost is projected to reach more people than the status quo. In particular, alternative 5 is more than two times as effective as the status quo in both components, even though the incremental cost of this alternative is one-third the cost of the status quo alone.

*“Alternative 5 is more than two times as effective as the status quo, even though the incremental cost of this alternative is only one-third the total cost of the status quo alone.”*

### *Political Feasibility*

There are two components of political feasibility I was interested in: the total degree of political support for an alternative and how bipartisan (how equal was the sum of support of democrats vs republicans) each alternative was.

### *Political Support*

This criterion tries to answer the question: How strong is the overall degree of support for this alternative in relevant committees? First, I assigned each chairman and ranking member of 12 relevant committees a score of 1 (will definitely vote for), 0.67 (will most likely vote for), 0.5 (unsure; no information found), 0.33 (will most likely vote against), or 0 (will definitely vote against) for each of the alternatives based on their voting records/stances on relevant issues/legislation (the specific voting issues and co-sponsored legislation used is elaborated on in Appendix B). The highest possible political support score was a 24. A score above 12 indicates more than half would support the alternative. A score under 12 indicates less than half would support the alternative. A score of 12 indicates indifference to whether the alternative is implemented or not.

# EVALUATIVE CRITERIA

**Table 4**

*Total Political Support Calculations for Alternatives 1-5*

Senate/ House	Committee	Chair/ Vice Chair	Name	Alternative 1	Alternative 2	Alternative 3	Alternative 4	Alternative 5
Senate	Appropriations	Chair	Patrick Leahy	0.66	1	0.5	1	0.5
Senate	Appropriations	Vice Chair	Richard Shelby	0.66	0.5	0.5	0.5	0.5
Senate	Finance	Chair	Ron Wyden	1	1	1	1	1
Senate	Finance	Vice Chair	Mike Crapo	1	0.5	1	1	0.5
Senate	HELP	Chair	Patty Murray	1	1	0.5	0.5	1
Senate	HELP	Vice Chair	Richard Burr	0.66	0.5	0.5	0.5	0.5
Senate	Aging	Chair	Bob Casey, Jr.	1	0.5	0.5	0.5	0.5
Senate	Aging	Vice Chair	Tim Scott	0.66	0.5	0.5	0.5	0.5
Senate	Veterans Affairs	Chair	Jon Tester	1	0.5	1	1	0.5
Senate	Veterans Affairs	Vice Chair	Jerry Moran	1	0.5	1	1	0.5
Senate	Rules and Admin	Chair	Amy Klobuchar	1	0.5	1	1	1
Senate	Rules and Admin	Vice Chair	Roy Blunt	0.66	0.5	0.5	0.5	0.5
House	Rules	Chair	Jim McGovern	1	1	1	1	0.5
House	Rules	Vice Chair	Tom Cole	0.66	1	1	0.5	1
House	Veterans Affairs	Chair	Mark Takano	1	1	1	0.5	0.5
House	Veterans Affairs	Vice Chair	Mike Bost	0.66	0.5	0.5	0.5	0.5
House	Appropriations	Chair	Rosa DeLauro	1	1	0.5	1	1
House	Appropriations	Vice Chair	Kay Granger	0.66	1	0.5	1	1
House	E&C	Chair	Frank Pallone	0.33	1	0.5	1	1
House	E&C	Vice Chair	Cathy McMorris	1	1	1	1	0.5
House	W&M	Chair	Richard Neal	1	1	0.5	0.5	0.5
House	W&M	Vice Chair	Kevin Brady	0.66	0.5	0.5	0.5	0.5
House	Education	Chair	Robert Scott	1	1	1	1	0.5
House	Education	Vice Chair	Virginia Foxx	0.66	1	0.5	0.5	0.5
<b>Total Score</b>				<b>20</b>	<b>19</b>	<b>17</b>	<b>18</b>	<b>16</b>

*Note.* This table elaborates on the political support scores each Senator/Representative achieved.

## EVALUATIVE CRITERIA

I summed up the individual scores of each of the congressmen to get a total political support score for each alternative. The higher the score, the stronger the degree of support. No alternative was projected to have as much support as the status quo alone, which makes sense because alternatives 2 through 5 call for additional spending beyond the status quo. However, because each score is above 12, it is still projected that Congress would lean towards supporting any of the alternatives.

### *Partisanship Penalty*

Currently, the vice chairs of each committee are Republicans, and the chairs of each committee are Democrats. This gives me a total sample of 12 Democrats and 12 Republicans. The maximum total support from either Democrats or Republicans is 12.

**Table 5**

*Subtotals of Political Support Calculations for Alternatives 1-5 by Chair/Vice Chair*

Alternative	1	2	3	4	5
<b>Total Support from Chairs (Democrats)</b>	11	11	9	10	8.5
<b>Total Support from Vice Chairs (Republicans)</b>	8.9	8	8	8	7
<b>Democrat / Republican Support Ratio</b>	1.2	1.3	1.1	1.3	1.2
<b>Partisanship Penalty: (-1) * (Ratio's magnitude from 1)</b>	<b>-0.2</b>	<b>-0.3</b>	<b>-0.1</b>	<b>-0.3</b>	<b>-0.2</b>

*Note. This table elaborates on the bipartisan nature of the support for each alternative.*

There are an equivalent number of Democrats and Republicans in this sample. So, I know that if an alternative is bipartisan (the total support from each side is equivalent), then dividing the total Democratic support by the total Republican support would result in a ratio of one. Therefore, anything other than one indicates some degree of partisanship and the further the magnitude from 1, the more partisan the alternative. A ratio above 1 would indicate the alternative is somewhat partisan to Democrats and a ratio below 1 would indicate the alternative is somewhat partisan to Republicans. None of the calculated alternatives were fully bipartisan – they all were somewhat partisan to Democrats. Therefore, each alternative received a partisanship penalty score (the magnitude of that alternative's ratio from a perfectly bipartisan ratio of one multiplied by negative one). If any alternative were fully bipartisan, their penalty would have been a zero. While none of the alternatives were perfectly bipartisan, the subtotals of political support by party were still fairly close for each alternative, so none were significantly partisan.



