Best Practices in Community Behavioral Health Respite Care for Children and Families

June 30, 2025

Ohio Children's Alliance
Leading change for child and family service providers

The Ohio State University
College of Nursing

Ohio Department of Mental Health & Addiction Services

Acknowledgements

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A Letter from the Chief Executive Officer of Ohio Children's Alliance

June 30, 2025

Dear Colleagues and Partners,

It is with great pride that I present to you *Best Practices in Community Behavioral Health Respite Care for Children and Families*, a white paper developed by the Ohio Children's Alliance in collaboration with researchers at The Ohio State University College of Nursing, providers, families, and policymakers across the country. This work is the culmination of a shared commitment to strengthening systems of care for youth with behavioral health challenges and supporting the families who love and care for them.

Every day, community-based organizations serve youth with complex emotional and behavioral needs. They witness firsthand the stress and sacrifice of caregivers navigating fragmented systems, limited resources, and few opportunities for relief. Respite care is a lifeline—offering caregivers essential time to rest, recharge, and continue supporting their youth at home. Yet despite its critical role in prevention and family preservation, behavioral health respite care remains vastly underutilized and unevenly available.

This white paper aims to change that.

By documenting promising practices, highlighting innovative state models, and offering actionable recommendations, this report provides a roadmap for expanding access to high-quality behavioral health respite care. It is not just a technical guide but a call to action—a call to build systems that are more compassionate and responsive to the needs of families.

Behavioral health respite care is an essential component of a healthcare system. In Ohio, this service has just recently become available as a resource and is beginning to be included on health insurance benefit plans. Integrating respite care into the healthcare system is crucial for providing families with the support they need to prevent more severe health issues and maintain stability. This white paper underscores the importance of behavioral health respite care as a preventative strategy and a means of empowering families to take control of their challenges.

We are grateful to the Ohio Department of Mental Health and Addiction Services for their vision and support of this effort. We also extend our sincere thanks to the providers, families, and national experts who shared their insights and experiences. Your voices shaped this work and made it stronger. At the Ohio Children's Alliance, we remain steadfast in our mission to advance the well-being of youth and families. We invite you to join us in that mission—by reading, sharing, and acting on the recommendations in this white paper. Together, let's reimagine what's possible-empowering children and families to reach their full potential.

Sincerely,

Mark Mecum
Chief Executive Officer
Ohio Children's Alliance

Executive Summary

Youth in the United States face a growing behavioral health crisis, with nearly one in five experiencing mental health disorders.[1] These challenges deeply impact families, caregivers, and communities. Behavioral health respite care—short-term, temporary relief for caregivers—can play a vital role in supporting family well-being, preserving home placements, and preventing caregiver burnout. Yet despite its benefits, respite care remains underutilized, understudied, and often misunderstood.

This white paper, produced by the Ohio Children's Alliance and researchers at The Ohio State University College of Nursing with support from the Ohio Department of Mental Health and Addiction Services, identifies best practices, guiding principles, and actionable recommendations for improving access to and delivery of behavioral health respite care for youth and families in Ohio and beyond. Drawing on national models, state-level innovations, stakeholder interviews, and current research, the white paper offers a comprehensive overview of the current landscape and future directions for respite care.

Importantly, the white paper recognizes that no element of the system of care, including behavioral health respite functions in isolation. The challenges facing respite care, such as provider shortages, eligibility restrictions, paperwork, low reimbursement rates, and limited public awareness, are deeply interconnected. For example, recruitment and retention of high-quality respite providers are shaped by funding structures and training systems, which are in turn influenced by broader policy and awareness efforts. Improvements in respite cannot be addressed through isolated fixes; rather, it requires integrated, system-level solutions that acknowledge and address these interdependencies. The recommendations offered here are intended to work in concert, reinforcing one another to create a more effective and sustainable respite care system.

