

Healing Communities: Centering Families to Support Bereaved Youth

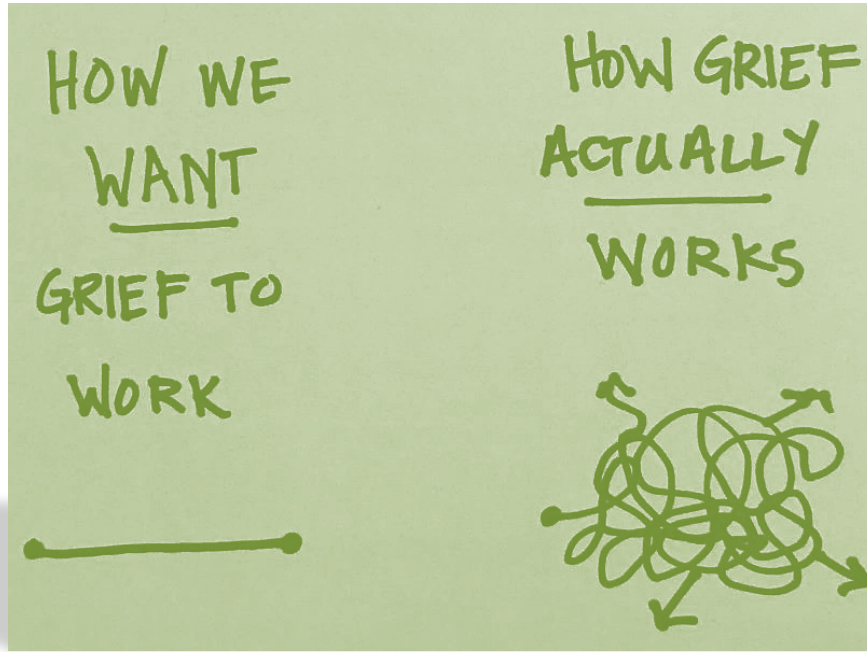
Heartlight Center 2024 Signature Series

November 5, 2024

Micki Burns, PhD



Grief is Complex



History of Judi's House/JAG Institute

- In 2002, by former NFL quarterback Brian Griese and spouse Dr. Brook Griese, in honor of Brian's mother Judi.
- JAG Institute, established in 2014 also named after **Judith Ann Griese**, to serve as a center of excellence for the field of childhood bereavement by developing innovative tools, disseminating research findings, and providing education locally and nationally.



Brian & Judi Griese



Mission & Vision

Mission: Help children and families grieving a death find connection and healing.

Vision: No child should be alone in grief.

By integrating **practice, research, and community**, Judi's House is uniquely positioned to create social change about the issue of childhood bereavement and serve as a national leader in the effort to increase access to effective, individualized care for the bereaved.

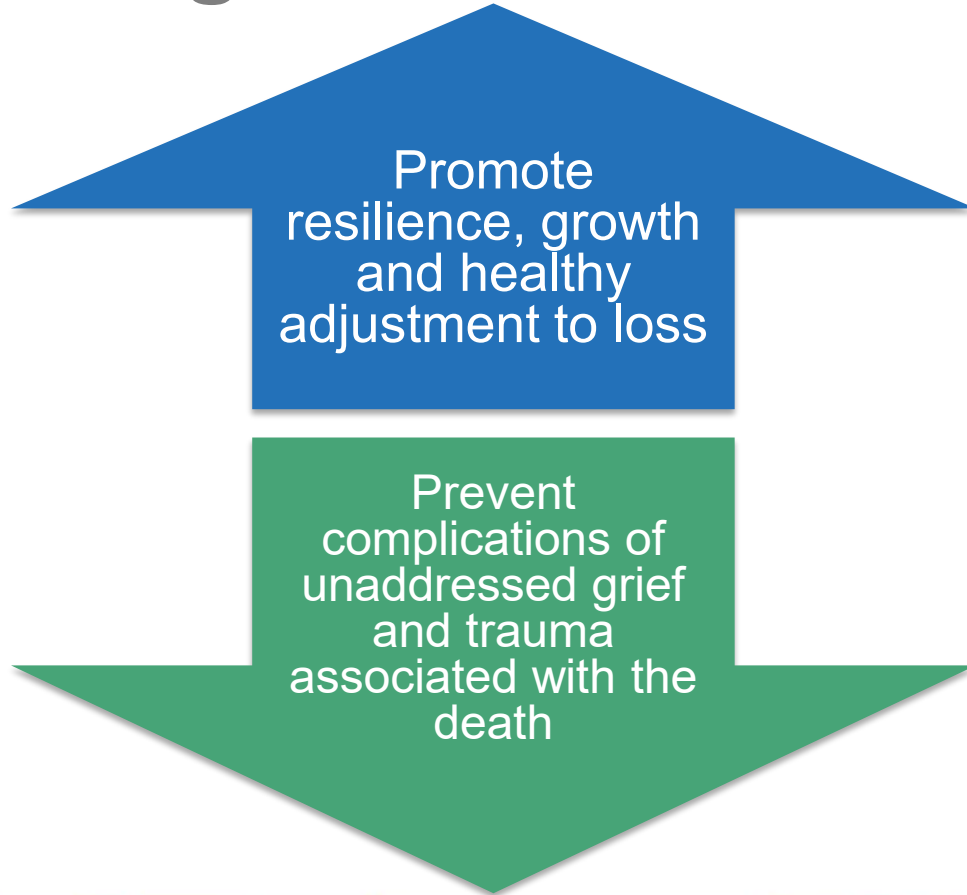




JEDI Statement

Judi's House/JAG Institute centers justice, equity, diversity, and inclusion. We strive to welcome, respect, value, and support our clients, staff, board of directors, and volunteers. Grief is a universal experience. Yet, we know that there are significant barriers that prevent some from accessing grief care. Therefore, we are taking active steps to engage in ongoing learning, reflect the families in our community, respond to the cultural needs of our clients, and address discrimination and inequity.

Overarching Goals



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Learning Objectives




Learning Objectives



Disparities

- Recognize current societal factors and disparities impacting grieving youth and families and identify personal action items for supporting equitable access to effective care.



Systems Thinking

- Identify and apply the concepts of systems to experiences of bereavement at the family, school, and neighborhood levels.



Cause of Death

- Understand the importance of differentially considering the cause of death and developmental understandings when addressing bereavement with children and families.



Reflection

- Consider ways your grief experiences, culture, and privilege complicate and enhance bereavement work with children and families.



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Bereavement Prevalence



Understanding Prevalence in the U.S.

- In partnership with the New York Life Foundation, we developed the **Childhood Bereavement Estimation Model (CBEM)** to understand the magnitude of the issue.
- The CBEM approximates rates of U.S. children and youth who will experience the death of a parent or sibling by the time they reach adulthood.
- The data helps communities campaign for grief resources, and contribute to improved outcomes for grieving families.