## Calculation of Individual Scaled Scores

Table 6

*Raw Totals Outcomes Matrix with Scaled Scores*

Alternative	Status Quo (1)	Public Information (2)	Hotline (3)	Certification (4)	Therapy Sessions (5)
Annual Cost in 2021 US dollars	<u>\$3 billion</u>	\$3.033 billion	\$3.013 billion	\$3.065 billion	\$4 billion
<b>Scaled Cost Score</b>	<b><u>3</u></b>	<b>3.033</b>	<b>3.013</b>	<b>3.065</b>	<b>4</b>
People dealing with Alcohol Dependence & Complicated Grief Reached Annually	1.20 million	1.26 million	1.21 million	2 million	<u>2.93 million</u>
<i>Scaled Score(a)</i>	2.4	2.52	2.42	4	<u>5.86</u>
People dealing with Non-Alcohol Substance Dependence & Complicated Grief Reached	600,000	630,000	605,000	1 million	<u>1.46 million</u>
<i>Scaled Score(b)</i>	1.2	1.26	1.21	2	<u>2.92</u>
<b>Scaled Effectiveness Score</b>	<b>3.6</b>	<b>3.78</b>	<b>3.63</b>	<b>6</b>	<b><u>8.78</u></b>
Political Support	<u>20</u>	19	17	18	16
<i>Scaled Score(c)</i>	<u>2</u>	1.9	1.7	1.8	1.6
Partisanship Penalty	-0.2	-0.3	<u>-0.1</u>	-0.3	-0.2
<i>Scaled Score(d)</i>	-0.2	-0.3	<u>-0.1</u>	-0.3	-0.2
<b>Scaled Political Feasibility Score</b>	<b><u>1.8</u></b>	<b>1.6</b>	<b>1.6</b>	<b>1.5</b>	<b>1.4</b>

*Notes.* These are the raw scores and scaled scores for each of the criteria components. I shaded the single cost component in purple, the two effectiveness components in aqua, and the two political feasibility components in teal. In addition, I underlined the scores for the alternative that performed the best for each of the components. Finally, to calculate the scaled effectiveness score, I added up the relevant scores from a and b. Similarly, to calculate the scaled political feasibility score, I added up the relevant scores from c and d.

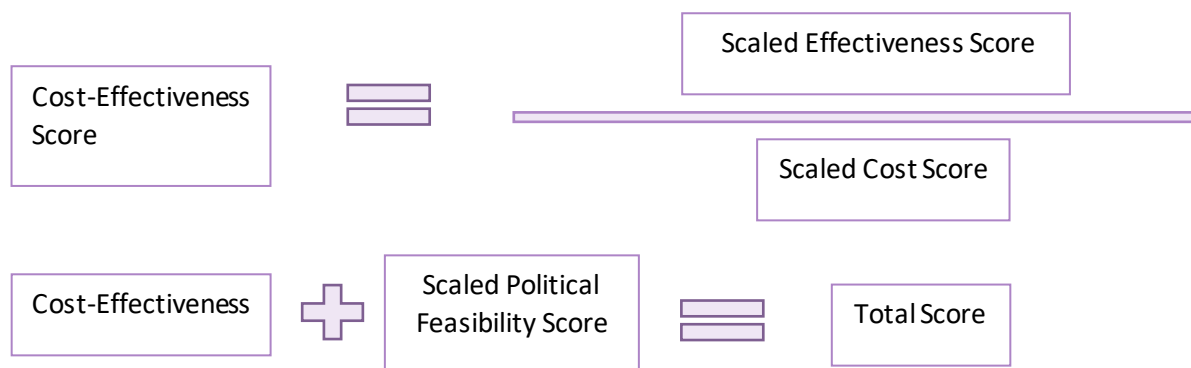
After looking at the data for the raw scores, I decided to divide the cost criterion raw score by 1 billion, the effectiveness criteria raw scores by 0.5 million, and the political support score by 10. I did this because, after discussing with my client, we wanted a formula that calculated out a total score which kept the impacts of cost, effectiveness, and political support relatively equal. I decided the best way to achieve this was scaling each of the raw scores so that each of the individual scaled scores fell between 1 and 10. From here, I used the following formula to calculate the total score.

## EVALUATIVE CRITERIA

### Calculation of Cost-Effectiveness and Total Scores

**Figure 8**

*Formulas for Cost-Effectiveness and the Total Score*



*Notes.* This figure elaborates on the calculation of the total scores for each alternative.

In example, to calculate the total score for alternative 1, I would divide the scaled effectiveness score (3.6) by the scaled cost score (3). This gives a cost-effectiveness score of 1.2. Adding this cost-effectiveness score (1.2) and the scaled political feasibility score (1.8) results in a total score of 3 for the status quo. The total scores and cost-effectiveness scores are discussed in the findings section.

## FINDINGS

**Table 4**

*Cost-Effectiveness and Total Score Outcomes*

Alternative	Scaled Cost Score		Scaled Effectiveness Score		Cost-Effectiveness		Scaled Political Feasibility Score		Total Score
Status Quo (1)	<u>3</u>	⊕	3.6	≡	1.20	+	<u>1.8</u>	≡	3
Public Information (2)	3.033	⊕	3.78	≡	1.25	+	1.6	≡	2.85
Hotline (3)	3.013	⊕	3.63	≡	1.20	+	1.6	≡	2.8
Certification (4)	3.065	⊕	6	≡	1.96	+	1.5	≡	3.46
Therapy Sessions (5)	4	⊕	<u>8.78</u>	≡	<u>2.20</u>	+	1.4	≡	<u>3.60</u>

*Notes.* I underlined the best scores in each row. In addition, I shaded the row which contained the alternative with the best cost-effectiveness and total score in purple.

Overall, Alternative 5 scored the best in cost-effectiveness and had the highest total score, even though it was shown to have the least political support in Table 3. The effectiveness of Alternative 5 was simply so much higher compared to the others (more than double that of the status quo effectiveness score) that it nudged it over the edge. As stated earlier, while the incremental cost of alternative 5 (\$1 billion) was the highest, it is only one-third that of the cost of the status quo alone (\$ 3 billion). This is reflected in the scores, While alternative 5 overall scored the best, Alternative 4 actually scored relatively close to it – Alternatives 4 and 5 were the only alternatives to outperform the status quo in terms of total score. However, strictly in terms of cost-effectiveness, every alternative outperformed the status quo beside Alternative 3 (A National Bereavement Care Hotline), which was roughly equal to the status quo.