Key findings and recommendations include:

1. **Value of Respite Care:** Research shows behavioral health respite care reduces caregiver stress, improves family cohesion, supports youth development, and may prevent costly out-of-home placements. Families who receive respite report greater optimism, improved relationships, and increased ability to care for their youth at home

2. **Barriers to Access:** Access to behavioral health respite care is inconsistent and often difficult to navigate. There is significant variation in eligibility requirements, assessment tools, and service models. Families seeking respite care report confusion, stigma, long waitlists, and difficulty locating providers. Provider shortages, especially in rural areas, further limit availability. Some caregivers face eligibility restrictions that exclude youth not meeting narrowly defined criteria for serious emotional disturbance.

3. **Innovative Solutions:** States such as Illinois and Wisconsin have implemented transformative approaches to improving access to behavioral healthcare including respite. Illinois' BEACON (Behavioral Health Care and Ongoing Navigation) portal offers centralized information and referrals for behavioral health services, while Wisconsin's Wayfinder connects families to trained navigators who guide them through available resources. States such as Michigan have developed public-facing family guides to reduce confusion and stigma. Additionally, models that embed respite into community-based settings (e.g., after-school programs, summer camps) and respite registries are expanding availability by leveraging existing infrastructure.

4. **Funding Strategies:** Current funding sources and policy frameworks for behavioral health respite care primarily rely on Medicaid. However, a diverse array of mechanisms contributes to

shaping access, including Early and Periodic Screening, Diagnostic, and Treatment (EPSDT); Medicaid waivers (1915(b), 1915(c), 1915(i), and 1115); state plan amendments; state general revenue funds; CHIP expansions; and federal grants. By examining both widely used and underutilized strategies, we can identify opportunities to expand access, address regional disparities, and enhance the long-term sustainability of behavioral health respite care systems for youth and families.

5. **Recruitment and Training of Respite Providers:** High-quality behavioral health respite care depends on well-trained staff who understand trauma-informed care, cultural humility, and strengths-based approaches. Regular supervision, peer consultation, and professional development should be built into respite models to ensure quality and consistency.

6. **Best Practices for Care Delivery:** Effective behavioral health respite care is built around core principles of the System of Care model—family-driven, culturally responsive, and community-based. Respite should be flexible (offered in-home or out-of-home, during day or overnight), trauma-informed, and rooted in youth strengths and family preferences. This white paper outlines practices such as individualized activities, safety standards, and inclusive service delivery.

7. **Evaluation and Accountability:** Ongoing evaluation is essential to ensure behavioral health respite care meets family needs and delivers intended outcomes. The white paper encourages utilization of standardized tools, family satisfaction surveys, and outcome tracking systems to monitor utilization and impact. Evaluation should also inform decisions about scaling, adapting, or discontinuing services to ensure they remain responsive to evolving community needs.

8. **Policy and Practice Recommendations:** To improve access and effectiveness of behavioral health respite care, the white paper recommends:

- Raising public awareness with stigma-reducing messaging and outreach.
- Creating centralized, family-friendly access points (e.g., websites, helplines).
- Broadening eligibility beyond narrowly defined diagnoses.
- Expanding recognition of behavioral health respite care as a health insurance benefit.
- Increasing provider pay and training support to grow the workforce.
- Expanding Medicaid waiver utilization and general revenue allocations.
- Increasing flexibility in service delivery models (e.g., evening, overnight care).
- Investing in evaluation systems that promote transparency and improvement.

This white paper is intended for use by a broad range of stakeholders, including but not limited to family- and youth-run organizations, managed care organizations, policymakers, Medicaid agencies, health insurance companies, behavioral health respite providers, and advocates working to expand and improve respite care services. By embracing these best practices and policy strategies, states and communities can strengthen the behavioral health system and better support youth and families.

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About This White Paper

The primary goal of this white paper is to provide guiding principles, best practices, and practical strategies for implementing and improving behavioral health respite care for youth and families. While we reference research findings and existing models, this is not a research study or a comprehensive literature review. Instead, this white paper is informed by both evidence-informed practices, grey literature (i.e., information produced by governmental agencies, research associations, or professional organizations) and the lived experiences of families, providers, and experts in the field.