CBEM Inputs

Population and Mortality data

United States™
Census
Bureau

CDC

CENTERS FOR DISEASE
CONTROL AND PREVENTION

 **WONDER Online Databases**

Caregivers age at childbirth



Sibling weight



2024 National CBEM Projected Prevalence

1 in 12



children in the U.S. will experience the death of a parent or sibling by age 18

8.6% ~ 6.3M

children will be bereaved by age 18



& MORE THAN
DOUBLES

15.2M

youth will be bereaved by age 25



NEW YORK LIFE
FOUNDATION



Pre/Post Pandemic CBEM

2021 CBEM Report

- 1 in 14
- 7.3% of all U.S. children by 18
- ~ 5.3 M
- ~ 13.3 M by 25

2024 CBEM Report

- 1 in 12
- 8.6% of all U.S. children by 18
- ~ 6.3 M
- ~ 15.2 M by 25



2024 State CBEM Projected Prevalence

KEY

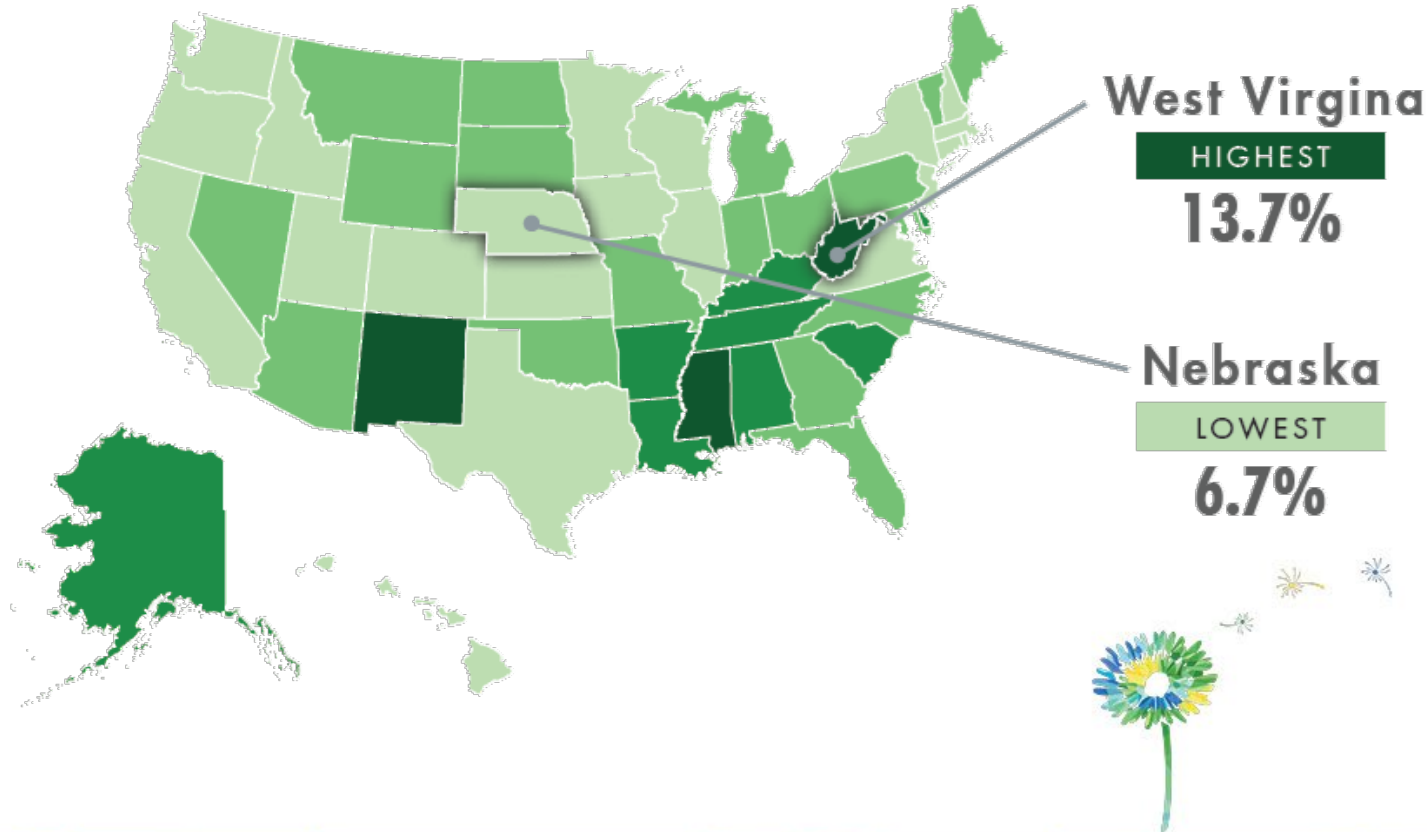
6.7% - 8.5%

8.6% - 10.2%

10.3% - 12.0%

12.1% - 13.7%

[†]Bereavement due to parent or sibling death by age 18

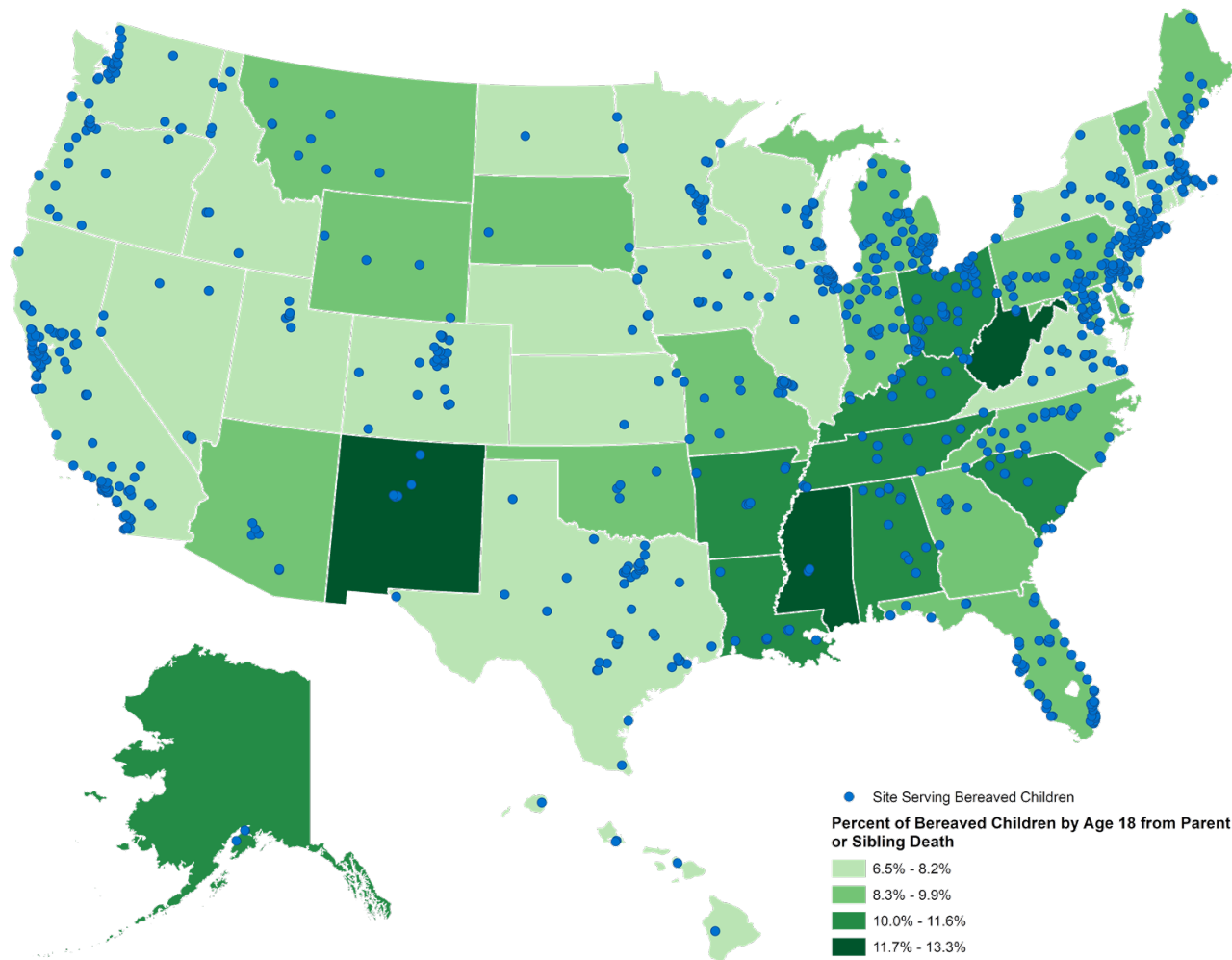


Childhood Bereavement Prevalence & Sites Serving Bereaved Children

**This map displays the projected percent of children who will be bereaved by a parent death by age 18 at the state level.*

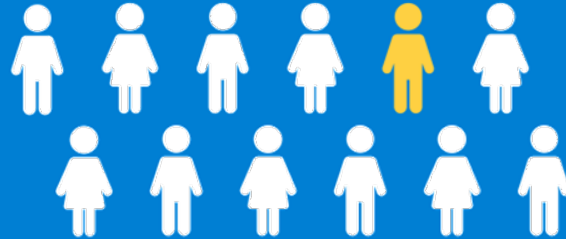
**A blue dot represents a site serving bereaved children.*

SITES SERVING BEREAVED CHILDREN DATA PROVIDED BY THE NATIONAL ALLIANCE FOR CHILDREN'S GRIEF (NACG), ELUNA, AND DOUGY CENTER, 2023
CBEM DATA PROVIDED BY JUDI'S HOUSE, 2023



2024 CBEM Colorado Projected Prevalence

1 in 12



children in Colorado **will experience** the death of a **parent or sibling** by age 18

35TH

CBEM
RANKING BY
STATE†

8.1% ~ 101K

children **will be** bereaved by age 18
LOWER than national rate of **8.6%**



& MORE THAN
DOUBLES

246K

youth **will be** bereaved by age 25

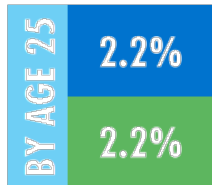
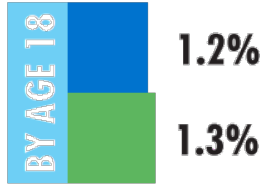


2024 CBEM Colorado Projected Prevalence

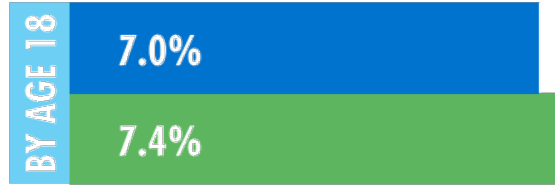
The CBEM provides separate, independent estimates for youth who will experience the death of a parent or the death of a sibling.



Sibling



Parent



Childhood Bereavement Estimation Model

Analyses

STANDARD
annual analyses use aggregated data inputs from the **most recently** available **five** years

SNAPSHOT
analyses use data inputs from a **select timeframe**

Model Results

The **CURRENT** CBEM approximates the number and percentage of youth who **HAVE EXPERIENCED** bereavement.

The **PROJECTED** CBEM approximates the number and percentage of youth who **WILL EXPERIENCE** bereavement.

Source of Bereavement

Death of Sibling

Death of Parent

Death of Sibling or Parent

Geography

National

State

County

Ages

Birth to 18



Birth to 25



Key Topics

Rural-Urban
2018

Substance Related
2019

Race and Ethnicity
2021

Cause of Death
2022

Pandemic Impact
2022
2023

Income
2024



CHILDHOOD BEREAVEMENT ESTIMATION MODEL

Key Topic 2023

Childhood Bereavement

Key Topic: Pandemic Impact

National 2023



- Childhood bereavement is not unique to the pandemic, the significant increase in bereavement due to the pandemic is.
- The pandemic compounded annual childhood bereavement rates, with more than 260,000 children bereaved in 2020.
- In 2021, this number grew to 383,000—a nearly 50% increase.

Childhood Bereavement

Key Topic: Pandemic Impact

National 2023



Why focus on parent death only?

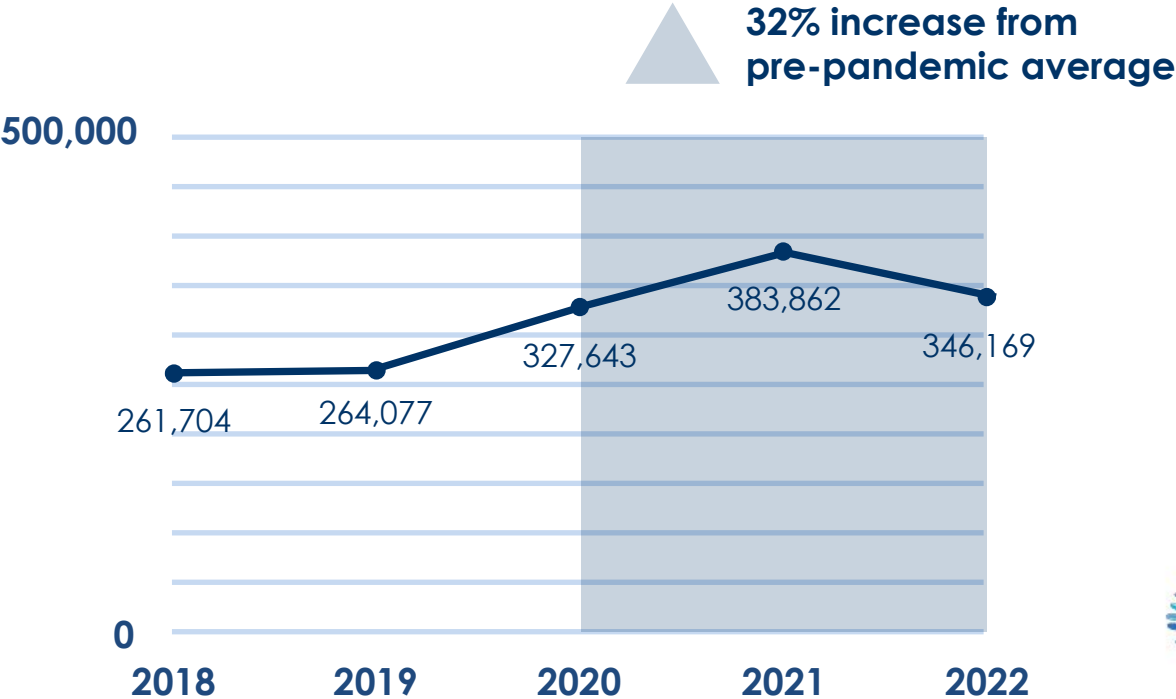
- Children are three to five times more likely to experience a parent's death in childhood than a sibling's death.
- COVID-19 deaths for children under age 18 are rare: there were 450 in 2021.



2022 CBEM Snapshot: Death of a Parent



2022 CBEM Snapshot: Children Bereaved Due to Death of a Parent Any Cause

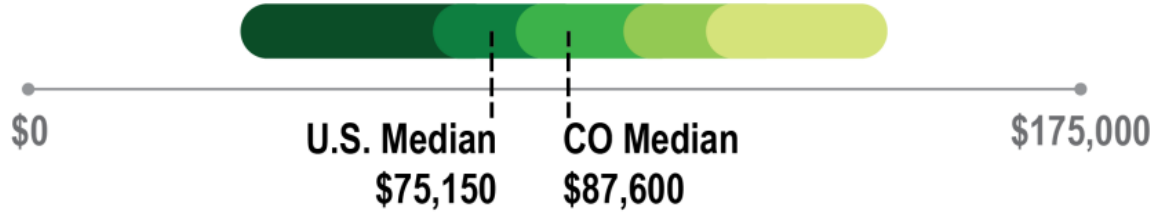


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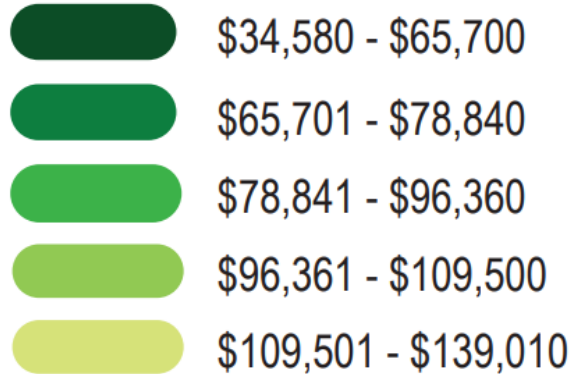
Prevalence: Income



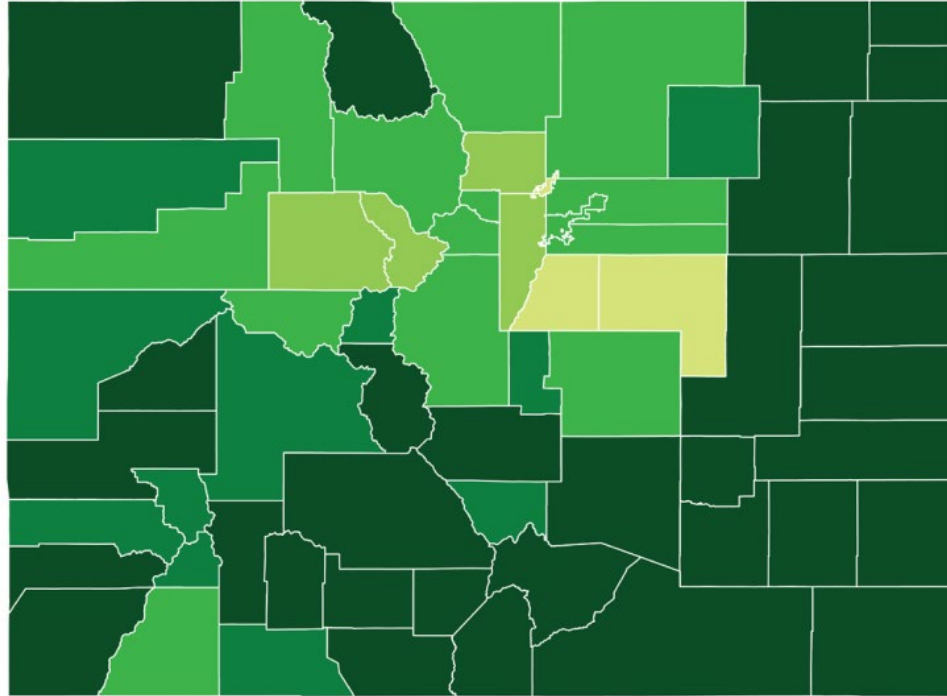
Median Household Income








Colorado Income Groups








County Income & Child Bereavement



Income Groups and CBEM Results

	Income	Bereavement
	\$34,580 - \$65,700	11.8% or 1 in 8
	\$65,701 - \$78,840	8.8% or 1 in 11
	\$78,841 - \$96,360	8.4% or 1 in 12
	\$96,361 - \$109,500	7.1% or 1 in 14
	\$109,501 - \$139,010	5.1% or 1 in 20