## RECOMMENDATION

Based on the results of this report, I recommend Alternative 5. To elaborate, this means that I recommended that NHPCO lobby Congress to:

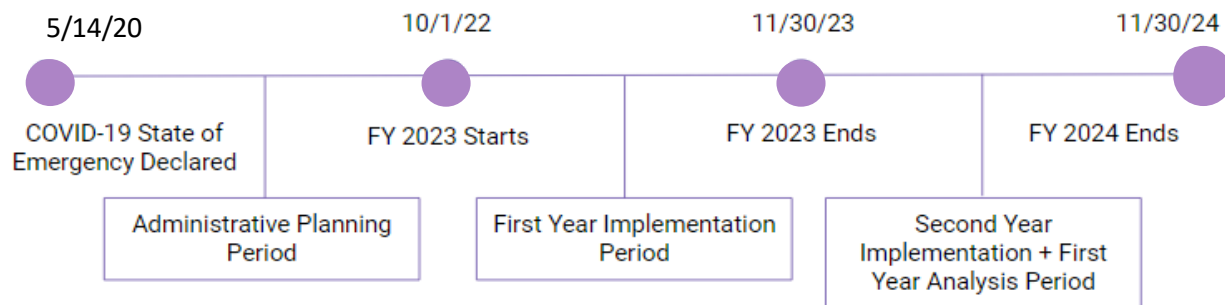
- Continue appropriating funds for the VA's veteran bereavement counseling program
- Appropriate additional money to SAMHSA to set up a grant program for the purpose of refunding individuals who have lost close kin due to a mass tragedy events.

# IMPLEMENTATION

## Implementation Timeline

Figure 9

### Timeline of Events



*Note.* This figure breaks up the timeline for rolling out necessary steps into three major periods. FY refers to ‘fiscal year’ as defined by the federal government.

The administrative planning period encompasses the steps that need to be completed before rolling out this alternative. The first-year implementation period covers how this alternative should function initially. The first-year analysis period covers data collection and analysis on the first-year implementation in order to adjust for the future.

Certain stakeholders must be involved: National Hospice Palliative Care Organization (NHPCO), Congress, Substance Abuse and Mental Health Services Administration (SAMHSA), Department of Veterans Affairs (VA), the Internal Revenue Service (IRS) and the general public.

## Administrative Planning Period

NHPCO’s role begins and ends in the administrative planning period. They must lobby legislators serving in relevant committees (listed in detail in Appendix C) From there, the government would take over. Congress should appropriate funds to the VA to continue providing free bereavement counseling to veterans and to SAMHSA to create a grant program to serve all Americans estimated to be suffering from complicated grief due to a mass tragedy event.

SAMHSA should need to develop a list of mass tragedies for which it will cover counseling costs. This can be done by consulting the Federal Emergency Management Agency website. Then, SAMHSA will need to coordinate with the IRS to create a bereavement care tax credit, paid for in full through the grant program, and work with the IRS to ensure information concerning the tax credit is identical on the IRS and SAMHSA webpages. The IRS page concerning the credit will link to the SAMHSA page and vice versa. SAMHSA will publish the list of mass tragedies that will be recognized in the next tax season on their page by the start of Fiscal Year 2023 (which is likely ~3 months in advance of the earliest day an individual can file taxes).

SAMHSA should make estimates of how many people are bereaved in each state due to mass tragedies on SAMHSA's list using a 9x multiplier for each COVID-19 death and 1-5x multiplier for other mass tragedies to help plan out distribution (Ashton, 2020; Antonucci, 2004).

## First Year Implementation Period

An individual will file for the bereavement care tax credit in a similar manner to filing for the individual health coverage tax credit (IRS, 2020). The credit will be applied to their income tax. This form will ask the individual to:

- disclose how many kin they had die due to a mass tragedy in the past fiscal year
- disclose if they have insurance and, if so, what kind
- disclose if the provider they saw accepted their insurance
- disclose what their out-of-pocket costs were for seeing that provider for a maximum of five sessions per deceased kin
- disclose if they have previously filed for this credit and, if so, who for (this will only be relevant starting the second year)

In addition to this form, individuals will be asked to provide documentation including:

- Photocopies of the form from any previous filings that were credited
- Receipts and health insurance bills related to each of the therapy sessions
- Proof of death including time of death and cause (in other words, prove it was caused directly by the tragedy)
- Proof of kinship (proof that the deceased is your kin i.e. through photocopies of birth certificates)

Individuals can only file for the bereavement care tax credit one time per deceased kin. That is to say, an individual cannot file for covering the cost of three counseling sessions due to the death of their spouse one year and then two counseling sessions the next due to the death of their spouse. Individuals must file by the 2022 IRS tax deadline to be eligible (4/18/22). The maximum credit per death is \$1000. If an individual is eligible and files but SAMHSA is unable to cover their credit, they will be notified that they will receive the tax credit the following fiscal year without needing to do any additional paperwork. Similar to the Earned Income Tax Credit, this will be a refundable credit. That is, if the tax credit exceeds the amount of tax an individual owes, their net liability will be zero and the remainder will be received through a refund.

Once an individual files, SAMHSA will be in charge of verifying with state boards that the individual saw someone license to provide bereavement counseling (psychiatrist, psychologist, or grief counselor working through hospice), that they lost someone who is kin, and that they lost their kin in a mass tragedy event that occurred at least one fiscal year prior to fiscal year 2023. If an individual is determined to be eligible, SAMHSA will notify the IRS and cover the cost of the tax credit and any related refund.

If the amount appropriated by Congress is not enough to cover costs, priority will be given to individuals who filed their taxes earliest. In the following fiscal year, priority will be

given first to giving tax credits to people who were eligible the previous year but were not able to receive it and then to individuals who filed their taxes early.

## Second Year Implementation Period & First Year Analysis Period

The alternative should be implemented in a similar manner as the first year. The only major difference should be that the IRS will be in charge of verifying that an individual has not filed for a bereavement tax credit for the same kin more than once. SAMHSA will send out surveys to any individuals who were determined to be eligible for a tax credit on 11/30/23 (end of fiscal year 2023). Using the survey, SAMHSA will assess the effectiveness of this alternative. With this, SAMHSA will judge whether to continue this alternative for a third year and, if so, how much money to request for the alternative from Congress. Even if SAMHSA decides to discontinue the program, any individuals who filed and was determined to be eligible for a tax credit should receive their tax credit and any associated refund before the discontinuation of the program.

