Circle of Care Statewide Landscape Analysis of Grief Support Services for Children and Families Impacted by Substance Use-Related Loss or Death: Summary Report

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Project Abstract:

The Circle of Care Statewide Landscape Analysis of Grief Support Services focuses on identifying available resources for children and youth experiencing grief, especially grief related to familial (parent/caregiver/sibling) substance use and death by overdose. Due to the scope of this project, the process was divided into two phases. *Phase 1* of the project focused on highly trained, licensed providers offering clinical grief treatment to children and youth under the age of 18. *Phase 2* of the project focused on a much broader array of services including, but not limited to: bereavement and hospice programs, speciality therapeutic camps, community support groups, faith-based support resources, school-based support resources, and other relevant sectors that may provide support services to the target population. Following the completion of this landscape analysis, the Hour House and Illinois Family Resource Center has developed a Grief Support Services Directory that may be utilized by professionals, natural helpers, families, and caregivers throughout the state to identify grief resources in their region. The data contained in this summary report represents the findings of the landscape analysis and should be considered baseline data because it is anticipated that additional data and resources will be collected throughout the Threads of Hope training sessions. A cumulative evaluative summary that includes elements of the landscape analysis as well as evaluation data related to project activities will be developed and provided following completion of the training sessions.

Dataset Description:

This dataset comprises information on clinical (licensed) providers and non-clinical resources currently available in the state of Illinois. The data was compiled using publicly available information from various sources, including the Illinois Department of Financial and Professional Regulation and public databases that list providers by billing taxonomy codes for Certified Social Workers (104100000X), Psychologists (103T00000X), and Counselors (103T00000X). The information in this dataset was categorized based on the Illinois Department of Human Services Regional Map.The criteria for inclusion in this landscape analysis included the following:

1. Clinical service providers must indicate they specialize or have expertise in the treatment of grief.
2. Clinical service providers must work with one of the selected age ranges or offer family counseling services.
3. Non-clinical resources must be related to general grief or grief specific to substance use-related loss.
4. Non-clinical resources must provide services to individuals in the selected age ranges or offer family support services.
5. Both clinical and non-clinical services must be offered either in person or virtually to residents of Illinois.

Data excluded from this landscape analysis includes grief support services with a specified loss designation (ie perinatal loss) that does not fit within the parameters of general loss or loss specific to substance use or overdose.

Data Collection Process:

1. Phase 1 - Clinical Providers:
    a. Initial Provider List: An extensive list of providers was generated based on their professional designation and billing taxonomy codes. This list was further refined by geographic location to ensure regional representation across the state of Illinois.
    b. Specialization Identification: Publicly available information for each provider was reviewed to identify those specializing in grief services. A significant portion of this data was obtained from the Psychology Today directory, which verifies and provides detailed information on provider specialties.
    c. Additional Verification: For providers not listed in the Psychology Today directory, Google searches were conducted to gather relevant information from practice pages and other publicly available sources.
2. Phase 2 - Non-Clinical Resources:
    a. Research: Extensive research was completed in each region to identify non-clinical resources including bereavement and hospice programs, school-based programs, faith-based programs, and other avenues of support. This research was completed using data available from the National Alliance for Children's Grief, GriefShare, and other national and regional collections of information.
    b. Survey: The Circle of Care launched a statewide survey in September 2024 to collect resource information from community members, professionals, and other individuals involved in the development of this initiative. This survey was shared via email blast, social media, and conference networking to ensure a wide representation of responses.
    c. Focus Groups: The Circle of Care conducted two focus groups with peer professionals and people with applicable lived experience. These focus groups provided a significant amount of qualitative data that informed the development of the training sessions and material, as well as provided deeper insight into the resource avenues often used by individuals in challenging situations.

Key Characteristics:

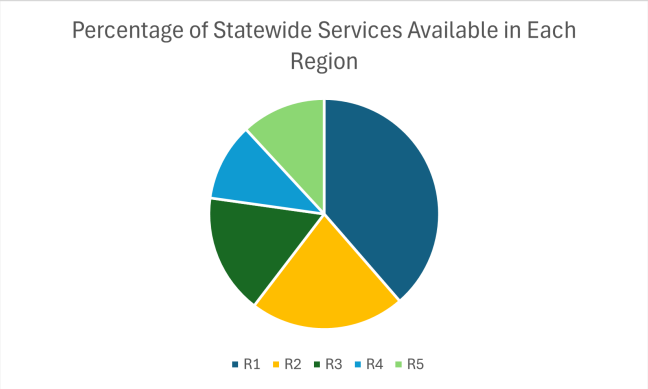
1. Grief Focus: All identified individuals in the dataset offer clinical or non-clinical support services that focus on grief. One shortcoming of this data collection is that there is no exhaustive list of licensed professionals with specific training or certification in grief

therapy. The American Academy of Grief Counseling's member list, a leading organization in the field, was found to have limited usable information.