County Income & Child Bereavement

	Income	Bereavement
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Children living in the lowest-income counties in Colorado are **131% more likely** to experience the death of a parent or sibling by age 18 than those living in counties with the highest-income

131%
MORE LIKELY



Childhood Bereavement



Stable Housing



Safe Community



Clean Water



Quality Education



Healthcare



Healthy Food



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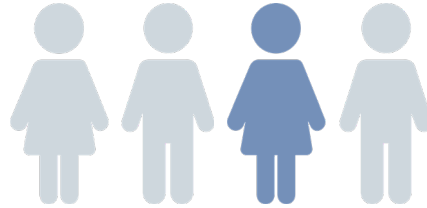
Prevalence: Accidental Overdose



2022 CBEM Snapshot: Accidental Drug Overdose



2022 CBEM Snapshot: Accidental Drug Overdose



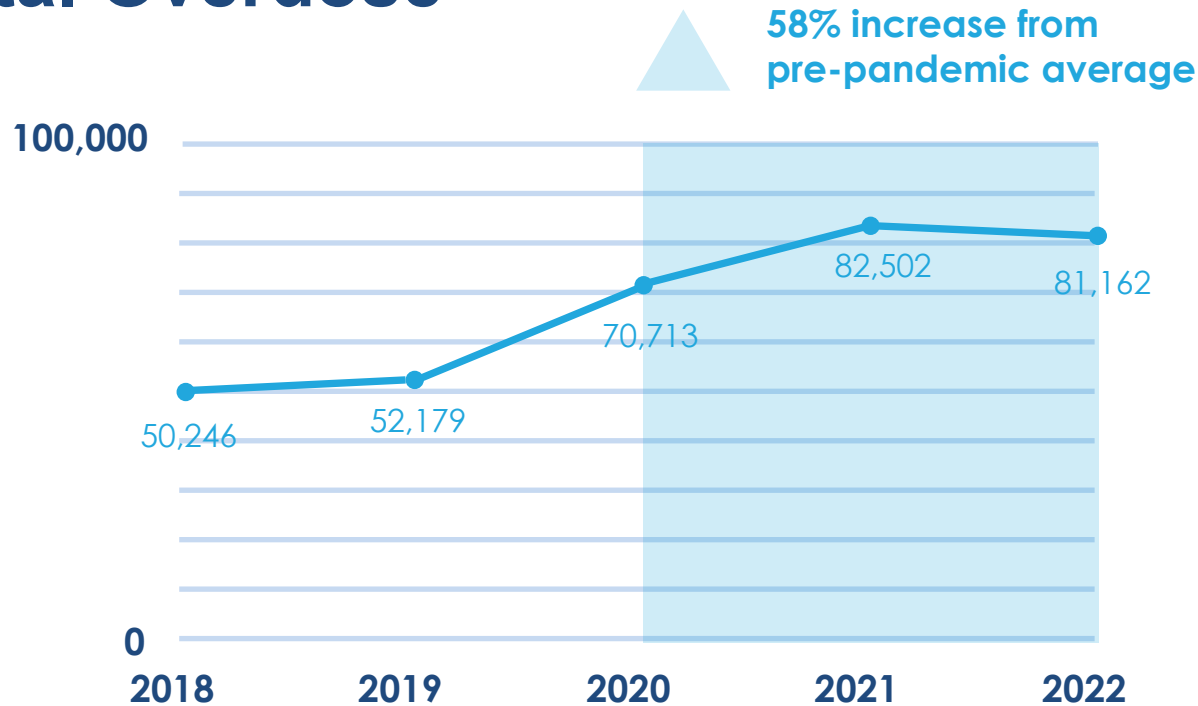
Nearly

1 in 4

children newly bereaved by the death
of a parent in 2022 grieved an
accidental overdose death



2022 CBEM Snapshot: Children Bereaved Due to Death of a Parent by Accidental Overdose



2022 CBEM Snapshot: Percentage of Children Bereaved Due to a Parent's Accidental Overdose Death

5. Delaware	32.9%
4. Massachusetts	33.7%
3. Vermont	35.6%
2. Maine	36.2%
1. West Virginia	40.3%



2023 CBEM Snapshot:

Pandemic Impact on Children Bereaved Due to Parent Death by Race & Ethnicity

- 700,000 children were newly bereaved due to a parent's death in 2020 and 2021
- In 2021, the highest rates of childhood bereavement due to parent death were among
 - Non-Hispanic Indigenous youth: 10.0%
 - Non-Hispanic Black youth: 6.4%



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Prevalence: Suicide



Risk Factors

- **Recently bereaved**
- Previous attempt
- **Access to lethal means**
- **Mental Health concerns, including substance misuse**
- **Constricted cognitive functioning**
- **Heightened amygdala activity**
- Chronic pain or serious illness
- **Lack of social connectedness/withdrawal**
- Relationship difficulties
- Active duty/Veteran status
- Financial strain/job loss
- Academic difficulties
- Hopelessness/Despair
- Impulsivity
- Bullying
- **Sleep and appetite changes**
- Talk of not wanting to go on
- Decrease personal hygiene
- Adjustment and coping difficulties
- Financial strain/job loss
- ACEs
- Lack of access to healthcare
- Systemic oppression/Historical trauma
- **Stress accumulation**
- Community violence



Why People Die by Suicide

- **Thwarted belongingness**, a disconnection from others, loneliness or isolation
- **Perceived burdensomeness**, you're worth more in death than in life
- **Ability**, drop in fear of death and maybe a desensitization to pain or violence, plus the means to carry out the act



Basic Risk Assessment

- **Desire:** No reasons for living; wish to die; wish not to carry on; passive attempt
- **Capability:** Confidence in ability to inflict self harm, available means, clear plan, intoxication, extreme emotional duress, sleep deprivation
- **Intent:** Imminent plan to hurt self/or another, preparatory behaviors, expressed intent to die



Protective Factors

- **Meaningful/Supportive relationships**
- Employment/Academic engagement
- Responsibility to others
- **Positive health/access to healthcare**
- Community connectedness
- Interests/Hobbies
- Medication compliance
- Fear of death/pain
- **Sobriety**
- **Rest**
- Hope
- Religious prohibition
- **Means restriction/harm reduction**
- **Safety planning**
- CBT/DBT
- Pets
- Positive self-esteem
- Stable housing





Suicide

Children Newly Bereaved due to Parent death from Suicide

What assumptions do you have about the prevalence of childhood bereavement due to parent suicide before and during the pandemic?





Suicide

Children Newly Bereaved due to Parent death from Suicide

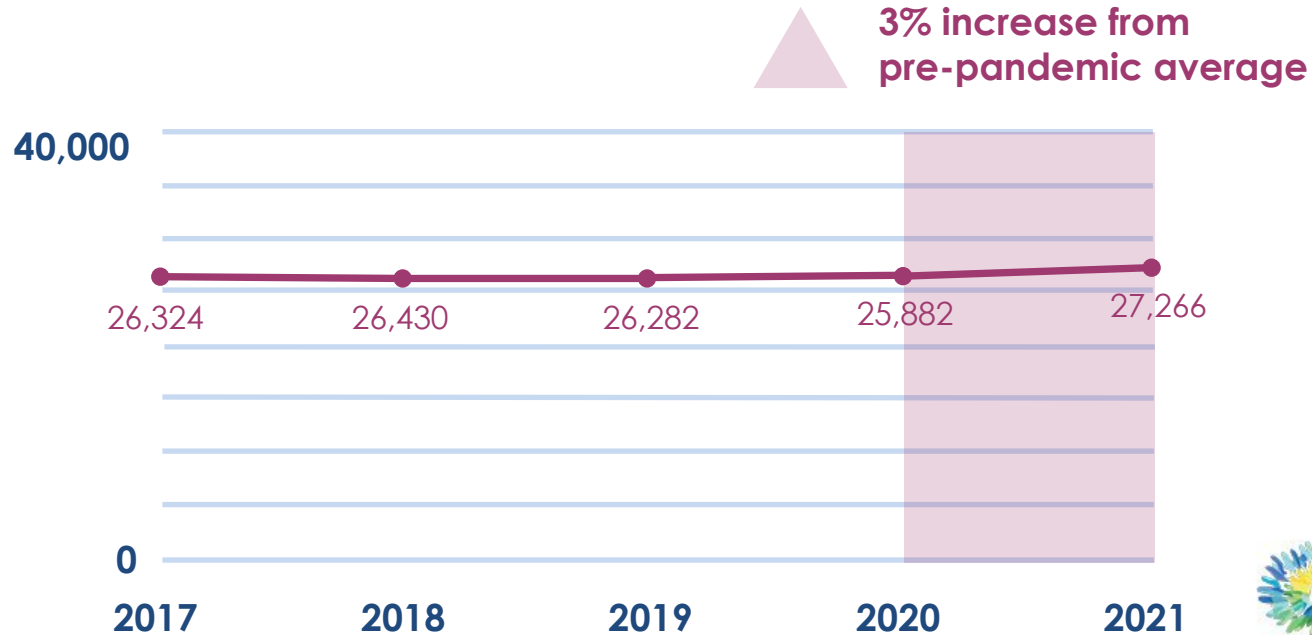
- Many are noting the recent rise in gun sales in discussing the likely increase in suicides due to easier access to firearms
- A 2014 article published in the British Journal of Psychiatry estimated 10,000 additional suicides were linked to the Great Recession between 2008 and 2019 in the North American and Europe.⁸
- A 2003 study published in the Journal of Epidemiology and Community Health that surveyed New Zealanders found a two to three times increased likelihood of death by suicide for the unemployed.⁹
- We know very little about the impact of social isolation on suicide rates as this is clearly an unprecedented time globally. This piece from USA Today highlights the opinions of several prominent practitioners and researchers in mental health.¹⁰

‘Isolation is a big trigger’: Feelings of suicide are amplified amid a pandemic



Suicide

Children Newly Bereaved due to Parent death from Suicide





Suicide

Children Newly Bereaved due to Parent death from Suicide



1 in 14

**children newly bereaved in 2021
experienced a parent's suicide.**



Ryan's Place Annual Grief Seminar

Prevalence: Race and Ethnicity

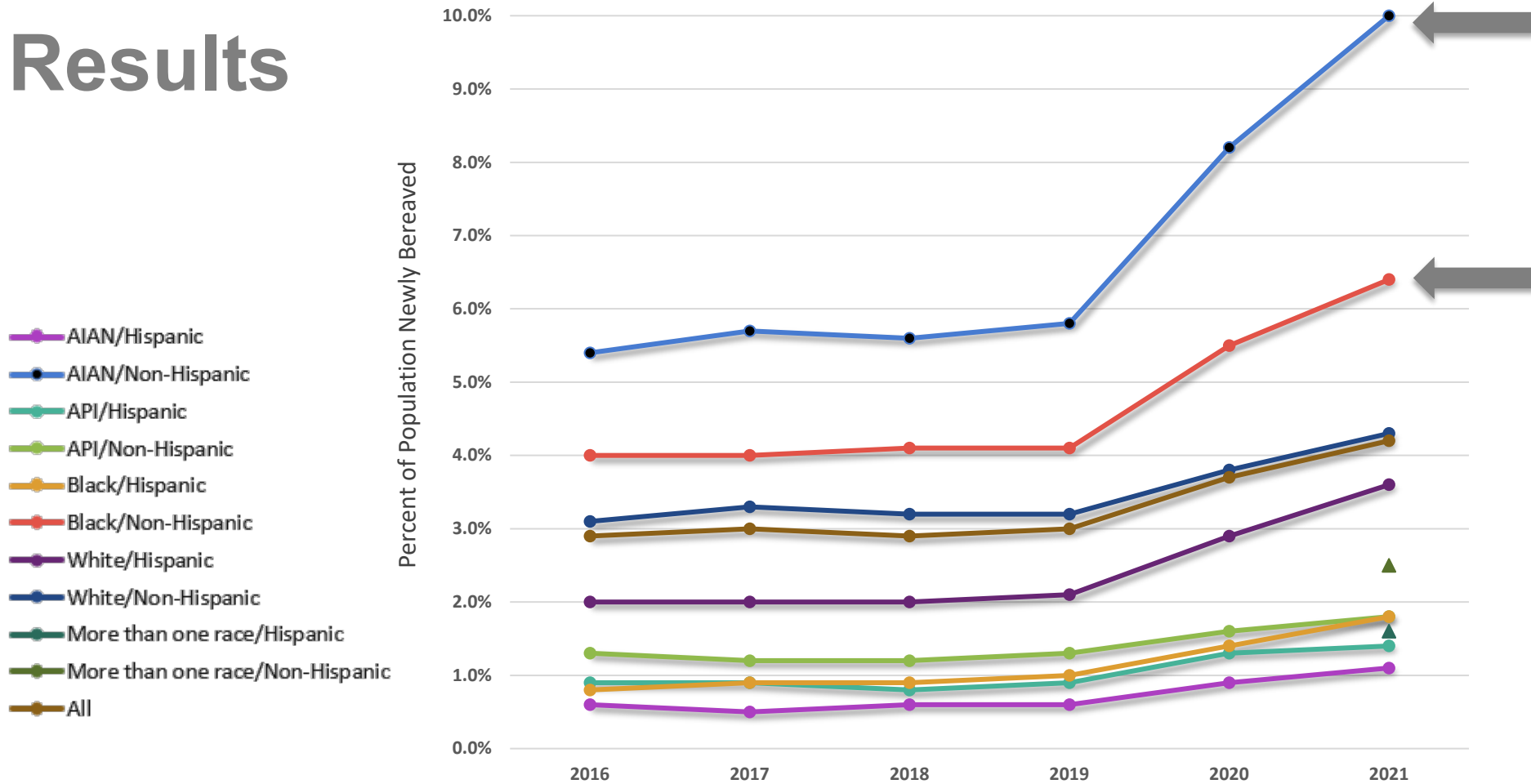


Methods

- CDC race and ethnicity categories were crossed to create 11 groupings



Results



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Addressing Bereavement in Families



Healing Communities

We all have something to offer.