Our team made a concerted effort to contact agencies in every state across the country to learn about offered behavioral health respite care. While many states did not respond, the information we gathered provides important insights into the current landscape. We also conducted interviews with key stakeholders and attended the ARCH National Respite Network and Resource Center's annual conference to learn about innovative programs and emerging practices in respite care.

This white paper serves as a resource for stakeholders involved in the design, funding, and implementation of behavioral health respite care. It is not a one-size-fits-all blueprint but rather a foundation for discussion, innovation, and policy development. Importantly, many of the challenges to and recommendations for improving respite care are deeply interconnected—no element of the system operates in a silo.

Given that respite care varies widely across states and programs—due to differences in funding structures, service models, and population needs—our aim is to highlight key considerations, share examples from the field, and support decision-makers in strengthening and expanding respite care options for youth and families. This report represents a snapshot of the currently available information and practices in the field.

Questions regarding this white paper may be directed to Ohio Children's Alliance:
admin@ohiochildrensalliance.org

Language and Terminology

This white paper focuses specifically on behavioral health respite care, which is distinct from other types of respite care such as medical respite, child welfare respite, or respite for youth with developmental disabilities. Behavioral health respite is designed to support youth experiencing emotional or mental health challenges and their families, offering temporary relief while addressing behavioral health-specific needs. Behavioral health respite care is integrated into a youth's individualized treatment plan—it's a strategic component of the overall care approach, not a stand-alone service. Recognizing and naming this distinction is essential, as the way we talk about behavioral health directly influences perceptions, policies, and services.

Disclaimer: *Unless otherwise specified, the terms "respite care" or "respite" are used throughout this white paper for brevity and refer specifically to "behavioral health respite care." Other types of respite will be referred to by their specific names (e.g., medical respite, child welfare respite) or by specifying the population they serve.*

Throughout this white paper, we have prioritized person-centered, strengths-based language that reflects the dignity and diversity of youth and families. Terminology evolves over time, and we aimed to use inclusive language that aligns with the preferences of the communities being discussed. We use "youth," to refer to individuals who require behavioral health respite care, including those transitioning into adulthood. "Families" and "caregivers" are used inclusively to represent parents, guardians, kinship caregivers, foster families, and others providing care. Wherever possible, we acknowledge the diversity of experiences and identities that shape the need for and delivery of respite care.

Common abbreviations used throughout this white paper include:

CHMI – Children's Mental Health Initiative
CMS – Centers for Medicare & Medicaid Services
EPSDT – Early and Periodic Screening, Diagnostic, and Treatment
HCBS – Home and Community-Based Services
HIPAA – Health Insurance Portability and Accountability Act
HRSA – Health Resources and Services Administration
SAMHSA – Substance Abuse and Mental Health Services Administration
SED – Serious Emotional Disturbance
SMI – Serious Mental Illness
SoC – System of Care
SPA – State Plan Amendment
YES Waiver – Youth Empowerment Services Waiver

SECTION 1

Introduction

Mental health challenges among youth in the United States have reached alarming levels, impacting not only the well-being of youth but also their families, schools, and communities. Approximately 20% of youth experience a mental health condition each year[1] with the most common conditions being anxiety (16.1%), depression (8.4%), and behavioral or conduct problems (6.3%).[2] These challenges often emerge early in life, with half of all anxiety disorders beginning by age six, behavior disorders by age eleven, mood disorders by age thirteen, and substance use disorders by age fifteen.[1] Among youth experiencing mental health challenges, one in ten meet the legal designation of Serious Emotional Disturbance (SED).[1] SED is used in state and federal statutes referencing youth either under 18 years old (21 years old in some states) with mental health challenges and exhibiting impaired functioning in at least one of the following domains: home life, school or vocational life, or community life.[3]