2. Client Demographics: All resources in this dataset are confirmed to serve families and/or youth under the age of 18 and are actively accepting new clients at the time of the analysis.
3. Licensure Distribution: All providers included in the phase 1 dataset hold a clinical license (LCSW, LCPC, Licensed Psychologist/Clinical Psychologist) or have completed an advanced degree and possess a preliminary license for clinical practice.

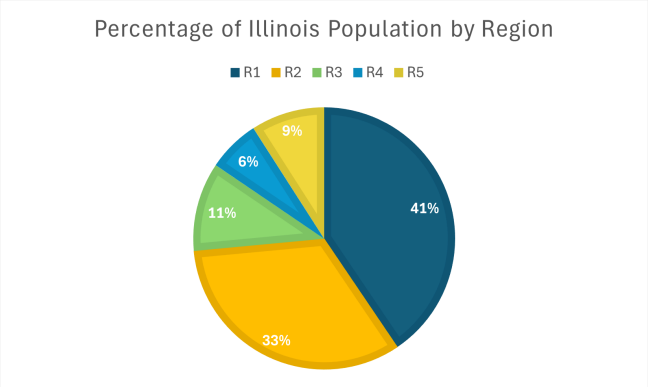
Landscape Analysis Findings

This report provides an analysis of the availability and distribution of licensed professionals and non-clinical support services specializing in grief treatment for children and youth across Illinois. The findings are based on data gathered from public sources, including licensure databases, provider directories, and information on community-based, non-clinical resources. Additionally, the report incorporates both quantitative and qualitative data collected throughout the duration of the Circle of Care project. By integrating multiple data sources and perspectives, this report aims to provide a comprehensive understanding of the current landscape of grief support services for children and youth in Illinois, especially those impacted by familial substance use and associated fatal drug overdose.

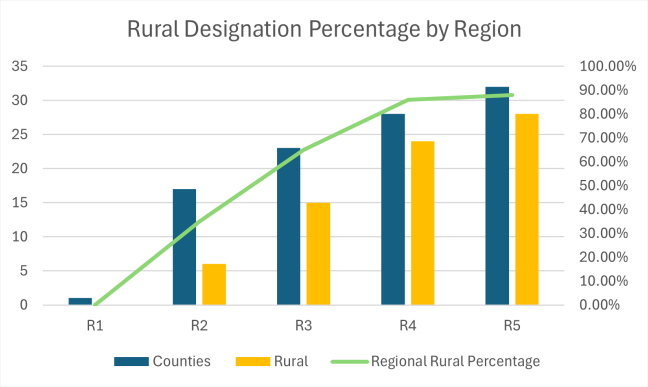


Overview: Review of the collected information highlights distinct differences in the service provision landscape across the state of Illinois. This research identified 249 clinical providers that serve children under the age of 18 and/or families and also possess a speciality or significant experience in the treatment of typical or complex grief. Region 1, which encompasses Cook County, unsurprisingly has a significantly higher concentration of clinical resources dedicated to addressing grief in children and youth compared to the rest of Illinois. Data collected indicate that the number of clinical providers specializing in this area within Cook County alone (117) is nearly equivalent to the total number of providers across all other IDHS regions combined (138). When examining the population distribution percentages across Illinois, Region 1, which includes Cook County, comprises 41% of the state's population, making it the most populous region by a significant margin. Region 2 accounts for 33%, while Regions 3, 4, and 5 collectively make up the remaining 26% (11%, 6%, and 9%, respectively). Although the larger population in Region 1 may partially justify its higher concentration of grief-focused clinical resources, the distribution of providers does not proportionally reflect the population needs in the other regions. For example, while Region 2

contains 33% of the state's population—almost equal to Region 1—it has access to far fewer clinical providers specializing in grief. Similarly, Regions 3, 4, and 5, which collectively account for over a quarter of the population, are significantly underserved. These disparities indicate a critical need to align resource allocation more equitably with population distribution to ensure adequate access to grief support services statewide.