Story
Corps[®]



Healing Communities

What do you have to offer?



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Defining terms



Grief Basics

What is grief?

All the thoughts, feelings and reactions we have after someone important in our lives dies



Grief Basics

What is bereavement?

Experiencing the death of an important person.



Grief Basics

What is mourning?

How we display our grief to others
and to the world.



Judi's House/JAG Philosophies



- Not normative
- Unexpected
- Shatter world view and sense of security



True or False



When talking to children you should avoid using words like dead, died or death.



True or False



Children should be told about death and causes of death.



True or False



Children and adults grieve in orderly, predictable stages.



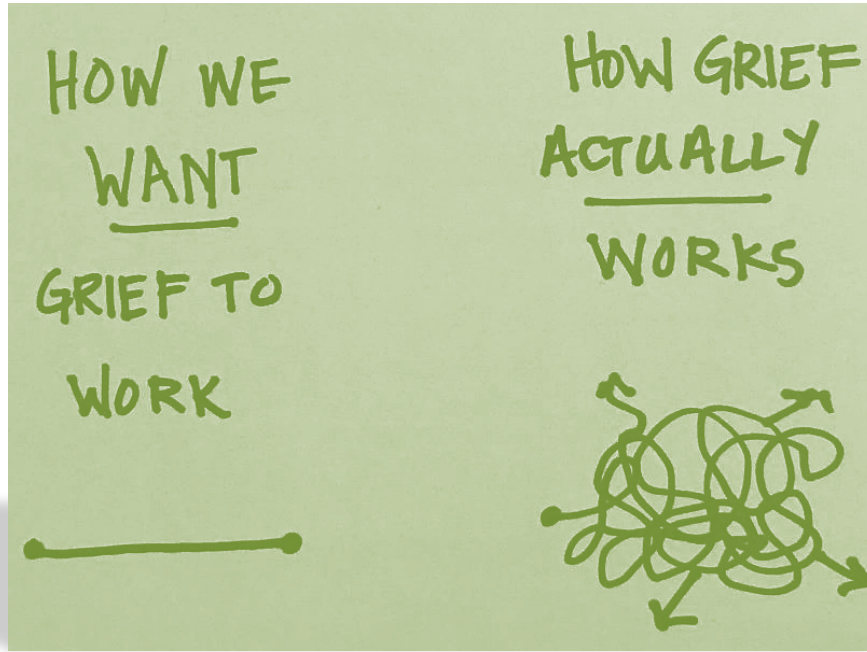
True or False



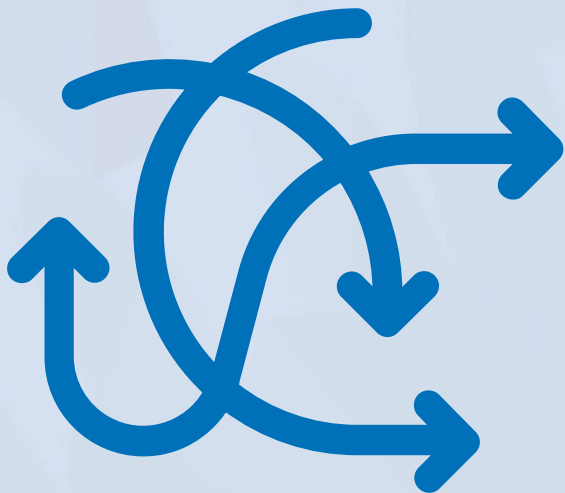
Children who experience a death can become stronger more compassionate adults.



Grief is Complex



Grief is Complex



Example of Suicide

- Sudden or anticipated
- Adult, teen or child
- Intentional or ambiguous
- Secret or public
- Violent or peaceful
- Often complicated by cultural, religious, and societal beliefs



Grief Basics

What is Trauma?

Result of terribly stressful events that impact your sense of security, making you feel helpless and vulnerable



ADVERSE CHILDHOOD EXPERIENCES INCLUDE:



ADVERSE CHILDHOOD EXPERIENCES HAVE BEEN LINKED TO:



Image from [PCA Illinois | THE ISSUES | Childhood Trauma](https://www.preventchildabuseillinois.org/) ([preventchildabuseillinois.org](https://www.preventchildabuseillinois.org/))

ADVERSE CHILDHOOD EXPERIENCES

Mental Illness
Homelessness
Substance Abuse
Emotional & Sexual Abuse

Divorce
Incarceration
Domestic Violence
Maternal Depression
Physical & Emotional Neglect

ADVERSE COMMUNITY EXPERIENCES

Holocaust
Slavery
Genocide

Poor Housing Quality & Affordability
Poverty
Lack of Opportunity, Economic Mobility & Social Capital

Systemic Racism
Community Violence

Mass Incarceration
Forced Displacement
Pandemics

ADVERSE COLLECTIVE HISTORICAL EXPERIENCES

Effects of Childhood Trauma

- **Unable to cope** with normal stresses
- **Difficulty trusting** and benefiting from interpersonal relationships
- **Trouble regulating** affect, cognition, attention and behavior
- **Hypervigilance** and arousal
- While some “bounce back” after adversity, others experience a significant disruption of development and profound long-term consequences.

Posttraumatic Stress Symptoms

- **Psycho-physiological** reactions and modes of coping
- **Normal** reaction to overwhelming stress

Problematic if they persist at an intensity that disrupts functioning or development.



Trauma-informed

- **Safety:** Transparency and Trustworthiness
- **Collaboration:** Mutuality and Inclusiveness
- **Empowerment:** Peer Support and Choice
- Recognize vulnerabilities, decrease triggers, provide supports
- Ongoing assessment, systems-based, grounding

Trauma-informed communities actively work to **recognize vulnerabilities** to **decrease** trauma activators that may go unnoticed in typical service delivery



Healing-Centered Engagement

Communities that prioritize healing-centered engagement use a resource orientation to repair and resilience rather than a focus on pathologizing damage

[Ginwright, S. \(2021\). The Future of Healing: Shifting From Trauma-Informed Care to Healing-Centered Engagement](#)



Defining Truth



Art Credit: The Three Umpires, Norman Rockwell

Healing Communities

The Cost of Inaction



GRIEF-RELATED ADVERSITY

Issues at home, financial strain,
death of an important figure,
move/loss of community,
mental health concerns

HEALTHY DEVELOPMENT

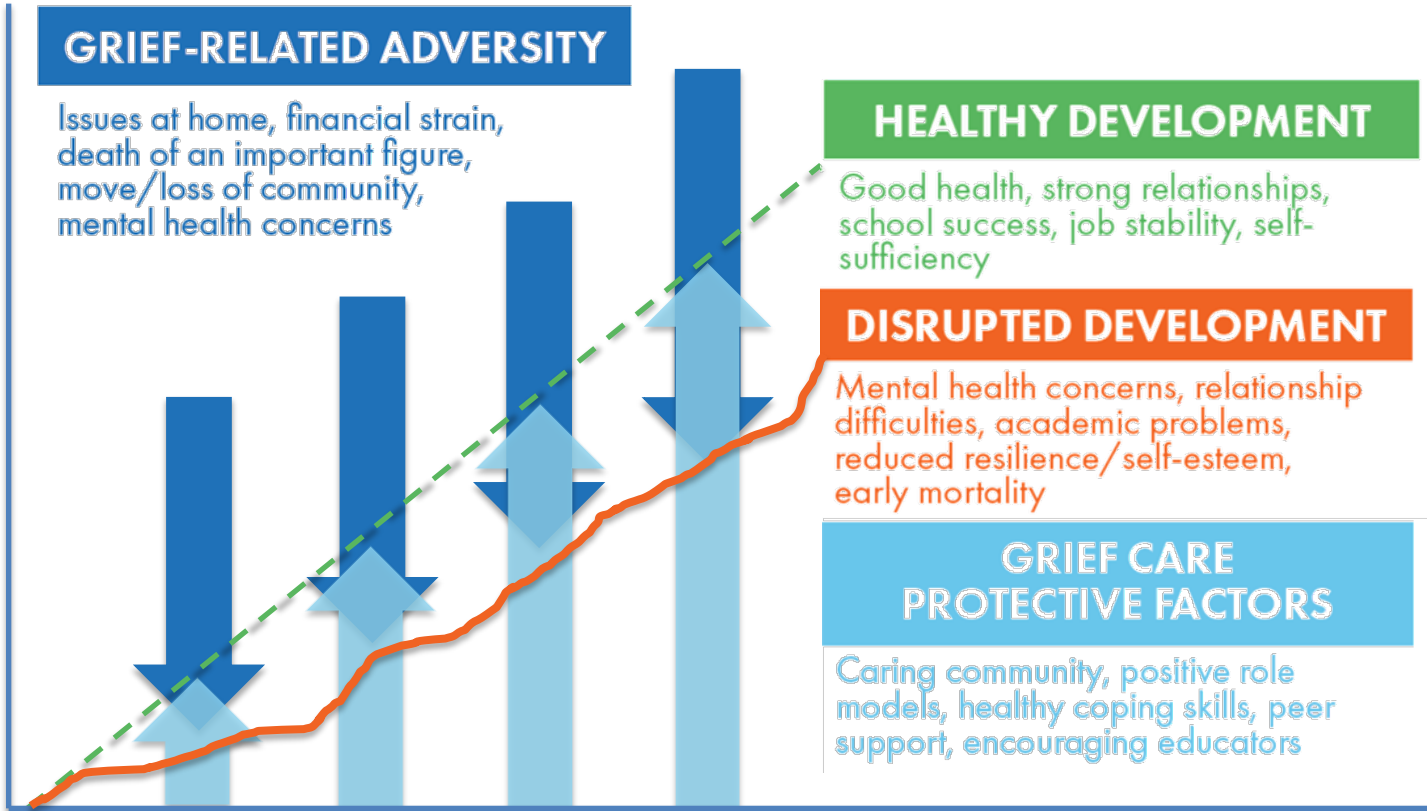
Good health, strong relationships,
school success, job stability, self-
sufficiency

DISRUPTED DEVELOPMENT

Mental health concerns, relationship
difficulties, academic problems,
reduced resilience/self-esteem,
early mortality

GRIEF CARE PROTECTIVE FACTORS

Caring community, positive role
models, healthy coping skills, peer
support, encouraging educators



Disenfranchised Grief

- Term was coined by Ken Doka and is defined as grief experienced following a loss that is not or cannot be openly acknowledged, social sanctioned, or publicly mourned because:
 - The loss is not deemed significant
 - The relationship is stigmatized
 - The cause of death is stigmatized
 - The griever is not recognized as significant or important
 - The way the individual is greiving is stigmatized



Suffocated Grief

- Term coined by Dr. Tashele Bordere to describe when natural grief reactions are penalized rather than supported. Examples include:
 - Receiving detention for distraction in the classroom
 - Being reprimanded for inability to “contain” grief
 - Being forced to return to work and maintain a professional demeanor
 - Losing job or being suspended or expelled for absences from school or work
 - Being labeled as angry or aggressive for responding to grief with anger



Bordere, T. C. (2019) Handbook of Social Justice in Loss and Grief Exploring Diversity, Equity, and Inclusion

5 A's of Culturally Conscientious Practice

- **Acknowledge** when a person describes their experience. There are multiple forms of oppression that people experience.
- **Ask** for clarity if you are uncertain.
- **Accept** that you do not know about this person's experience and be open to it
- **Align** with the individual. Be an activist and an ally.
- **Apologize** for the harms they have experienced and the missteps you make