## Implementation Concerns

This implementation strategy's success depends on the buy-in of state departments of audit and the IRS, so I decided to minimize fraud concerns (an individual who is not really grieving receiving a refund anyways) by setting a high standard. Minimizing this concern exacerbates another concern that many people suffering complicated grief due to the death of someone who is not close kin (cousin, close friend) will be unable to qualify. Trying to cover everyone would make it impossible for SAMHSA to reliably estimate how much money is needed in advance. If a far higher number of people apply for a refund beyond those estimated, the appropriated budget might get stretched so thin that the federal government cannot meet most people's claims. This would mean that the alternative is ineffective. It is better to reliably cover the needs of less people. The survey results could be used to develop new estimates of how many people grieve each mass tragedy event beyond just close kin. With more bereavement research, this program could be expanded to cover people grieving losses beyond those of close kin later on.

## Conclusion

A significant minority of grieving individuals develop complicated grief after a loss, which can cause/exacerbate many serious mental disorders. One of the most critical risk factors of this is loss of kin. These individuals exist in a society with a lack of mental healthcare providers and high costs related to seeing mental healthcare providers, making it difficult for them to seek help. In addition, while this affects individuals living in every state, it does not affect individuals from all ethnic/racial backgrounds equally and much existing bereavement research is focused on white Americans – the group which tends to have the most access to mental healthcare as compared to other groups.

Non-epidemic mass tragedies do not significantly increase the total amount of grieving individuals, but they do increase the proportion of these individuals who will develop complicated grief. Therefore, individuals who develop complicated grief as a result of mass tragedies deserve particular attention. In particular, epidemic mass tragedies can substantially increase the total number of grieving individuals. For at least 100 years, no mass tragedy has increased the total amount of grieving individuals and the total proportion of those individuals who will develop complicated grief in the way COVID-19 has. The COVID-19 pandemic has completely altered the bereavement care landscape and its effects will be felt for many decades and in the coming years, its effect on the mental health landscape deserves particular focus.

After evaluating a number of alternatives aimed at decreasing barriers related to cost, a lack of providers, and education, the alternative best supported by the current research is alternative 5 – continuing to fund bereavement counseling through the VA and appropriating money to SAMHSA so that they can set up a bereavement program which funds 5 counseling sessions for each death of close kin due to a mass tragedy that an individual experiences.

This alternative addresses the cost barrier and was found to be more cost-effective and have a higher overall score than the status quo alone or any of the other considered alternatives. However, two other alternatives (Alternative 2 [public information campaign] and Alternative 4 [grief counseling certification]) were also more cost-effective than the status quo alone and it's possible a combined approach incorporating alternatives 2,4, and 5 could be considered. However, priority should be given to lobbying the federal government to appropriate additional funds to SAMHSA and continue appropriating funds to the VA as it relates to alternative 5.

Ideally, this could be expanded to individuals experiencing the loss of people who are not kin (i.e. cousins) later on, but more research needs to be done that is inclusive of minority groups and studies the nature of grief when an individual loses someone besides close kin first.



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## APPENDIX A – Effectiveness Calculations

Exposure to resources is defined as a singular interaction with a mental health professional/responder and/or singular interaction with a public information campaign. The median number of psychotherapy sessions is 5, so the effect size of therapy will be 5x that of exposure to resources in section V (Connolly-Gibbons, 2012)

### **Alternative 1**

The status quo results in approximately 600,000 people (one-third of 1.8 million) suffering from complicated grief receiving treatment (Macais, 2019). One study found that, of people with serious mental health issues suffering from complicated grief, ~40% had developed lifetime alcohol dependence and ~20% developed lifetime substance dependence (Sung, 2011). Therefore, of these 600,000, I can infer that ~240,000 people dealing with alcohol dependence and complicated grief and ~120,000 people dealing with substance dependence and complicated grief are receiving mental health treatment in a year.

Including the 5x therapy effect, that is equivalent to reaching 1.2 million people per year with alcohol dependence and 600,000 people per year with non-alcohol substance dependence annually.

### **Alternative 2**

In the general population, it is estimated that ~28% are grieving at a given time (Parkes, 1998). Therefore, in a national public information campaign similar to 'Every Try Counts' that reaches 5.8 million adults, I estimate that ~1.6 million are grieving and of those, 320,000 are dealing with complicated grief (Bonanno, 2001; Middleton, 1996). Of those, I estimate ~130,000 people who have developed lifetime alcohol dependence and complicated grief ~64,000 people who have developed substance dependence and complicated grief will be exposed to resources as a result of a national public information campaign in two years (Sung, 2011). Annualized based on the program lasting two years, that is 65,000 people with alcohol dependence and 32,000 people with non-alcohol substance dependence.

Discounting the 7.1% of people who are veterans (under the assumption veterans will rely on the status quo rather than the new SAMHSA program, that is 60,385 people reached with alcohol dependence and 29,778 with non-alcohol substance dependence reached (Frohlich, 2020). Including the status quo, that is 1,260,385 people with alcohol dependence and 629,728 people with non-alcohol substance dependence reached annually.

### **Alternative 3**

The national suicide hotline, which the national bereavement lifeline would be based on, received ~ 2.2 million calls annually in FY 2018. Because there would likely be a lot of overlap in the population of people choosing to call the national suicide hotline and the national bereavement hotline, I will assume that of the callers to National Suicide Hotline, ~28% are redirected to the National Bereavement Lifeline because they express that they are suffering from loss (Parkes, 1998). From that number, I will infer that of the 620,000 callers, ~120,000 are suffering from complicated grief (Bonanno, 2001; Middleton, 1996). Of those, I estimate ~48,000 people dealing with lifetime alcohol dependence and complicated grief and between



## APPENDIX A – Effectiveness Calculations

~24,000 people dealing with substance dependence and complicated grief will be exposed to resources as a result of this alternative in 5 years (Sung, 2011). Annualized based on this being over 5 year, that is 9,600 people with alcohol dependence and 4,800 people with substance dependence reached.

Discounting the 7.1% of people who are veterans (under the assumption veterans will rely on the status quo rather than the new SAMHSA program, that is 8918 people with alcohol dependence and 4459 people with non-alcohol substance dependence reached (Frohlich, 2020). Including the status quo, that is 1,208,918 people with alcohol dependence and 604,459 people with non-alcohol substance dependence reached annually.