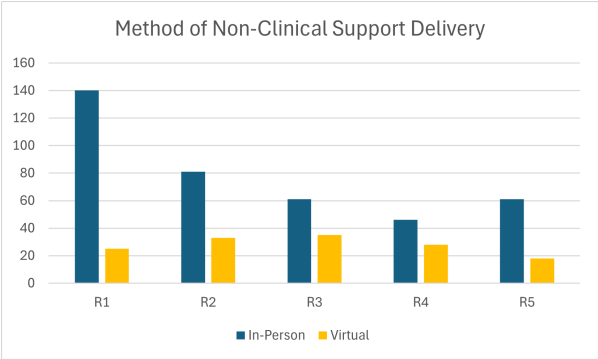


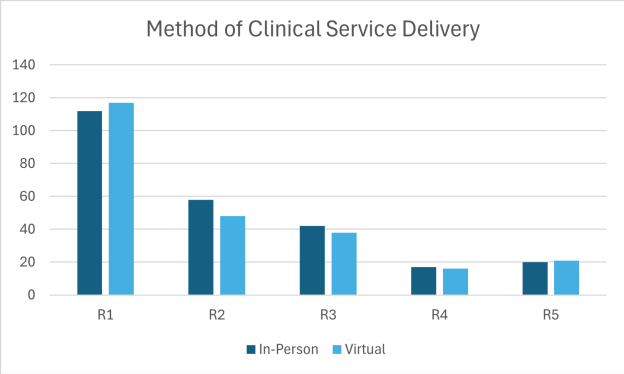
<u>Geographic Factors Impacting Accessibility:</u> Rurality significantly impacts access to support services and resources, particularly in the regions outside of Region 1. Region 1 encompasses 1,635 square miles, none of which are designated as rural by the Health Resources and Services Administration (HRSA). In contrast, Regions 2 through 5 span much larger areas—9,350, 17,317, 14,817, and 14,937 square miles, respectively—with increasing percentages of rural designations: 35% in Region 2, 65% in Region 3, 86% in Region 4, and 88% in Region 5. This rural classification poses unique challenges, as rural communities commonly face significant barriers to accessing care, including limited transportation options, long wait times for services, and a shortage of trained providers. Additionally, research indicates that rural communities face disproportionately high rates of fatal drug overdoses, particularly involving opioids, due to limited access to substance use treatment and harm reduction services (Faul et al., 2015). These barriers disproportionately affect residents in the more rural regions, where greater geographic distances and lower provider densities compound access difficulties. This reality underscores the critical need to develop and implement strategies to address the unique challenges of rurality, ensuring that grief support services are accessible and equitable for all Illinois residents, regardless of their location.



To gain a better understanding of the accessibility options available for residents around the state, this landscape analysis reviewed services available both in-person and via virtual platforms. In the realm of clinical services, this research found similarities in the availability of both methods of engagement; however, non-clinical services were almost exclusively delivered in-person without a virtual option. Again this highlights the importance of community and

geographic awareness to improve access and availability of support services, especially in rural communities.