Tasks of Grieving

- ***Accepting*** the reality of the death and its permanence
- ***Allowing*** for diverse emotional, cognitive and physical reactions to the loss
- ***Adjusting*** to life without the person who died in a way that allows for maintaining a meaningful connection while moving forward in normal development



Meeting the Needs of Grieving Youth

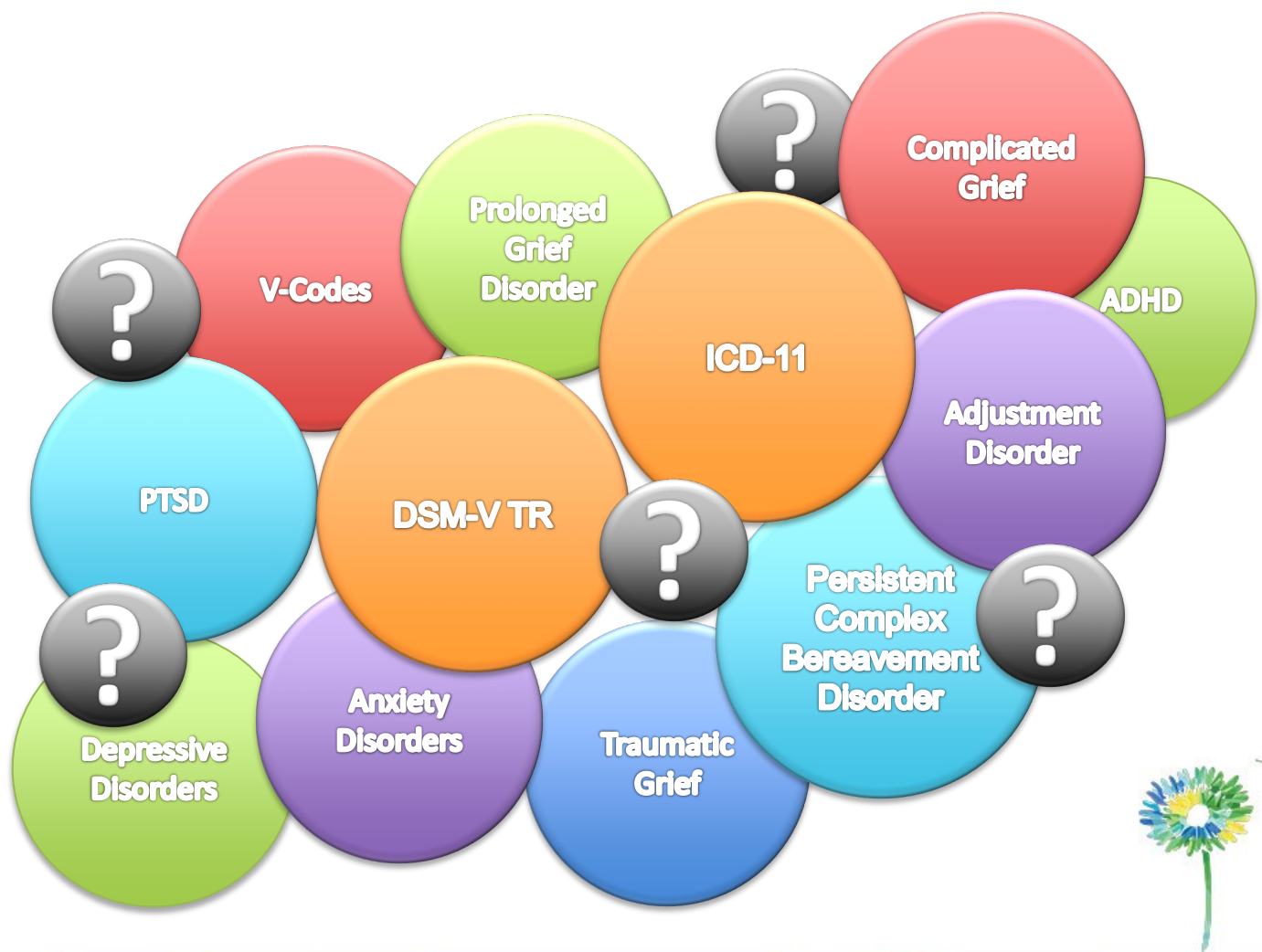
- Assist in **maintaining or regaining ability to function** in school or work, at home and with peers
- Provide a **safe place to express thoughts** and feelings
- Support developing **healthy coping skills** and avoiding negative coping behaviors
- Encourage **reinvesting in life** and creating a hopeful, productive future



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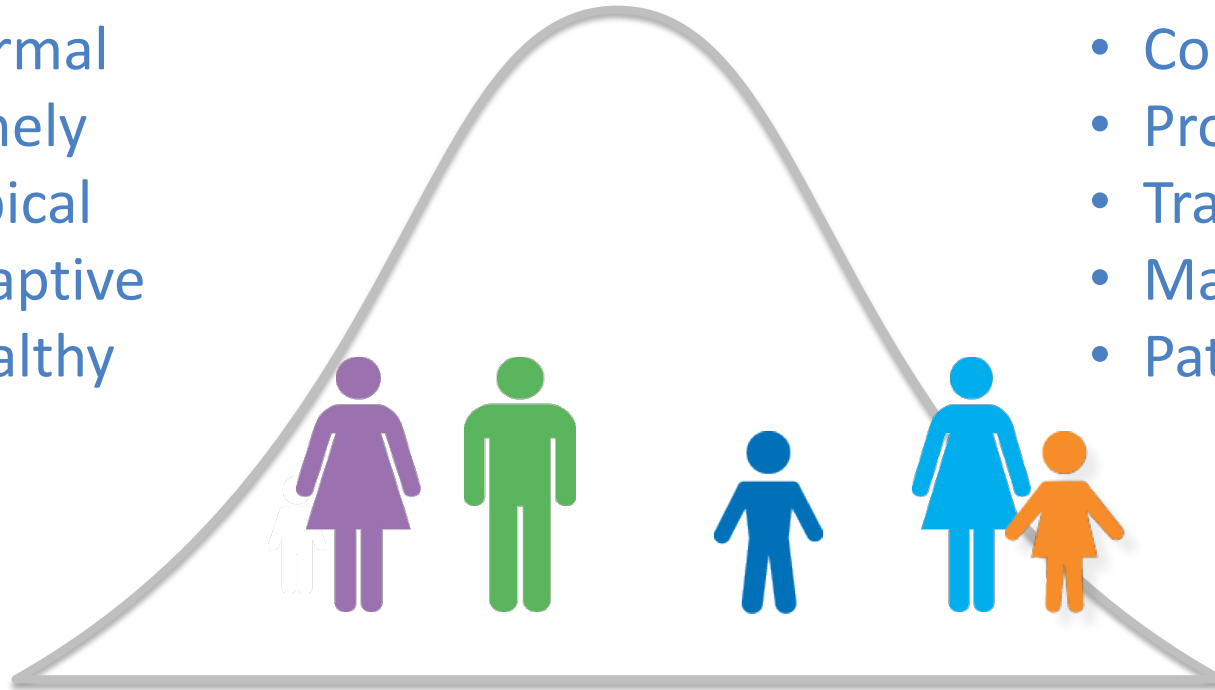
Diagnostic Dilemmas