Despite the prevalence of mental health challenges and critical need for intervention, nearly half of youth with treatable mental health disorders do not receive adequate care.[4] These challenges extend beyond the youth to their entire family system.[5] Caregivers of youth with mental health challenges face unique stressors that can affect their employment, relationships, and overall well-being.[5,6] Many struggle to balance frequent medical and therapy appointments, school meetings, and crisis interventions, all while trying to support their youth's complex needs.[6] Traditional child care services are often ill-equipped to accommodate youth with significant emotional or behavioral challenges, further compounding the stress on families.[7]

Behavioral health respite care plays a critical role in addressing these challenges. By providing temporary relief to caregivers, respite can reduce family stress, improve overall family stability, and prevent or delay costly out-of-home placements.[7] Respite offers structured support in various settings, including but not limited to in-home care, community-based programs, and specialized facilities.[8] It allows youth to engage in safe, supportive environments while giving caregivers the opportunity to rest and attend to other responsibilities. Moreover, respite can help prevent crises, support social and emotional development, and enhance the overall quality of life for youth and their families.[9–11] Yet, respite remains an underutilized and often misunderstood component of the behavioral health system.[12]

The System of Care

Respite is a key component of the System of Care (SoC), a model developed to address long-standing challenges in youth mental health services.[13] The SoC approach was catalyzed by the landmark 1982 report *Unclaimed Children* by Knitzer and Olsen.[14] This report highlighted significant gaps in mental healthcare, such as a lack of access to care, overreliance on restrictive settings, fragmented service systems, limited community-based options, and the exclusion of families and cultural considerations.[13,14] In response, Knitzer and Olsen called for a "coordinated services system of care" to ensure youth and families could access and transition across services more effectively.[14]

This vision gained traction with the 1984 launch of the Child and Adolescent Service System Program (CASSP), which funded state-level planning to build systems of care and offered the first formal definition[15]:

> **"A system of care is a comprehensive spectrum of mental health and other necessary services which are organized into a coordinated network to meet the multiple and changing needs of severely emotionally disturbed children and adolescents."**

Federal efforts continued with the 1992 Children's Mental Health Initiative, which, through the Substance

Abuse and Mental Health Services Administration (SAMHSA), has since invested over $1 billion to expand systems of care nationwide.[16] Over time, the SoC framework has evolved. While early definitions of the SoC focused on youth with SED, later iterations broadened to include all youth at risk of mental health challenges.[16,17] The 2010 definition emphasized family partnerships, cultural responsiveness, and coordinated, community-based supports to promote well-being at home, in school, and in life.[16] The most recent update in 2021 adopts a public health approach that incorporates prevention, early identification and treatment, and includes children, youth, and young adults.[17]

Although the SoC is not a rigid model, it represents a guiding philosophy for organizing and delivering services. Across its evolution, three core values have remained consistent: ***Family driven and youth guided, community-based, and culturally and linguistically competent***.[13,16,17] Guiding principles have expanded to include interagency collaboration, care coordination, use of evidence-informed practices, developmental appropriateness, trauma-informed care, and early intervention—all reflecting the growing and diverse needs of youth and families.[16,17]

Behavioral Health Respite Care

The Lifespan Respite Care Act defines respite care as "planned or emergency care provided to a child or adult with a special need in order to provide temporary relief to the family caregiver of that child or adult.[18]" To expand on this, the ARCH National Respite Network, the only national organization solely focused on the development of quality respite programs, defines respite care more broadly as a vital support that helps sustain the health and well-being of caregivers and families by offering temporary relief from the demands of caregiving:[19]

> **"Planned or emergency services that provide a caregiver of a child or adult with a special need some time away from caregiver responsibilities for that child or adult, and which result in some measurable improvement in the well-being of the caregiver, care receiver, and/or family system."**

Behavioral health respite care is a specialized form of respite care for youth with behavioral or mental health challenges, including those with SED.[20] Unlike medical respite care, behavioral health respite does not involve direct medical care or clinical supervision. Instead, its emphasis is on emotional and behavioral support, delivered in ways that are responsive to the youth's unique needs.[20] Services can be provided by trained behavioral health professionals or paraprofessionals in various settings, including in-home, out-of-home, or community-based environments. Importantly, behavioral health respite is not delivered in isolation—it is integrated into the youth's individualized treatment plan as part of a coordinated, comprehensive approach to care, rather than serving as a stand-alone or ad hoc support.