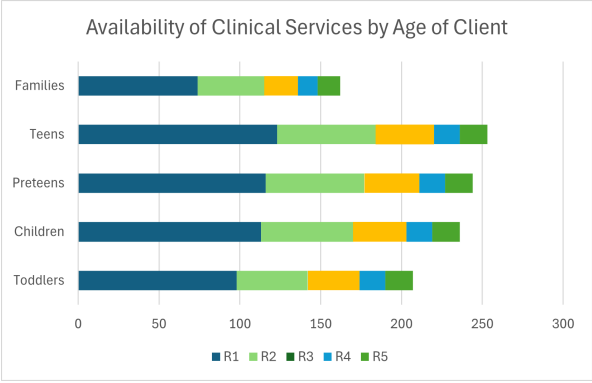


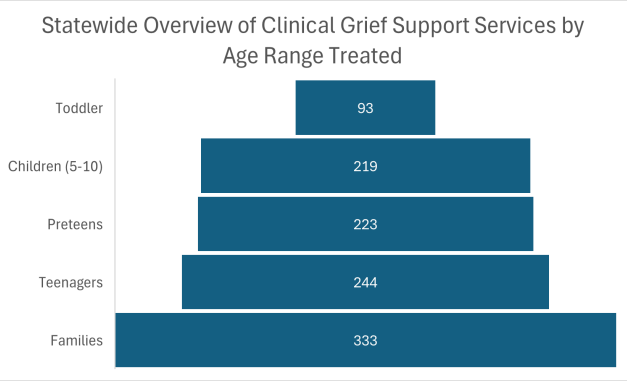
Funding Availability: The distribution of state and federal funding for clinical services and treatment programs often reflects disparities between rural and metropolitan areas of Illinois, further exacerbating inequities in access to care. Research indicates that metropolitan areas such as Region 1, which includes Cook County, tend to receive a disproportionate share of funding due to higher population densities and the perception of greater service utilization (Probst et al., 2018). Meanwhile, rural regions frequently receive less funding on a per capita basis, despite facing significant challenges, including higher rates of poverty, limited healthcare infrastructure, and greater geographic barriers to accessing care. This funding imbalance can leave rural communities in Regions 3, 4, and 5 particularly underserved, with fewer resources to address critical needs such as mental health services, substance use treatment, and grief support. Addressing these funding disparities is essential to ensure equitable access to clinical and non-clinical support services across the state, particularly for rural areas where resource gaps are most pronounced.

Disparities in Age-Appropriate Support Service Availability: A significant body of research supports the importance of early intervention and support to minimize the impact of developmental traumatic experiences such as foster care placement, death of a parent, and changes in caregivers. Specifically, evidence indicates that untreated early childhood trauma can lead to adverse outcomes, including difficulties with emotional regulation, attachment issues, and cognitive impairments, which may persist into adulthood (Van der Kolk, 2014). Developmental trauma and other Adverse Childhood Experiences (ACEs) are strongly correlated with an increased risk of early initiation of substance use that often progresses to dependency and ultimately a substance use disorder in adulthood (Felitti et al., 1998). These findings were reinforced through the Circle of Care Peer Listening Sessions which involved 20 individuals who identify as people in recovery, also currently working in the field of substance use treatment and recovery support services. The overwhelming majority of these participants identified the presence of at least one parent or caregiver in their childhood who struggled with a substance use disorder. Some common themes were highlighted by focus group participants including trauma,

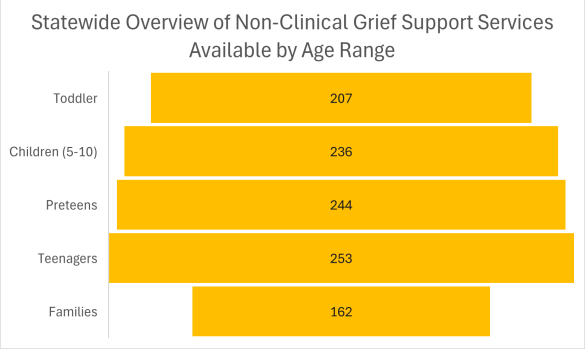
abuse, feelings of unimportance, low self-worth, instability, and lack of awareness of the dysfunction present in their childhood.

According to one participant, “For me, growing up as a child, my parents were both addicted to alcohol. I was surrounded with the chaos of physical altercations as well as moving and being uprooted from my home and friends too many times. I went to 9 different schools before I was 17. I ended up quitting school my senior year. We lived in several different houses between moving to new towns." This was again reinforced by another participant who stated "As a child, I spent a lot of time wondering where my mother was." As adults in recovery, many participants expressed unintentionally repeating the cycle of substance use and trauma throughout their own parenthood. Interestingly, many participants stated that, as children, they had some knowledge of resources in the community that could potentially help them; however, discussion themes emerged reinforcing the common sentiment of “don’t talk, don’t trust, don’t feel”. One participant summarized this sentiment with the statement “‘That's family business.' Even if you did feel like you wanted to talk to someone, it was like 'we don't talk about that outside of home'." Additional factors such as fear of DCFS involvement, the desire to protect their parents, and fear for their own safety as well as the safety of their siblings were identified as barriers to accessing support services. One participant shared "I had in my mind… you can't talk about it, you can't trust…. Because what if they go back and talk to my family. I was afraid, I was threatened. In the back of my head, I would hear that voice telling me not to say anything because I may be in more danger." These reflections as well as the current understanding of the experiences of children impacted by substance use disorders underscores the importance of creating safe spaces for all ages, both in clinical settings and in community settings.