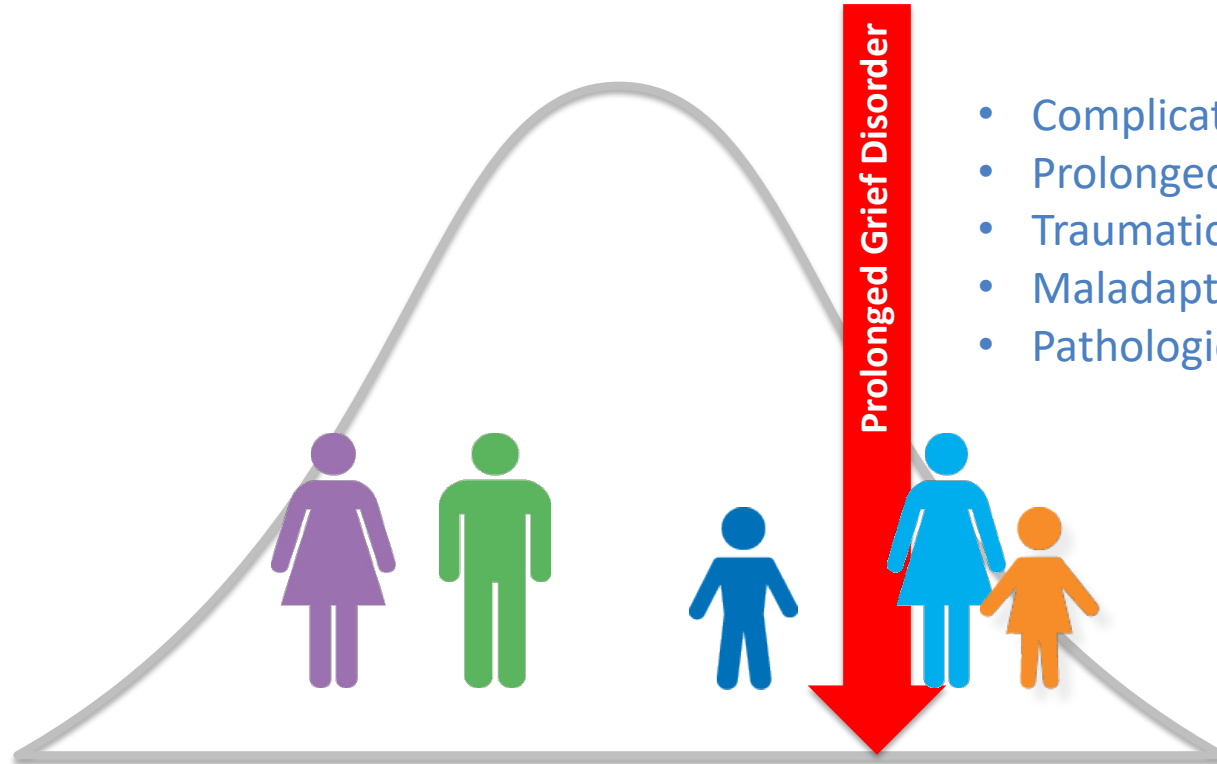


- Normal
- Timely
- Typical
- Adaptive
- Healthy



- Complicated
- Prolonged
- Traumatic
- Maladaptive
- Pathological



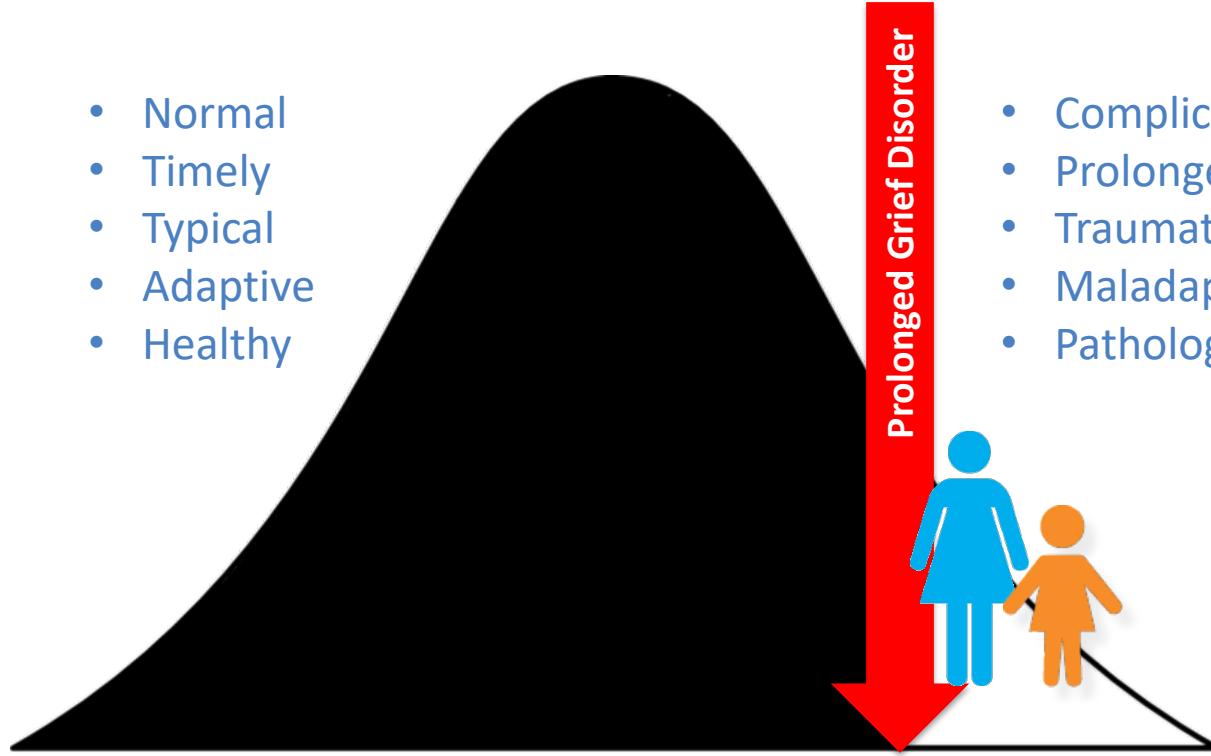


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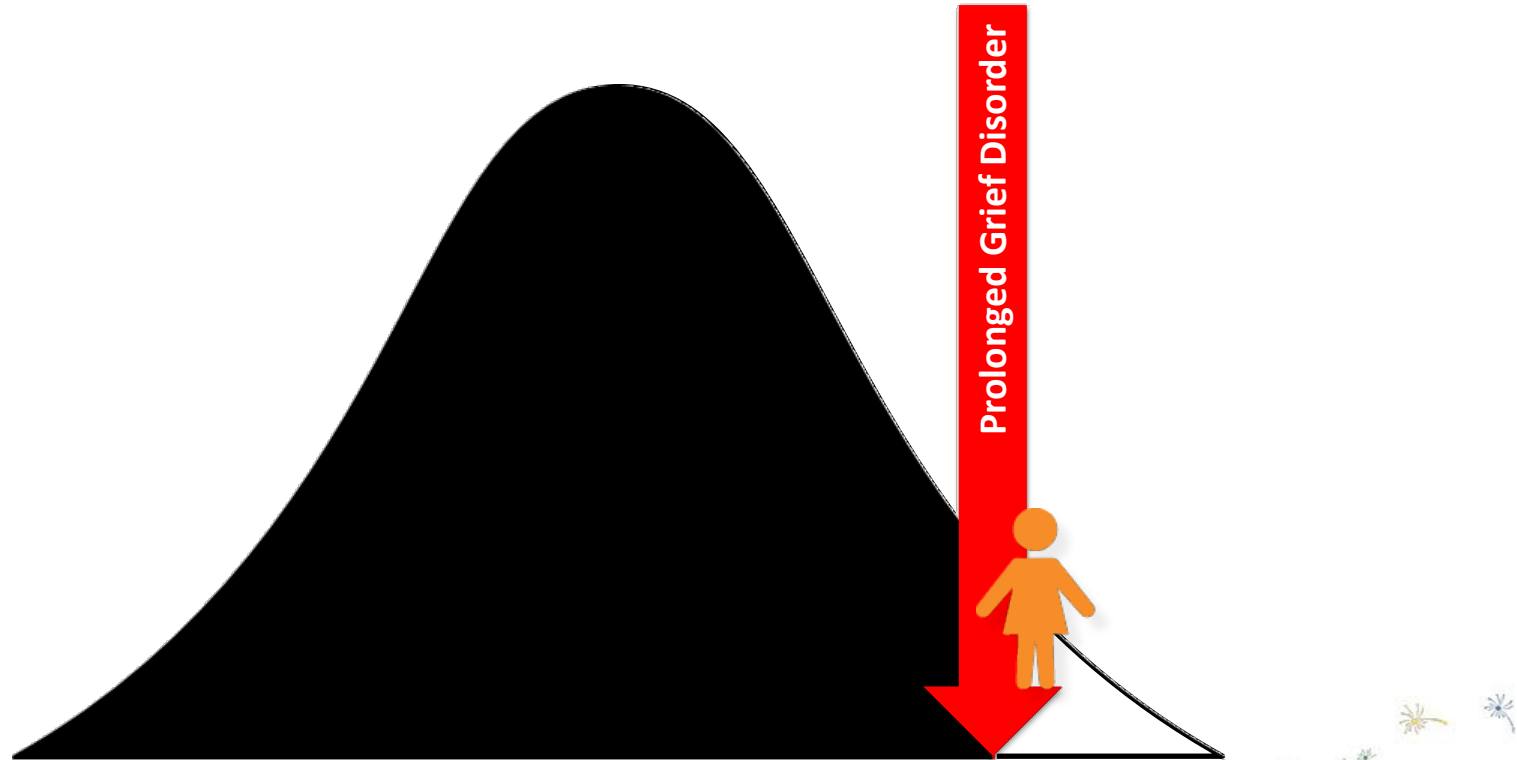
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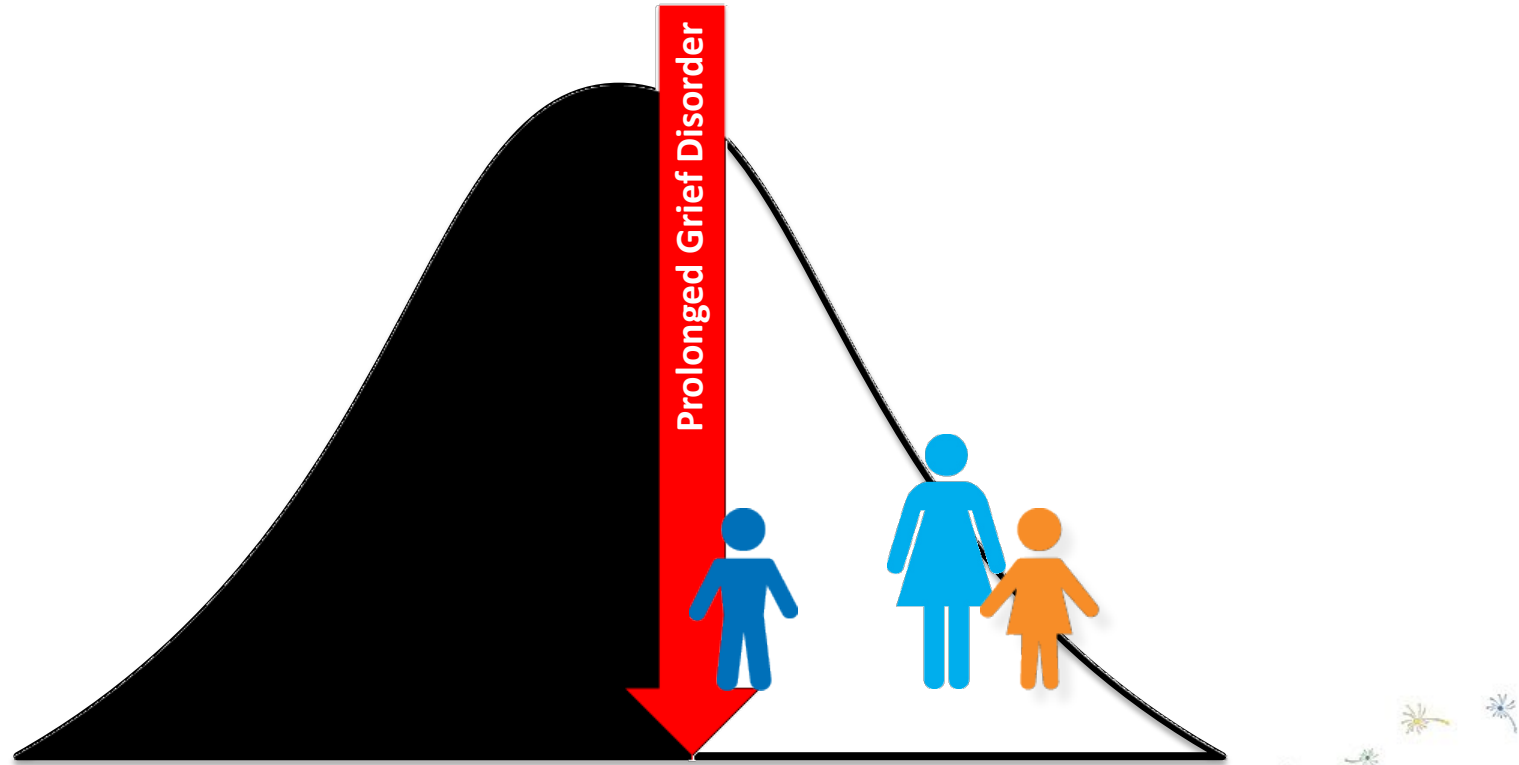


Prolonged Grief Disorder

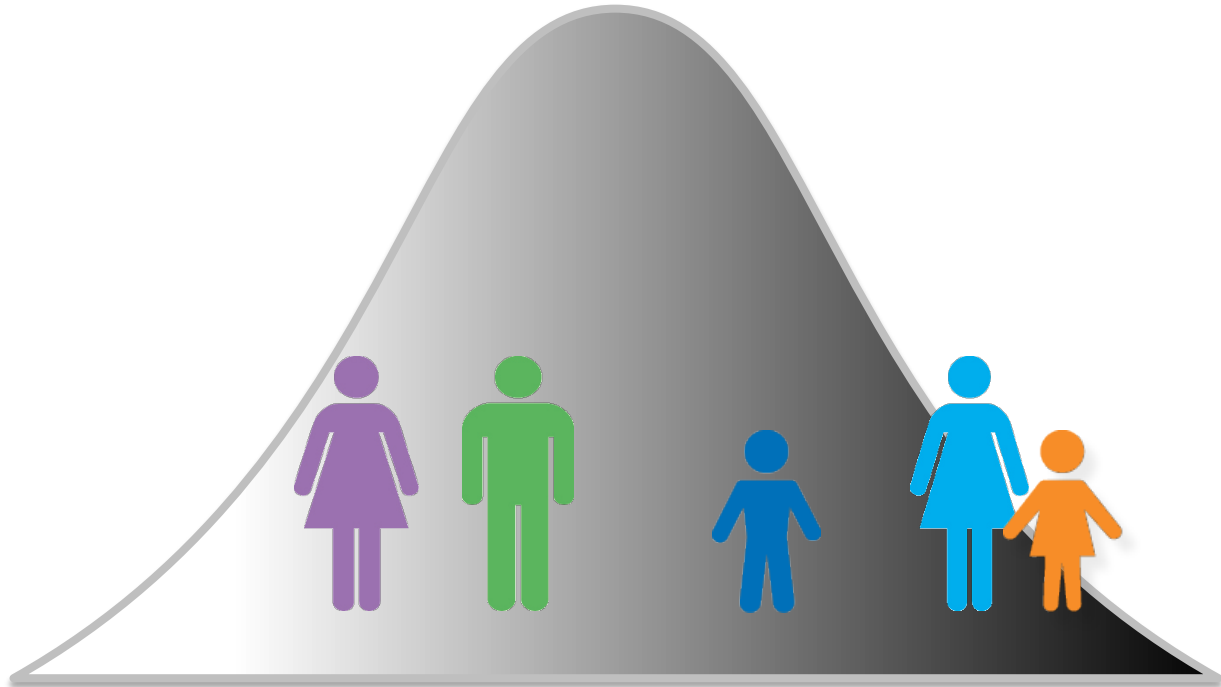
Disruptiveness of Grief Reactions



Disruptiveness of Grief Reactions



Disruptiveness of Grief Reactions



Disruptiveness of Grief Reactions



Potential Risks:

- Could be experienced as invalidating or pathologizing grief reactions
- Could have detrimental effects to receive a psychiatric diagnosis
- Could be used to limit access to care when criteria are not met
- Could lead to psychiatric medications being misused or overprescribed for grief

Potential Benefits:

- Could be experienced as validating the intensity of grief reactions
- Could have comforting effects knowing they are not alone in their experience
- Could be used to increase access to reimbursed, grief-specific care
- Could be helpful to some to have appropriate psychiatric medications available



**“We, who live in a world in which
a large part of our reactions to what are
in fact, universal human experiences
are treated as an illness from which,
with the proper expert guidance,
we will be cured.”**

~Dr. Phyllis Silverman



Bereavement Care

Where are we now?

- Accessibility
- Cost
- Quality
- Competence
- Interventions
- Grief
- Trauma
- Families



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Considering Bereavement in Systems



What are the essential elements in a system?

