Data and Research

According to the Childhood Bereavement Estimation Model (judishouse.org/cbem), 1/15 kids in MA will experience the death of a parent or sibling before the age of 18. Nationally, 1/13 kids will, which translates to an estimated 5.6 million children. **Added to this population is the substantial number of children experiencing the death of a primary attachment figures such as a grandparent, aunt or uncle, or even a close friend.** This number more than doubles by the age of 25. These children are at risk for negative health outcomes, including traumatic grief, substance abuse, lower self-esteem, dropping out of school and making unhealthy choices – and at a higher risk for mental health disorders such as depression and anxiety.

More than 140,000 children lost a parent or caregiver during COVID-19. Given the currently trajectory of COVID-19 and the opioid crisis, we anticipate that our intakes and community needs for bereavement support will expand exponentially.

Despite these startling statistics, there is no standardized measure to understand the feelings experienced by bereaved youth, and the social support they receive. The knowledge that would come from a large dataset of diverse youth from different programs across the world would inform program development and implementation, policy development and standards of prevention and care for youth experiencing traumatic loss. These data would be invaluable for individual programs and for the field.
Research Study Purpose:
To provide evidence informed tools to grief programs so they can demonstrate how their services change lives. To develop and sustain effective bereavement interventions to improve the lives of the diverse population of bereaved children, we must understand the feelings they experience and their social support, and how these change over time. While many programs seek to assess child and family experiences, there are few standardized and even fewer empirically based instruments available for use. Without which, little can be known about the population of children experiencing grief beyond each individual program. There are standardized and empirically based measures of social and psychological wellbeing, and none that measure how childhood loss, such as bereavement, impacts how a child feels, communicates, is supported by or connects with others. The development of the Inventory of Youth Adaptation to Loss (IYAL) filled this gap, making it a keystone in changing the lives of children by preventing long-term mental health sequelae.

By disseminating the IYAL to and supporting its use by grief programs across the nation, a diverse and robust dataset would be built. The knowledge that would come from this large dataset would inform program development and implementation, policy development and standards of prevention and care for youth experiencing traumatic loss. These data would be invaluable for individual programs and for the field.

This initiative will provide the missing piece by making the IYAL broadly available and use the data to demonstrate the strength and usefulness of the measure. And most importantly, to show how different grief support services help different children worldwide, how programs can grow and change to better serve children and give the world a glimpse into the experiences of children moving through profound loss.

From there, additional measures can be developed including one for younger children and caregivers. The broader use of these measures will also be testable with children, youth and families who have experienced different kinds of profound loss.

With the goal of improving the lives of children and youth experiencing grief in every domain through evidence-informed programs, policy supporting these preventative services and research to understand how and why, this initiative is a springboard.

The conceptual frameworks of developmental assets, received and perceived social support, the dual-process model of adaptive coping with bereavement, and continuing bonds guided the development of the IYAL. Each of these contributed to the overall conceptual framework that informed understanding the nature of bereaved adolescent’s individual coping and social support relationships.