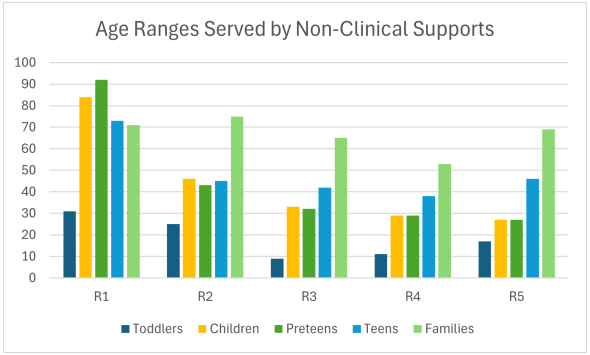




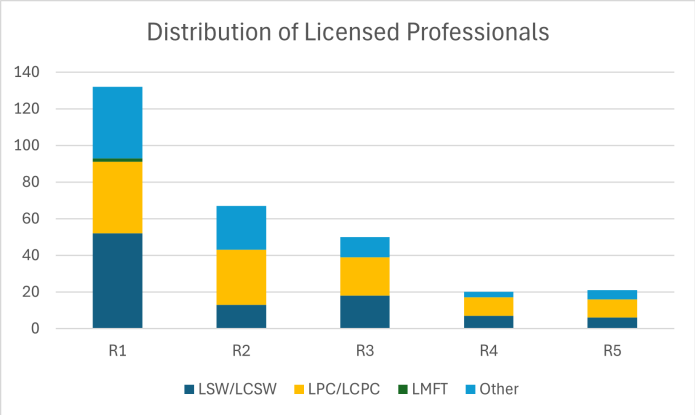
The above charts highlight the disparity in clinical grief support services available across different age groups, with significantly fewer options for younger children, particularly toddlers, compared to older children and families. Only 93 services statewide cater to toddlers, while 219 serve children aged 5-10, and the number increases steadily for older age groups and families. The regional breakdown for these services paints a similar picture, and again highlights the disparity of available services between Region 1 and the remainder of the state. This limited availability of clinical support for younger children is concerning given the critical importance of addressing early childhood trauma, such as the death of a parent, to prevent long-term developmental consequences.



The importance of non-clinical, natural grief support services for children and families cannot be understated. These non-clinical helpers—teachers, coaches, neighbors, and other natural supports— are typically aware of challenges faced by children long before these families are brought to the attention of child protective services and other formalized modes of intervention. This chart highlights the statewide availability of age-appropriate non-clinical grief support services, offering a distinct comparison to the previously discussed clinical grief support services. Non-clinical grief support services are generally more available across younger age groups compared to clinical services. For toddlers, non-clinical services total 207, more than double the 93 clinical grief services available for the same age group. Similarly, non-clinical services outpace clinical services for children aged 5–10 (236 vs. 219), preteens (244 vs. 223), and teenagers (253 vs. 244). However, the trend reverses for family-focused grief support, where clinical services (333) are significantly more prevalent than non-clinical options (162). This suggests a notable disparity in the availability of non-clinical grief support for families compared to children and youth, emphasizing the need to strengthen family-centered non-clinical resources. Overall, the data indicates that non-clinical services play a vital role in filling service gaps, especially for younger children, where clinical options remain limited. Expanding both clinical and non-clinical services in a complementary fashion is critical to ensuring comprehensive grief support coverage across all age groups and family units.



Provider Availability: This research utilized four main licensure types to classify professionals fitting the description of clinical service providers specializing or experienced in treating grief in children and youth: Licensed Clinical Social Workers (LCSW), Licensed Social Workers (LSW), Licensed Clinical Professional Counselors (LCPC), Licensed Professional Counselors (LPC), Licensed Marriage and Family Therapists (LMFT), and Licensed Psychologists and Licensed Clinical Psychologists (classified as "other").