Purpose	The reason something is done, created, exists
Structure	The arrangement or relations between parts of something complex
Roles	The part played by a person or thing in a defined situation
Rules	Explicit or understood regulations or principles that govern behavior
Boundaries	Something that indicates or fixes a limit
Tasks	Something that must be done
Patterns	A reliable sample or traits, acts, tendencies, or characteristics



Lessons Learned from Grieving Youth



Whole-Family, Team-Based Care



Allows for complexity of:
Relationships in Families
Nature and Cause of Death



Rules

Each family has
spoken and
unspoken grief
rules

Is it ok
to show
feelings



Rules

Each family has
spoken and
unspoken grief
rules

When to
talk about
grief and
with whom



Rules

Each family has spoken and unspoken grief rules

What words are acceptable (e.g., dead, died, suicide)



Rules


Each family has spoken and unspoken grief rules

What truths about the death and grief are shared



Rules

Each family has
spoken and
unspoken grief
rules




If the
deceased is
talked about



Rules

Each family has
spoken and
unspoken grief
rules

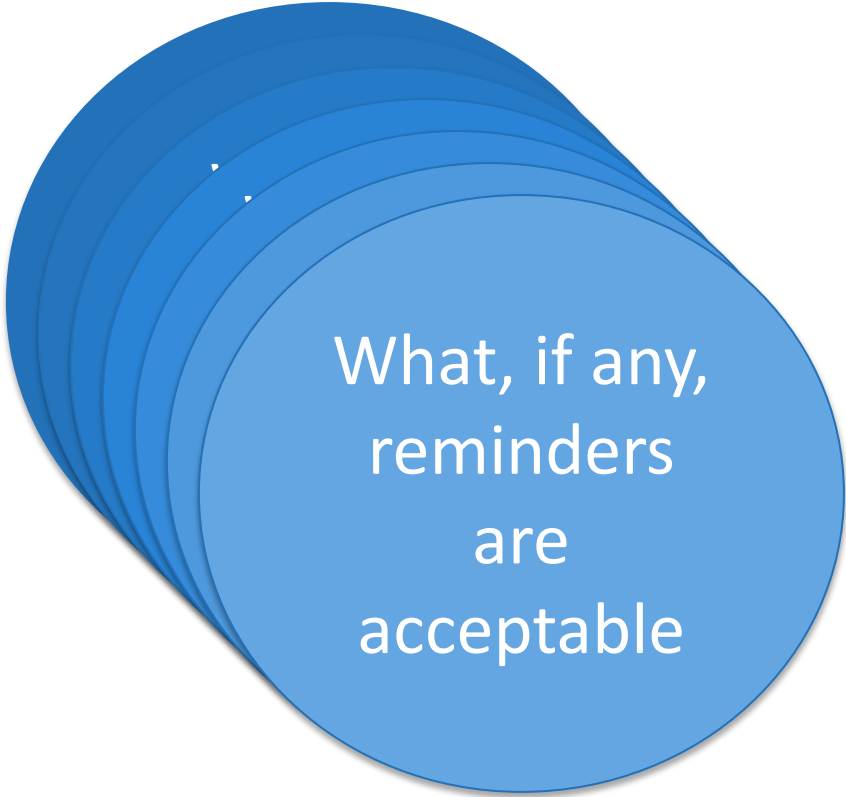


How
anniversaries
are handled



Rules

Each family has
spoken and
unspoken grief
rules




What, if any,
reminders
are
acceptable



Rules

Each family has
spoken and
unspoken grief
rules



If grief
timelines are
enforced or
expected



Rules

Each family has
spoken and
unspoken grief
rules



If open
honest
conversations
are
welcomed

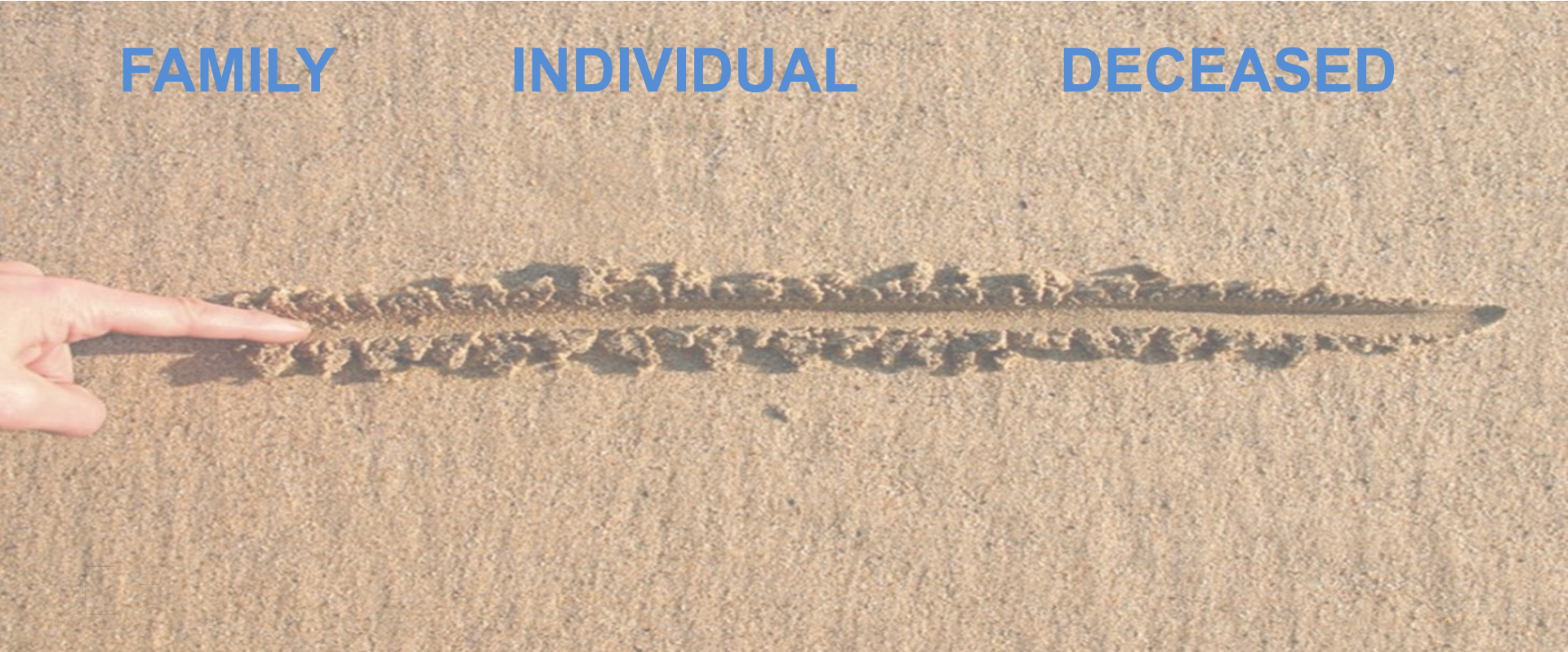


Boundaries

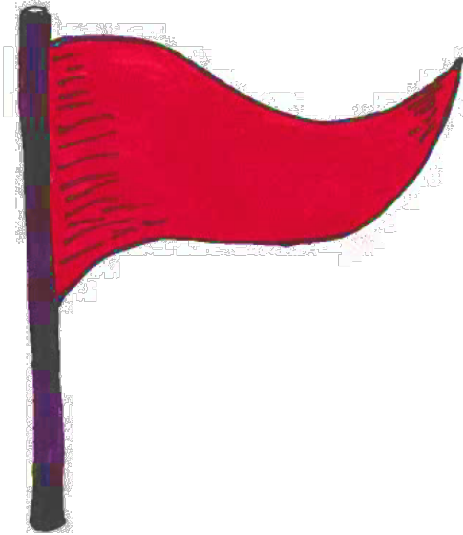
FAMILY

INDIVIDUAL

DECEASED



Red Flags



Suicidal thoughts

Self Harm

Substance abuse

Reckless behaviors

Dangerous aggression

Severe withdrawal

Giving up on relationships



Tasks of Grieving

- ***Accepting*** the reality of the death and its permanence
- ***Allowing*** for diverse emotional, cognitive and physical reactions to the loss
- ***Adjusting*** to life without the person who died in a way that allows for maintaining a meaningful connection while moving forward in normal development



Patterns

Each family has established patterns and experiences



History



Patterns

Each family has established patterns and experiences



Patterns

Each family has established patterns and experiences



Patterns

Each family has established patterns and experiences



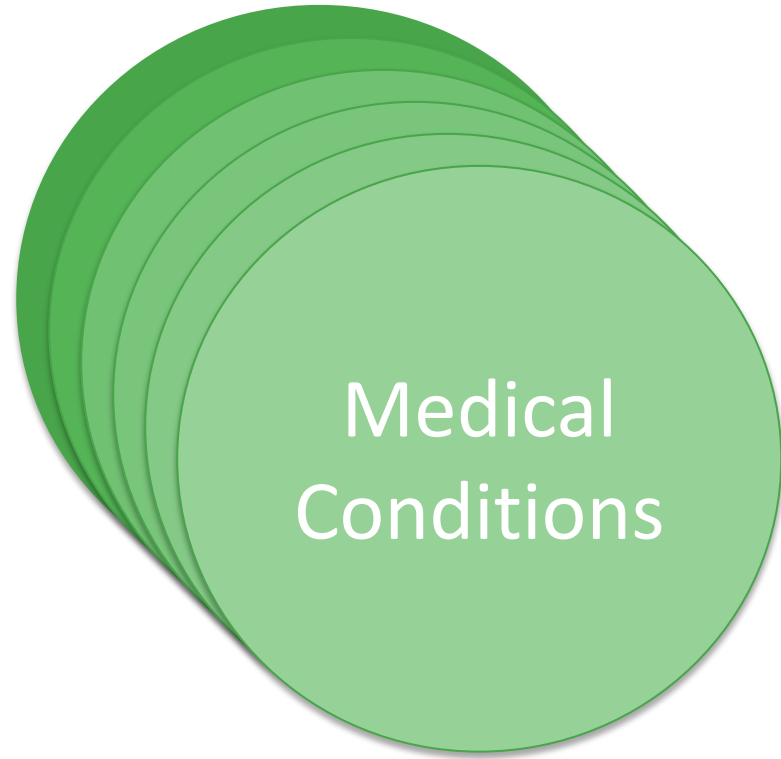
Patterns

Each family has established patterns and experiences



Patterns

Each family has established patterns and experiences



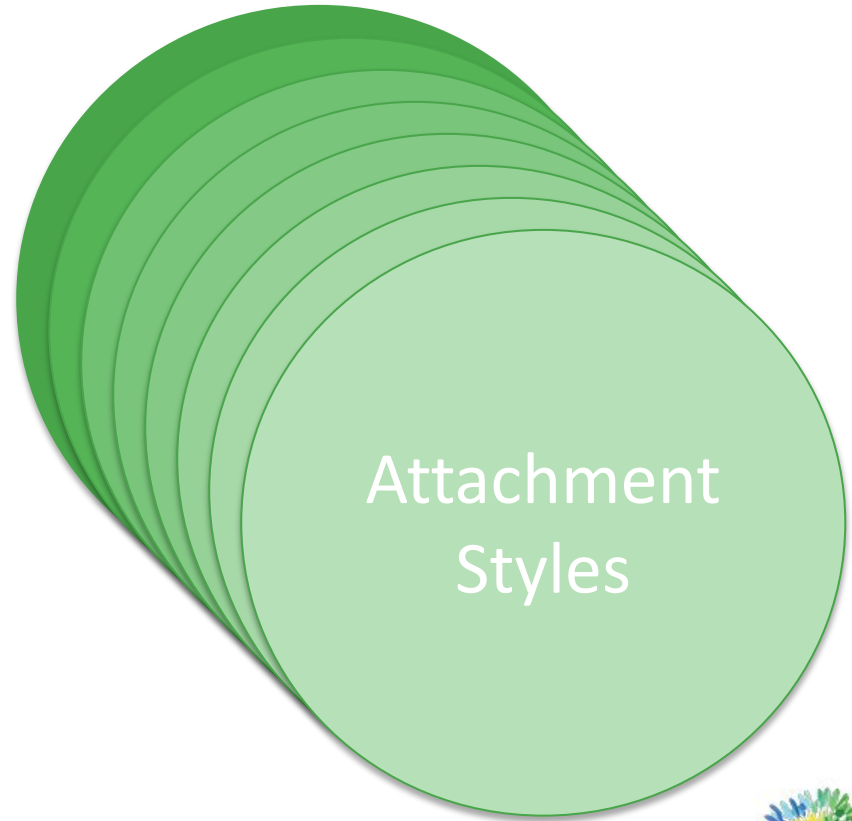
Patterns

Each family has established patterns and experiences



Patterns

Each family has established patterns and experiences



Patterns

Each family has established patterns and experiences



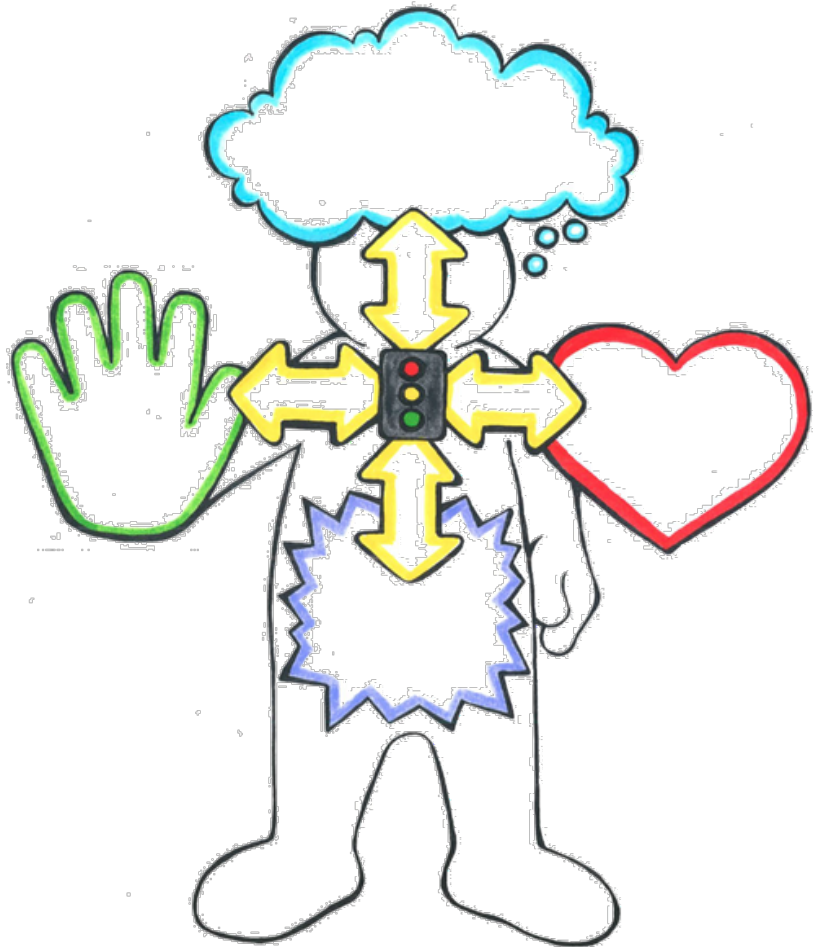
Caregiver Focus

- Primary means for creating systemic approach
- Recognizes and appreciates differences in grief
- Provides space to process grief and focus on youth
- Offers general and specific view of child's experience with each cairn
- Caregiving and parenting skills are prominent
- Balances activities with discussion, awareness and education