### **Alternative 4**

One-third of counselors, clergy and social workers becoming certified grief counselors would be 165,260 people (Macais, 2019). While I could not find the average caseload for a grief counselor, the average caseload for a substance dependence counselor is 26 clients per counselor in 2 years (Knight, 2008). Assuming that each grief counselor sees at least 26 people over 2 years, that is a total of ~4.3 million clients. From there, I will estimate that 0.9 million of those clients are dealing with complicated grief (Bonanno, 2001; Middleton, 1996). Of those, I estimate ~344,000 people dealing with lifetime alcohol dependence and complicated grief and ~172,000 people dealing with lifetime substance dependence will be treated as a result of this alternative in 2 years (Sung, 2011). Including the 5 times effects and annualizing based on a duration of 2 years (multiplying by 5 and dividing by 2), that is 860,000 people with alcohol dependence and 430,000 people with non-alcohol substance dependence reached per year.

Discounting the 7.1% of people who are veterans (under the assumption veterans will rely on the status quo rather than the new SAMHSA program, that is 798,940 people with alcohol dependence and 399,470 people with non-alcohol substance dependence reached (Frohlich, 2020). Including the status quo, that is 1,998,940 people with alcohol dependence and 999,940 people with non-alcohol substance dependence reached annually.

### **Alternative 5**

As stated in section II, assuming therapy sessions are provided for everyone dealing with complicated grief as a result of COVID, that is 0.5 to 1 million people treated. Of those, I estimate ~400,000 people dealing with lifetime alcohol dependence and complicated grief ~200,000 people dealing with lifetime substance abuse and complicated grief will be treated as a result of this alternative annually. Including the 5x therapy effect, that is 1.86 million people with alcohol dependence and 929000 people with non-alcohol dependence reached annually.

Discounting the 7.1% of people who are veterans (under the assumption veterans will rely on the status quo rather than the new SAMHSA program, that is 1727940 people with alcohol dependence and 863,041 people with non-alcohol substance dependence reached annually (Frohlich, 2020). Including the status quo, that is 2927940 people with alcohol dependence and 1463041 people with substance dependence reached annually.

## APPENDIX B – Political Feasibility Calculations

Up until Roy Blunt, everyone is a Senator. From Jim McGovern downwards, everyone is a Representative.

Alternative 1 Considerations									
Co-sponsors to S. 785: Veterans Mental Health Care Improvement Act of 2019 (each received a 1)									
Jon Tester									
Jerry Moran									
Amy Klobuchar									
Bob Casey									
Ron Wyden									
Mike Crapo									
Patty Murray									
On Expanding private care options for veterans on May 23, 2018 (projectfivethirtyeight profiles)									
Congressperson	Voted?	Score							
Patrick Leahy	Yes	0.66							
Richard Shelby	Yes	0.66							
Richard Burr	Yes	0.66							
Tim Scott	Yes	0.66							
Roy Blunt	Yes	0.66							
The House unanimously passed S.785, so this will be disregarded for them.									
On Expanding private care options for veterans on May 23, 2018 (projectfivethirtyeight profiles)									
House Rep	Voted?	Score							
Tom Cole	Yes	0.66							
Mike Bost	Yes	0.66							
Kay Granger	Yes	0.66							
Frank Pallone	No	0.33							
Kevin Brady	Yes	0.66							
Virginia Foxx	Yes	0.66							
Co-sponsor to H.R.5396 - Veterans Mental Health Care Access Improvement Act of 2006									
Cathy McMorris									
Co-sponsor to H.R. 1725 - Veterans menal health Accessibility Act (each receieved a 1)									
Jim McGovern									
Mark Takano									
Rosa DeLauro									
Richard Neal									
Robert Scott									



## APPENDIX B – Political Feasibility Calculations

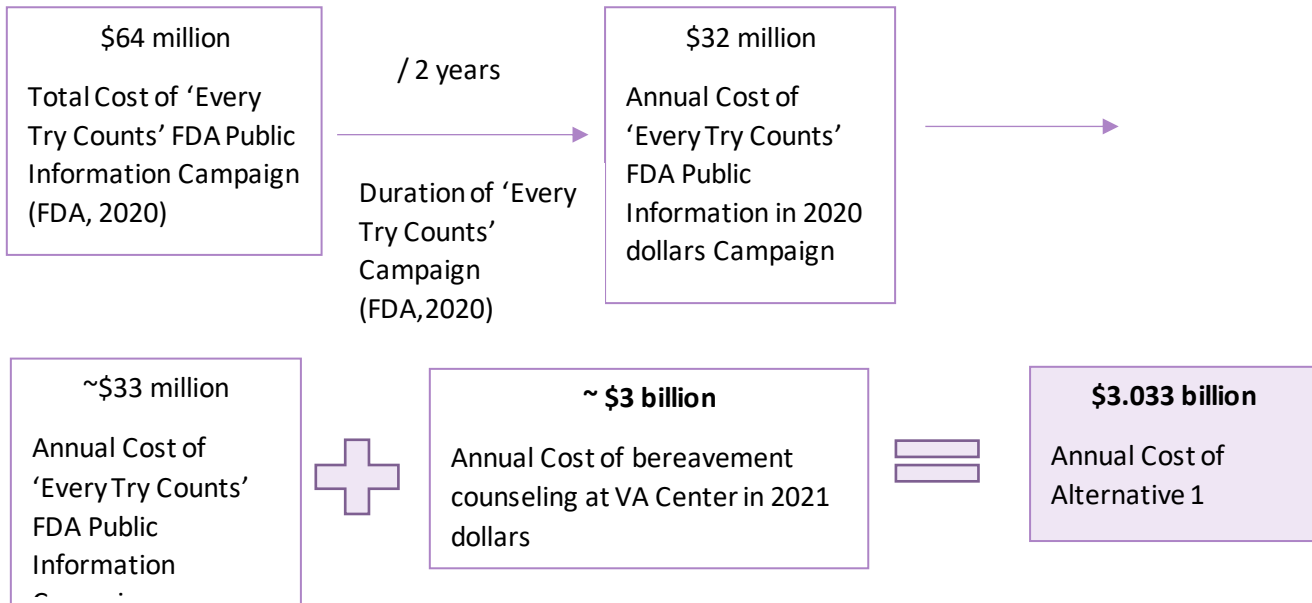
<b>Alternative 2 Considerations</b>									
Co-sponsors to H.R. 1109 (Mental Health Services for Students Act of 2020) (each received a 1)									
Jim McGovern									
Co-sponsors to H.R. 1245 (Johanna's Law) (each received a 1)									
Tom Cole									
Rosa DeLauro									
Kay Granger									
Frank Pallone									
Jim McGovern									
Cathy McMorris									
Richard Neal									
Virginia Foxx									
Co-sponsors to S.1172 - Gynecologic Cancer Education and Awareness Act of 2005 (each received a 1)									
Patrick Leahy									
Ron Wyden									
Patty Murray									
Co-sponsor to H.J.Res.360 - To designate the week of April 25, 1994, to May 1, 1994, as "Let's Stop Kids Killing Kids Week". (each received a 1)									
Robert Scott									
Co-sponsor to H.Res.151 - Condemning all forms of anti-Asian sentiment as related to COVID-19. (each received a 1)									
Mark Takano									
<b>Alternative 3 Considerations</b>									
Co-sponsors to S. 2661 - National Suicide Hotline Designation Act of 2020 (each received a 1)									
Ron Wyden									
Mike Crapo									
Jon Tester									
Jerry Moran									
Amy Klobuchar									
Co-sponsors to H.R. 4194 - National Suicide Hotline Designation Act of 2019 (each received a 1)									
Jim McGovern									
Tom Cole									
Mark Takano									
Cathy McMorris									
Robert Scott									