The chart illustrates the distribution of licensed professionals specializing in grief support services across the five regions of Illinois. Region 1 (R1), encompassing Cook County, has a significantly higher number of licensed professionals, with a total exceeding 120 providers. This includes a substantial representation of Licensed Social Workers/Clinical Social Workers (LSW/LCSW) and Licensed Professional Counselors/Clinical Professional Counselors (LPC/LCPC). In comparison, Region 2 (R2) has fewer providers, while Regions 3 (R3), 4 (R4), and 5 (R5) demonstrate even lower availability, with the numbers declining sharply in these more rural areas. The data suggests a diverse mix of licensure types providing grief services, though certain regions may have limited access to specific types of professionals, particularly in the southern parts of the state.

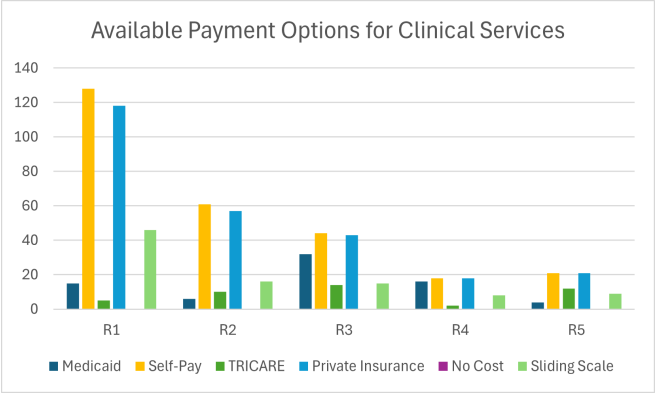
Several factors may explain these regional differences. Region 1's high population density, greater funding opportunities, and urban infrastructure likely support the higher concentration of licensed professionals. Additionally, urban areas are more likely to attract and retain professionals due to higher salaries, professional development opportunities, and access to amenities. Conversely, rural regions (R3, R4, R5) face challenges such as limited funding, lower pay scales, and difficulties in recruiting and retaining a highly skilled workforce. These disparities highlight the pressing need for targeted policies and funding to expand the availability of grief support professionals in underserved rural areas. Most importantly, this information underscores the importance of the Circle of Care Program which seeks to train non-licensed individuals in evidence-based practices for providing support to children, youth and families impacted by grief due to substance use and subsequent fatal overdose.

Utilization of Evidence-Based Practices (EBPs): For the purposes of this landscape analysis, four evidence-based practices (EBPs) were identified for the clinical treatment of typical and complex grief in children and youth: Trauma-Focused Cognitive Behavioral Therapy (TF-CBT), Eye Movement Desensitization and Reprocessing (EMDR), Managing Grief Therapy (MGT), and Trauma and Grief Component Therapy for Adolescents (TGCTA). Among these, TGCTA

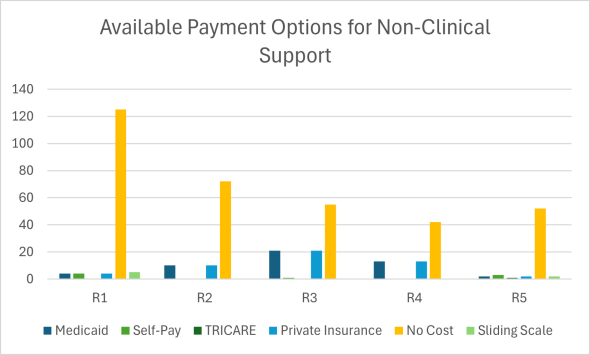
emerged as the most widely utilized EBP at the state level, with significant concentrations in Region 1 and Region 5. Clinical providers trained in EMDR were identified in all regions except Region 3; however, its utilization remains minimal compared to TGCTA. Limited use of TF-CBT was noted in Regions 1, 4, and 5, while MGT was not identified as being used to serve the target population in any region of Illinois. Notably, Region 1 dominates in TGCTA usage, likely reflecting robust training efforts concentrated in that area.

Several factors may explain the differences in EBP utilization across regions. These practices require intensive training and consultation, posing significant barriers to implementation in areas with workforce shortages or limited access to professional development opportunities. Additionally, the high costs associated with EBP training often hinder providers, especially in regions where compensation is lower. While some organizations in Illinois may secure grant funding to cover training expenses, providers are frequently required to finance these programs themselves, creating further limitations. The lack of widespread EBP utilization among providers highlighted in this analysis underscores the need for increased organizational funding to support professional and clinical development. Expanding access to affordable training opportunities and encouraging broader implementation of diverse therapeutic approaches are critical steps to address these disparities and improve access to evidence-based grief treatment statewide.