This form of respite aligns closely with the SoC framework by offering flexible, family-driven, and community-based services that promote family preservation.[13,16,17] Behavioral health respite can play a critical role in preventing psychiatric hospitalizations or residential treatment stays, thereby reinforcing the SoC's commitment to home- and community-based care.[17,19] It offers families the opportunity to rest and reset during times of acute stress, which can be especially important in preventing crises and out-of-home placements.[20]

In contrast, child welfare respite care is offered within the child welfare system and serves a different but equally important purpose. Child welfare respite provides temporary relief to foster parents, kinship caregivers, or biological parents involved in child protective services. Its primary goals are to support placement stability, prevent caregiver burnout, and assist with reunification efforts.[21] Child welfare respite is usually provided in licensed foster homes or other approved settings and is overseen by child welfare agencies.[21] The focus is more on ensuring the youth's safety and supporting permanency planning.[21] Although both types of respite provide short-term care and support for caregivers, they are governed by different systems, serve different populations, and pursue distinct goals.

It is also important to note that behavioral health respite care is not a new concept—it has long existed

in various non-clinical forms at the community level. Historically, respite has been offered informally by neighbors, faith communities, and foster care systems as a way to support families during times of stress.[22] These community-based approaches have laid the groundwork for the more structured, system-integrated models of respite care that exist today.

Current Insights on Behavioral Health Respite

Behavioral respite care is emerging as a pathway for avoiding more disruptive or costly treatments. Since behavioral-specific respite care is still emerging in the United States—with some states yet to offer it and others only beginning to implement it in the past decade—the peer-reviewed literature on this topic remains limited.

While the use of large datasets to examine barriers to respite care is a strength of the existing literature,[6,12] there remains a critical gap in direct evaluation of respite care. Specifically, there is a near absence of rigorous research designs, such as randomized controlled trials[10], and limited consensus on key outcomes to measure effectiveness. Many existing studies rely on small samples or are conducted in international contexts, limiting their applicability to U.S.-based populations and policy decisions.

As noted in one prominent study:[10]

> **"Providers who design services for children experiencing emotional behavioral disturbance and their families are confronted with a doubly problematic situation in that, nationally, there is a virtual nonexistence of literature on respite for this population. This is largely due to a significant lag in the development of formal family supports for families caring for children with emotional problems, compared with those for families with children with developmental problems and chronic illness."**

There have been numerous calls across the literature for additional research on respite care and in particular longitudinal studies to more accurately understand the outcomes that respite may provide.[10,19,20] Yet, researchers have examined behavioral respite care for youth and other studies which focus on youth in foster care[23,24] or with special healthcare needs[11,25–27] may provide useful insights into the potential impact of behavioral health respite care. Beyond peer-reviewed scientific literature, we can examine respite evaluation reports, expert panel recommendations, and state assessments to help begin to fill in the gaps to both identify potential benefits of respite and help form a clearer picture of the potential benefits behavioral respite may provide to youth and families.

Caregiver and Youth Outcomes

Caring for youth with emotional and behavioral challenges can put stress on the family unit.[11] Accordingly, the impact of respite care on families of youth have frequently focused on examining if respite care decreased parental stress or offers other psychological improvements for family members.[27] For example, one study found significant decreases in parenting stress following episodes of respite care for their youth.[28] In a survey of families using respite in Massachusetts, the majority (57%) of parents said respite helped reduce their stress.[28]