Alternative 4 Considerations					
Co-sponsor to S.515 (Each Recieved a 1)					
Amy Klobuchar	(received a 1)				
Co-sponsor to H. Res 1134 - Supporting the goals and ideals of Mental Health Month. (Each Received a 1)					
Jim McGovern					
Rosa Delauro					
Kay Granger					
Cathy McMorris					
Robert Scott					
Co-sponsor to H.R.945 - Mental Health Access Improvement Act of 2019 (each received a 1)					
Jim McGovern					
Cathy McMorris					
Co-sponsor to S.286 - Mental Health Access Improvement Act of 2019 (each received a 1)					
Patrick Leahy					
Jon Tester					
Jerry Moran					
Co-sponsor to H.R.4574 - Strengthening Mental Health in Our Communities Act of 2014 (received a 1)					
Frank Pallone					
Co-sponsor to S. 162 - Justice and Mental Health Collboration Act of 2013 (each received a 1)					
Patrick Leahy					
Ron Wyden					
Mike Crapo					
Jerry Moran					
Amy Klobuchar					
Roy Blunt					
Co-sponsor to S.195 - Mental Health in Schools Act of 2013 (received a 1)					
Jon Tester					

<b>Alternative 5 Considerations</b>					
<b>Co-sponsors to H.R.2646 - Helping Families in Mental Health Crisis Act of 2016 (each received a 1)</b>					
Tom Cole					
Mike Bost					
Kay Granger					
<b>Co-sponsor to H.R.4574 - Strengthening Mental Health in Our Communities Act of 2014 (received a 1)</b>					
Frank Pallone					
<b>Co-sponsor to S.Res.90 - A resolution designating the week of February 1 through 5, 2021, as "National School Counseling Week". (recieved a 1)</b>					
Amy Klobuchar					
Ron Wyden					
Patty Murray					
<b>Co-sponsor to S.2499 - Elementary and Secondary School Counseling Act (received a 1)</b>					
Ron Wyden					

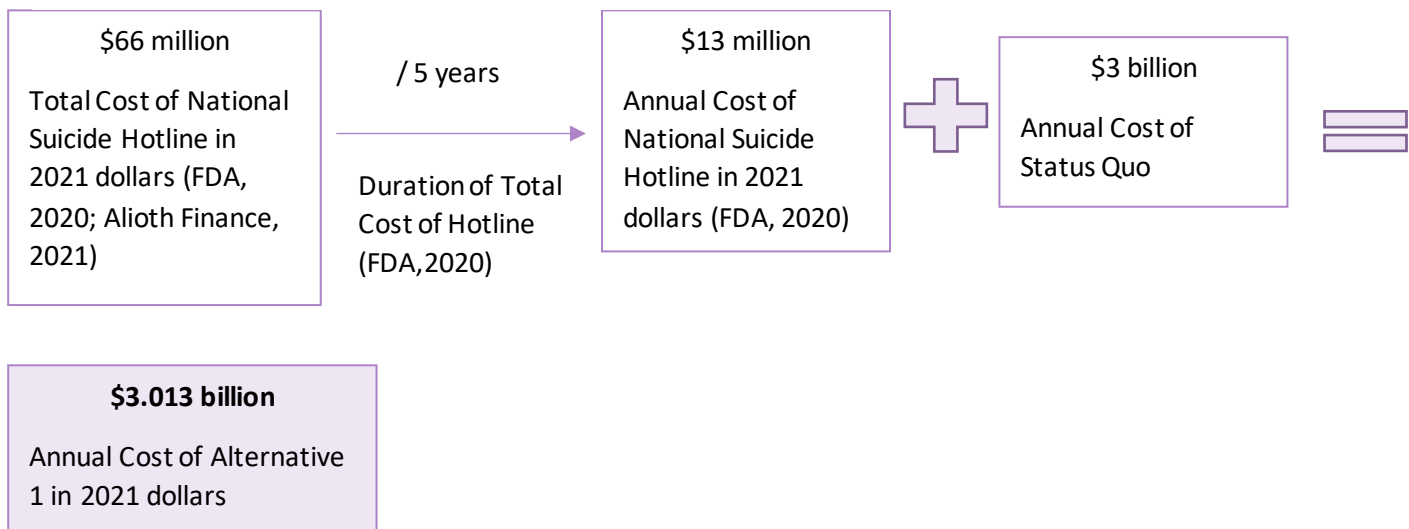
## APPENDIX C – Cost Calculations

*Alternative 2 Cost Formula: Money Needed By SAMHSA + Money Needed By VA*



*Note.* Alternative 2 was based on the 'Every Try Counts' Campaign. Therefore, I assumed the annual cost to SAMHSA of implementing Alternative 2 was the same as the annual cost to the FDA of 'Every Try Counts'