Accepted Payment for Clinical and Non-Clinical Support Services: Fee for services is a challenge for many Illinois residents. As of 2021, approximately 7.0% of Illinois residents, or about 875,000 individuals, were uninsured, including both adults and children (USAFacts, 2021). Among children under 19, the uninsured rate was approximately 3.4% as of 2022, indicating that thousands of Illinois children lack access to consistent healthcare coverage (Statista, 2022). This chart highlights the availability of various payment options for clinical services across the five regions of Illinois, with a particular focus on Medicaid, self-pay, TRICARE, private insurance, no-cost services, and sliding-scale fees. Region 1 (R1) shows the most extensive availability of payment options, with a significant number of providers accepting Medicaid, private insurance, and self-pay. In contrast, Regions 2 through 5 have fewer providers accepting Medicaid, and these regions also show reduced availability of no-cost and sliding-scale services. The decline in Medicaid-accepting providers is particularly pronounced in Regions 4 and 5, which are predominantly rural. The limited availability of qualified clinicians accepting Medicaid in these regions disproportionately impacts children and families who are at higher risk of experiencing or being impacted by substance use disorders due to social determinants of health (SDOH) such as poverty, resource scarcity, and poor community environments. Families



in poverty are more likely to rely on public insurance programs like Medicaid for access to mental health and grief support services. When providers who accept Medicaid are scarce, these families face significant barriers to accessing care, exacerbating risks associated with untreated trauma and adverse childhood experiences (ACEs). Furthermore, regions with fewer no-cost or sliding-scale options may place additional financial strain on vulnerable families, further limiting access to necessary clinical support. Addressing these disparities requires targeted investments to increase Medicaid-accepting providers and expand affordable service options, especially in underserved rural areas.



Non-clinical support service payment options create a stark contrast to the state of clinical services. This chart provides an overview of the available payment options for non-clinical grief support services across the five regions of Illinois. Region 1 (R1) demonstrates the most diverse payment options, with a substantial number of no-cost services being the dominant payment method. Regions 2, 3, 4, and 5 also show a notable reliance on no-cost services, but the availability is significantly lower compared to Region 1. Self-pay options are present in all regions but are most prominent in Region 1 and Region 2. Medicaid and private insurance acceptance are consistently less common across all regions, with minimal representation compared to other payment methods. TRICARE and sliding-scale payment options are limited, with low availability across all regions. This information highlights the critical role of no-cost services in providing access to non-clinical grief support, particularly in regions with fewer Medicaid or insurance-accepting providers. This suggests that many families, especially those in more rural areas or with limited financial resources, may rely heavily on free services to address grief-related needs. However, the disparities in payment options across regions point to potential gaps in equitable access, emphasizing the need for expanded payment flexibility to ensure broader service availability for underserved populations.

Limitations of this Landscape Analysis:

The *Circle of Care Statewide Landscape Analysis of Grief Support Services* provides critical insights into the availability of grief support resources for children and youth across Illinois. However, the analysis has several limitations:

1. Scope and Exhaustiveness: The dataset focuses on resources related to grief stemming from familial substance use and overdose-related deaths, excluding grief services addressing other loss types, such as perinatal loss. Additionally, there is no exhaustive list of licensed professionals specifically trained or certified in grief therapy, as existing

professional directories, such as the American Academy of Grief Counseling, were found to have limited usable data.

2. Regional Imbalances: The analysis reveals stark disparities in service availability between urban (Region 1) and rural (Regions 2-5) areas, driven by geographic, funding, and workforce challenges. These disparities leave significant gaps in access for rural populations, where transportation barriers, workforce shortages, and funding limitations are more acute.
3. Data Collection Constraints: The analysis relies on publicly available information and surveys, which may omit informal or less publicly visible resources. This creates potential gaps in capturing the full breadth of available services, particularly in rural or underrepresented areas.
4. Focus on In-Person Services: While virtual service options were analyzed for clinical services, non-clinical grief support was found to be predominantly delivered in person. This lack of virtual options disproportionately impacts rural residents, who may face challenges in accessing in-person services due to geographic isolation.
5. Professional Training and EBP Utilization: The availability of evidence-based practices (EBPs) such as TGCTA and TF-CBT is limited outside of Region 1 due to the high costs and intensive training requirements associated with these approaches. Workforce shortages and low provider compensation further restrict the adoption of these EBPs in underserved areas.
6. Payment Barriers: The analysis highlights significant disparities in payment options for clinical services, with Medicaid and no-cost options being limited in rural regions. Non-clinical services are more reliant on no-cost options, but their availability remains insufficient to meet the needs of underserved populations.
7. Baseline Nature of Data: The report explicitly states that the findings represent baseline data, with additional resources expected to be identified through ongoing training sessions. This highlights that the analysis may not fully capture the current and evolving landscape of grief support services.
8. Exclusion of Lived Experience: While focus groups provided valuable qualitative insights, these reflections were not systematically integrated into the quantitative analysis, potentially limiting the scope of findings related to the lived experiences of those affected.