Beyond stress, the benefits for parents include reductions in feelings of isolation related to parenting and increased time to spend with their other youth.[29] Studies with families of youth with autism have also noted that parents may experience improved energy levels that lead to a perception of improving the care they provide to their youth.[9] Along with reductions in parental stress, families have also noted increased family stability, improved well-being, and improved ability to care for youth.[24] Additionally, when a study has failed to show change related to family function or parental coping related to respite, parents still endorse a high level of satisfaction with respite.[26] Finally, one of the most valuable benefits of respite identified by parents is providing them time to spend with other family members.[11]

Benefits of Respite for Caregivers and Youth

Caregiver Outcomes

- ↓ Parental Stress
- ↓ Isolation
- ↑ Family Stability
- ↑ Energy & Well-Being
- ↑ Time with other family members

Youth Outcomes

- ↓ Out-of-Home Placements
- ↓ Hospitalizations Days
- ↑ Social Skills & Activities

Cost Effectiveness

Respite costs far less than hospital stays or residential treatment.

Regarding special populations, reductions in psychological distress and stress have been noted in parents of youth with developmental disabilities receiving respite care.[11,25] Most foster parents in one survey indicated that respite made a positive impact on their ability to care for youth at home (68%) and increased family stability (54%).[29] However, the benefit of respite care for stress reduction among caregivers of youth with autism spectrum disorder is less clear, with some studies reporting lower stress levels and others finding higher stress or no association.[30]

Research on the outcomes of youth receiving respite care for behavioral health issues is less clear. In one of the few longitudinal randomized controlled trials that examined behavioral health respite care, Bruns and Burchard (2000) identified a significant reduction over time in out of home placements for youth who had received respite care compared to those who had not received respite care. However, there were not significant differences related to crisis intervention for youth or improvements in youth behavior related to youth receiving respite care in the same study.[10]

Cost Effectiveness of Respite

The cost of behavioral health treatment for youth can be high, with expenditures on emergency department, inpatient hospitalizations, and residential treatment among the most significant financial costs.[31] However, respite may be a more cost-effective treatment option. For example, CareSource who is part of the Ohio Medicaid health plan, evaluated data from emergency department, inpatient behavioral services, and day treatments for 77 youth receiving respite in 2021.[32] CareSource identified decreases in the volume and cost of all services. Specifically, average emergency department cost per member dropped 59% from $21,535 to $8,903.[32] In another example, a 2013 evaluation of respite in Massachusetts, estimated that ten hours a week of respite care for three months would cost about $3,000 compared to three months of residential care which would cost around $29,000.[33]

Similarly, data collected directly from states suggests that respite care reduces hospitalizations and is a cost-effective intervention. For example, data from Kansas suggest that the annualized cost of short-term respite for youth with SED was $13,545 compared to $32,671, the annualized cost of youth's psychiatric hospitalization.[34] Additionally, Wyoming which provided access to respite through the High Fidelity Wraparound (HFW) program notes that such a program is less than half the annual cost per individual compared to psychiatric residential treatment facility (PRTF) ($21,482 for HFW; $47,045 for PRTF).[35]

SECTION 2:

Accessing Behavioral Health Respite Care

While respite care is a vital support for caregivers of youth with behavioral health needs, navigating access to these services can be complex and inconsistent. Furthermore, respite care is not available in all areas nor states. Families primarily use respite care as a planned break from caregiving, but many also seek it during times of crisis.[36] Families often encounter barriers such as unclear eligibility criteria, limited provider availability, and stigma surrounding service use.[12] This section provides a comprehensive overview of how families access respite care, the range of eligibility assessments used, and the structural barriers that limit utilization and access. It also highlights differences in eligibility criteria and service limits and showcases initiatives like Illinois' BEACON portal, the Wisconsin Wayfinder, and respite registries which are making strides in improving access, navigation, and coordination of behavioral health services.