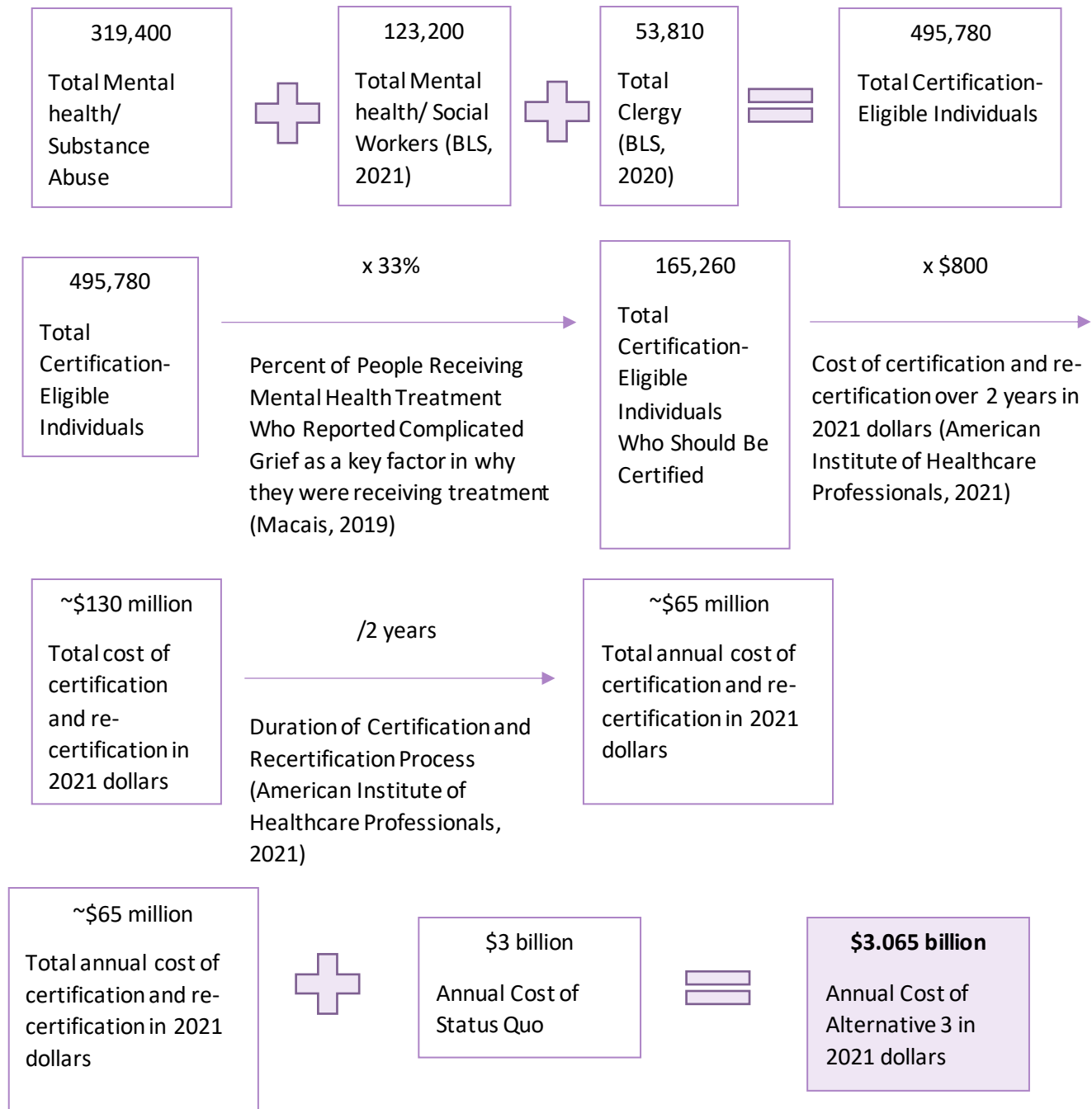
*Alternative 3 Cost Formula: Money Needed by SAMHSA + Money Needed By VA*



*Note.* Alternative 3 was based on the the National Suicide Hotline. Therefore, I assumed the annual cost to SAHMSA of implementing Alternative 2 was the same as the annual cost to them of running the Naitonal Suicide Hotline.