Conclusions and Recommendations:

The findings of this landscape analysis suggest a significant variation in the availability of support services specializing in child and youth grief across Illinois. This variation represents the complex interplay of societal and community factors that either enhance or extinguish resource availability and service provision, with the most vulnerable populations often paying the highest

price. The following recommendations are provided based on the information gathered through this research:

1. *Expand Training in Evidence-Based Practices (EBPs):*
    - Provide state-funded or grant-supported training opportunities for EBPs such as Trauma-Focused Cognitive Behavioral Therapy (TF-CBT), Eye Movement Desensitization and Reprocessing (EMDR), and Trauma and Grief Component Therapy for Adolescents (TGCTA).
    - Prioritize training programs in rural regions (Regions 3, 4, and 5) to address the geographic disparities in EBP utilization.
    - Develop incentive programs to encourage providers to undergo EBP training, particularly in underserved areas.
2. *Increase Access to Medicaid-Accepting Providers:*
    - Expand the number of providers who accept Medicaid by offering financial incentives or enhanced reimbursement rates for Medicaid services.
    - Target rural regions where Medicaid-accepting providers are particularly scarce to reduce barriers for low-income families.
3. *Enhance Non-Clinical Grief Support Options:*
    - Strengthen the availability of no-cost and sliding-scale non-clinical grief support services across all regions, with a focus on Regions 2-5.
    - Promote partnerships with schools, faith-based organizations, and community groups to provide grief support in accessible, non-clinical settings.
    - Increase virtual non-clinical support options to address accessibility issues for rural populations.
4. *Address Regional Funding Disparities:*
    - Advocate for equitable state and federal funding allocations for clinical and non-clinical grief support services, particularly in rural areas with high poverty and resource scarcity.
    - Support community-based organizations in applying for funding by offering technical assistance and grant-writing resources.
5. *Develop and Support Workforce Retention Strategies:*
    - Implement loan forgiveness or tuition reimbursement programs for mental health professionals who commit to working in underserved rural regions.
    - Offer competitive salaries and professional development opportunities to attract and retain a highly skilled clinical workforce in Regions 3-5.
6. *Broaden the Scope of Identified Grief Services:*
    - Conduct ongoing updates to the Grief Support Services Directory to reflect new resources identified through community feedback and training sessions.
7. *Promote Awareness and Utilization of Existing Resources:*
    - Increase outreach efforts to raise awareness of the Grief Support Services Directory among families, caregivers, and professionals.

    - Partner with schools, healthcare providers, and community organizations to disseminate information about available grief support resources.
8. *Address Barriers to Access in Rural Areas:*
    - Develop transportation assistance programs to help rural residents access in-person grief support services.
    - Increase the availability of virtual grief support options to overcome geographic and transportation barriers.
9. *Strengthen Community Engagement:*
    - Foster collaboration with natural supports such as teachers, coaches, and neighbors to identify and address grief-related needs before families reach crisis situations.
    - Create safe spaces within communities for individuals to seek support without fear of stigma or repercussions, particularly for families impacted by substance use disorders.
10. *Conduct Ongoing Evaluation and Data Collection:*
    - Regularly update the landscape analysis to track changes in resource availability and identify emerging gaps.
    - Use qualitative data from focus groups and lived experience narratives to inform the development of trauma-informed and culturally responsive grief support strategies.
11. *Develop Comprehensive Policies for Early Childhood Support:*
    - Prioritize the expansion of grief support services for younger children, especially toddlers, where service availability is critically low.
    - Integrate grief support into early intervention programs to mitigate the long-term impact of developmental trauma.

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Appendix: Additional Data Visualization