Grieving

Experience the complex emotions, cognitions, and physical reactions of grief



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Pathfinders

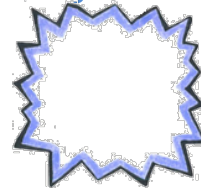


Grief Reactions

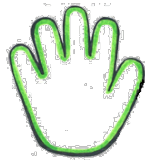
Emotional



Physical



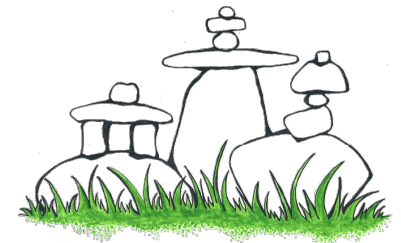
Behavioral



Cognitive



Pathfinders

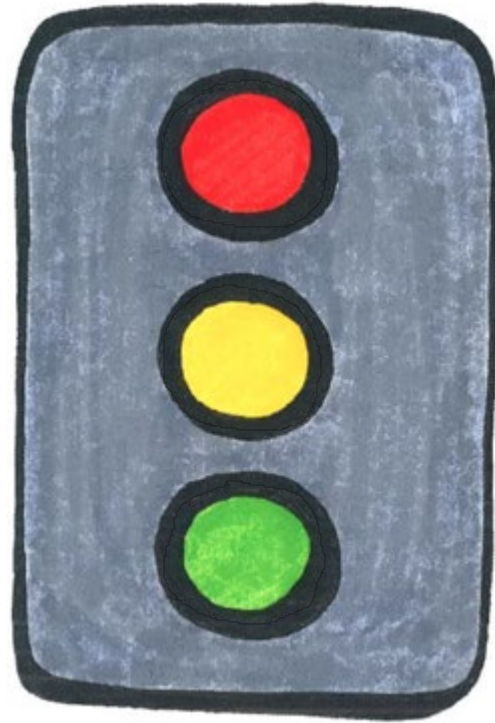


Coping Connections

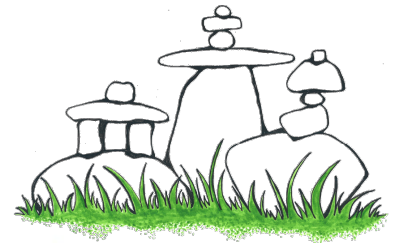
Stop

Slow Down

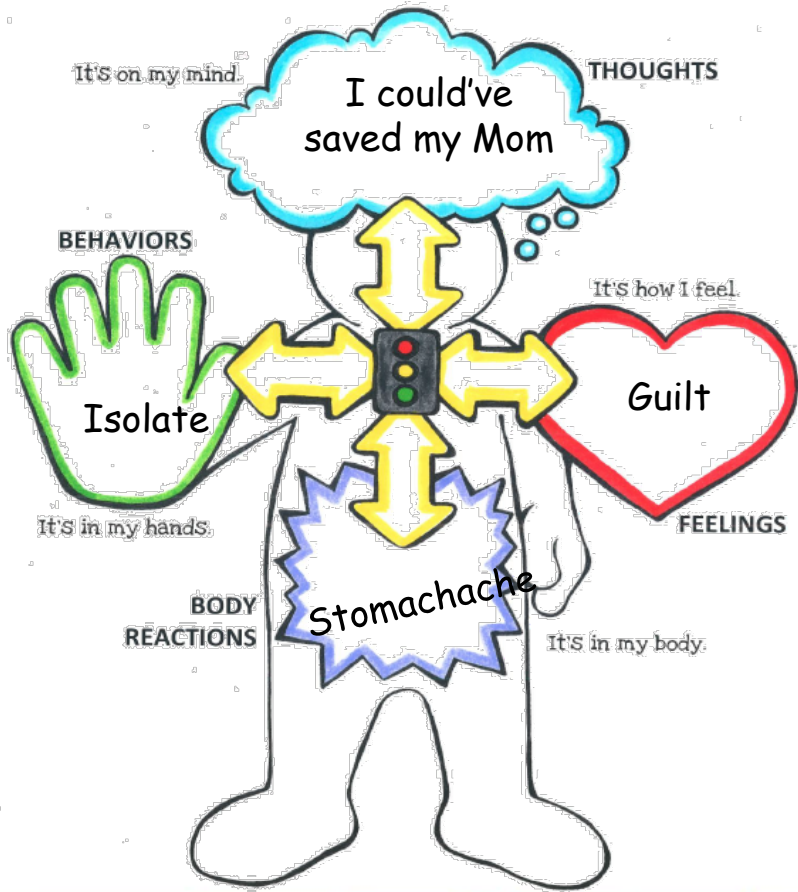
Go



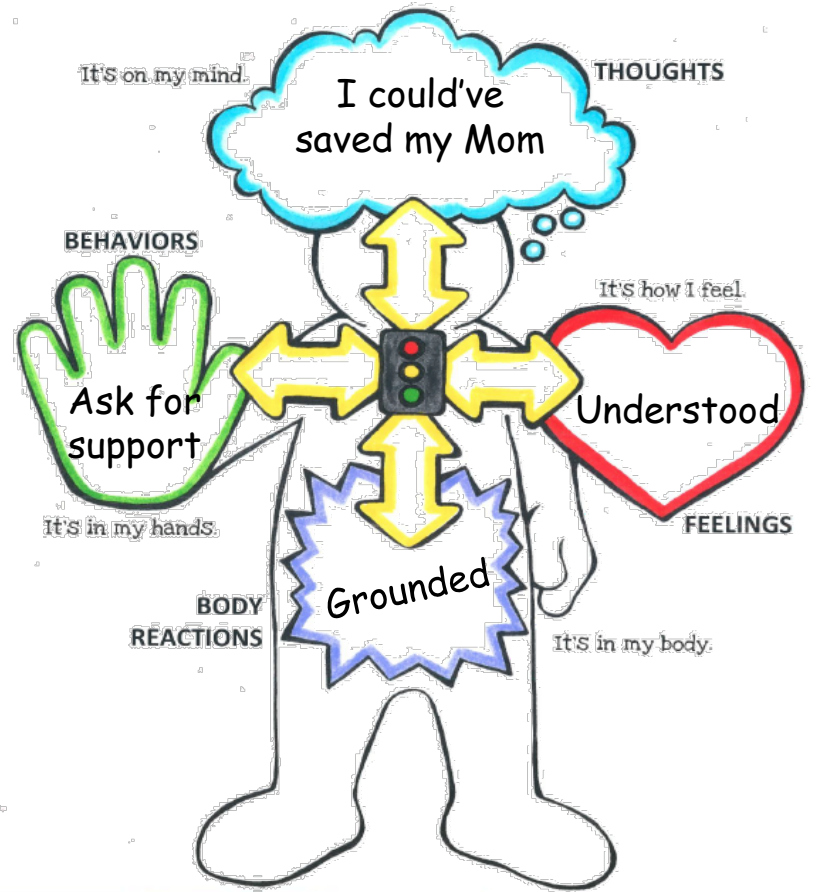
Pathfinders



Coping Companion



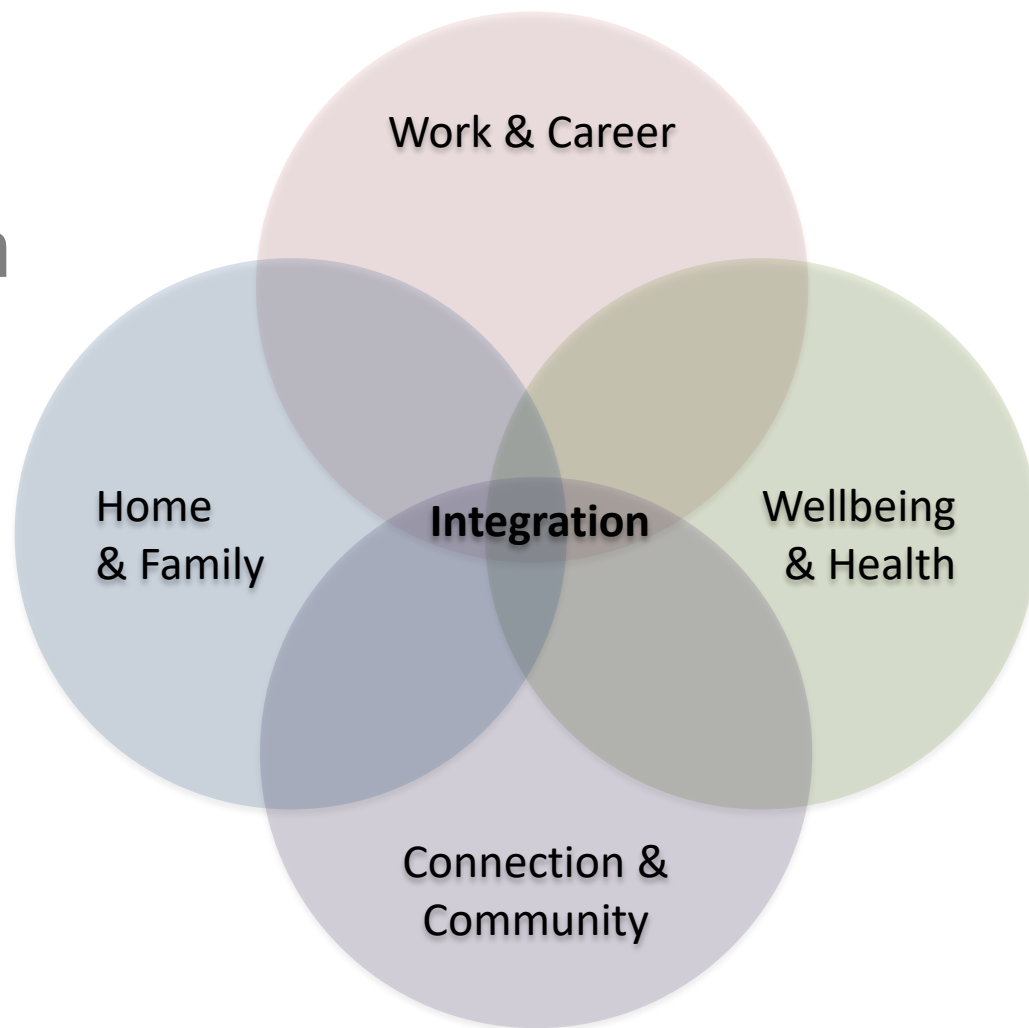
Coping Companion



Coping Tools



Work Life Integration



Children's Grief Awareness Month/Day



Children's Grief Awareness Month/Day



Whose Truth?



Art Credit: The Three Umpires, Norman Rockwell








Questions

What do you have to offer?



It all starts with LOVE

-  Love yourself and your loved ones fiercely and unconditionally. Prepare to be an advocate.
-  Let yourself and your loved ones have space to grieve openly and honestly.
-  Listen carefully to what you tell yourself and what you hear/see from your loved ones. Speak less. Listen more.
-  Learn that even though you cannot fix grief, you can get the support you need to gain the skills necessary to navigate grief reactions and live a happy, healthy life.
-  Lean into your community. Relying on others and asking for support may not come naturally, but this is a time to take people up on “let me know how I can help.”

Thank you!

judi's house JAG Institute
For Grieving Children and Families

CBEM

CHILDHOOD BEHAVIOR ESTIMATION MODEL