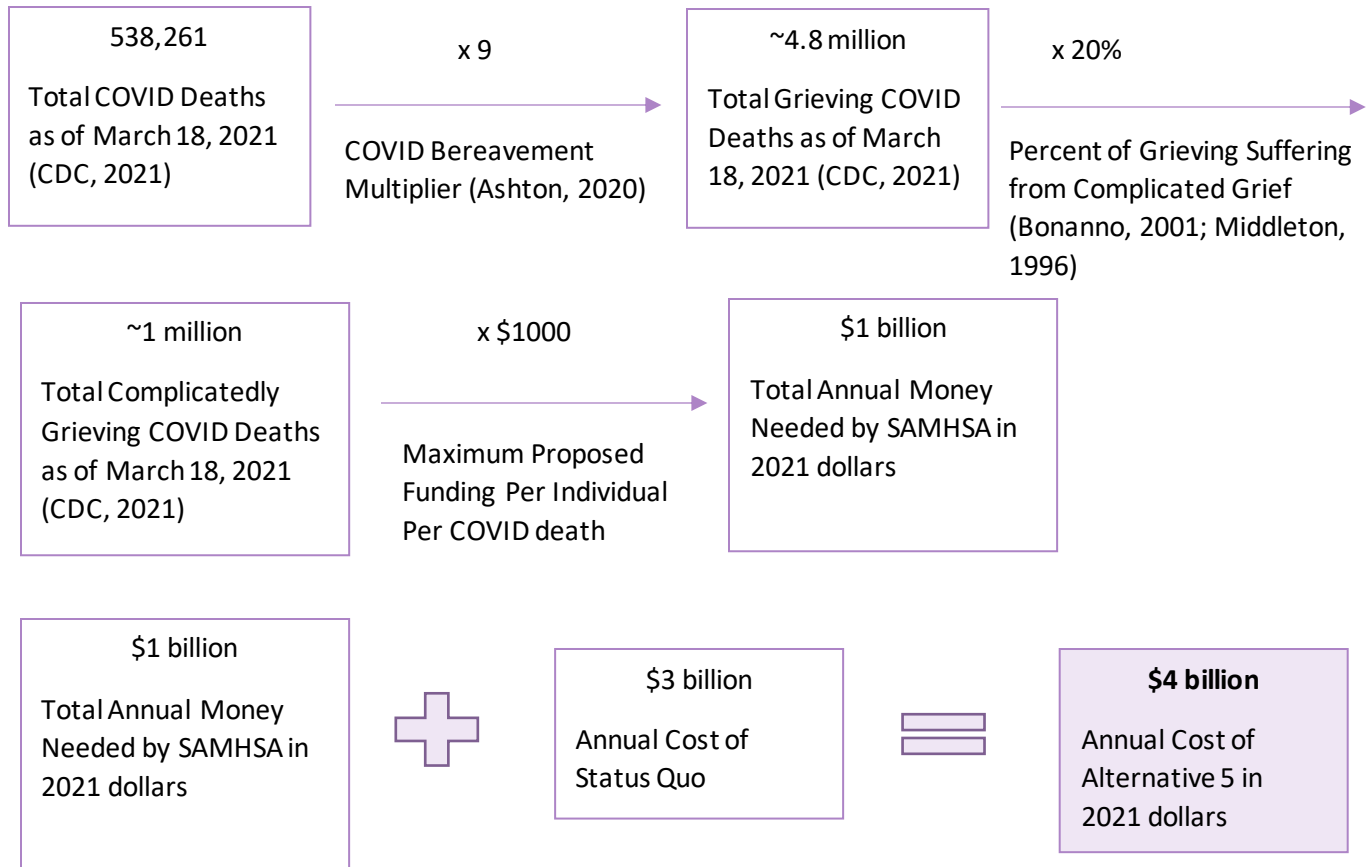
## APPENDIX C – Cost Calculations

*Alternative 4 Cost Formula: Money Needed by SAMHSA + Money Needed By VA*



*Note.* Alternative 4 was based on the cost of an online grief certification program that appeared to be representative of the costs of most online grief certification programs.

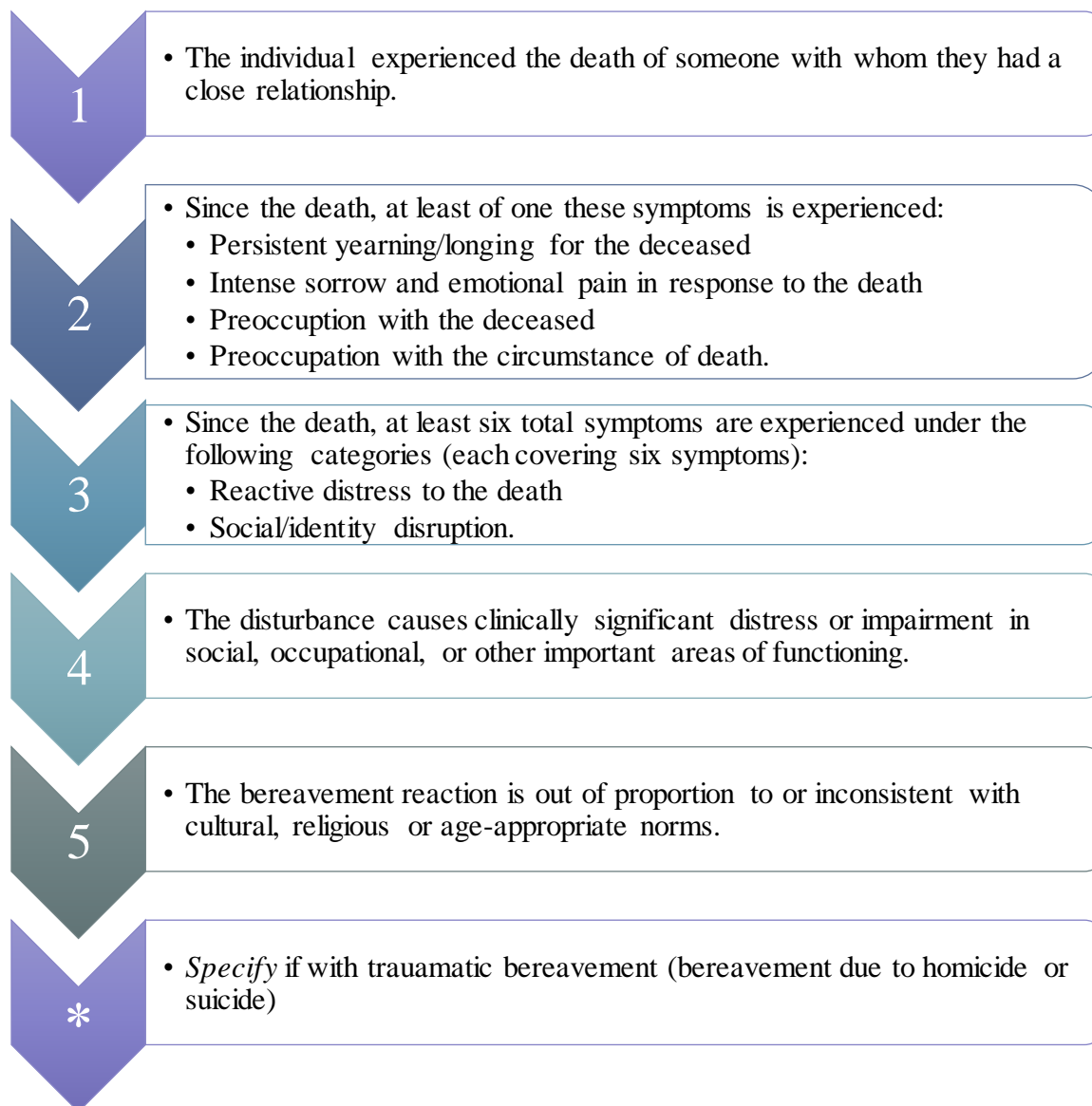
*Alternative 5 Cost Formula: Money Needed by SAMHSA + Money Needed By VA*



*Note.* Alternative 5 was based on the costs related to the COVID-19 pandemic because, in order to realistically estimate the cost for this alternative in the short-term, it is necessary to account for the extraordinary impact of COVID-19 that far exceeds the total death toll of other mass tragedies.

## APPENDIX D - Criteria for the Diagnosis of Persistent Complex Bereavement Disorder

### *Proposed Criteria for the Diagnosis of Persistent Complex Bereavement Disorder*



*Notes.* This information is taken directly from the DSM-5 (APA, 2013). For criteria 2 and 3, symptoms must be experienced at least four days per average week to a clinically significant degree. Furthermore, symptoms must have persisted beyond 12 months after death in the case of a bereaved adult and 6 month after death in the case of a bereaved child.