Barriers to Accessing Respite

Respite care utilization and access varies widely across states.[37] Workforce shortages play a significant role in limiting service access,[38] particularly in rural states, where recruiting and retaining respite providers is an ongoing challenge.[39] Provider shortages not only limit service availability but also create long wait times, preventing qualifying youth and families from receiving timely respite care.[39]

Stakeholder surveys in states like Oregon have identified key barriers to respite access: too few providers, restrictive funding models, stigma, programs that don't align with youth needs, and lack of information about how to access services.[36] Families often face confusion over eligibility criteria, bureaucratic obstacles, and limited guidance in navigating the system.[12] Both caregivers and providers highlight the need for support roles (e.g., care coordinators, system navigators) to help

families access respite, but such roles are often unavailable.[40] Families frequently cite challenges not just in accessing respite initially, but in maintaining consistent respite.[9,12] Early barriers include emotional hurdles in admitting the need for help, difficulty finding appropriate care, and discomfort with unfamiliar providers.[12,20] Once families decide to seek respite, they often encounter delays, lack of transparency, and difficulty locating qualified, trustworthy providers.[9] Continuity of care is further disrupted by rigid service models, strict eligibility rules, transportation issues, and administrative delays.[41] Emotional factors—such as guilt, fear of judgment, or distrust of providers—can persist and reduce continued use.[41]

Stigma around mental health services remains a significant barrier.[42] Families may fear being seen as inadequate or worry their youth's behavior is "too severe". Much of this stigma stems from limited public knowledge about what respite care is and how it benefits families. Without widespread education efforts, misconceptions may persist, making it even harder for families to take advantage of available services.

Eligibility Assessments and Criteria

Eligibility criteria for respite access vary widely and are often not easily accessible to the public. In some cases, eligibility depends on specific scores on standardized assessments. Table 2.1 displays different assessments used to determine eligibility for services including respite.

Appendix Table 1 outlines youth eligibility criteria from exemplar states, which range from stringent clinical requirements to more flexible models where families simply need to identify a need for respite. It's also important to note that in many programs, respite care is embedded within a larger program, so eligibility criteria often mirror those of the larger program (e.g., Wraparound).

While there are differences in criteria, several common elements emerge across the states reviewed. All states define an age range for eligibility,

Table 2.1 Eligibility Assessments by State

Assessment name	Domains assessed	Exemplar states using the assessment
Child and Adolescent Needs Assessment (CANS)[43]	Suggests pathways for service planning through assessing behavioral and emotional needs, caregiver needs and resources, cultural factors, life functioning, risk behaviors, and strengths	Illinois[44] Michigan[45] North Dakota[46] Ohio[47] Texas[48]
Child and Adolescent Service Intensity Instrument (CASII)[49]	Risk of harm, functional status, co-occurring conditions, recovery environment, resilience and response to services, involvement in services	Minnesota[50] Wyoming[51]
Child Behavior Checklist (CBCL)[52]	Social problems, thought and attention problems, rule-breaking behavior, aggressive behavior, anxiety, depression, somatic complaints	Kansas[53]

Table 2.1 Eligibility Assessments by State *(continued)*

Assessment name	Domains assessed	Exemplar states using the assessment
Child and Adolescent Functional Assessment Scale (CAFAS)[54]	Problem behaviors, strengths, and goals across school, thinking problems, behavior towards others, self-harm, moods/emotions, substance use, home, community, material needs, and family/social support	West Virginia[55] Kansas[53]
The Early Childhood Service Intensity Instrument (ECSII)[49]	Degree of safety, youth-caregiver relationships, caregiving environment, functional/developmental status, impact of the youth's condition, services profile fit	Minnesota[50] Wyoming[51]
Modified Caregiver Strain Index[56]	Strain related to care provision across financial, physical, psychological, social, and personal domains	Montana[57]

typically capping at eighteen. All states require that youth have a diagnosed mental or behavioral health condition that significantly impairs functioning, often categorized as a SED. In addition, several states require youth to be at risk of higher levels of care, such as inpatient psychiatric hospitalization, or to have unsuccessfully attempted outpatient services. Family involvement is also emphasized in many programs. For example, Illinois requires caregivers to agree to program terms,[58] while Ohio requires respite to be part of a structured care plan.[59] West Virginia mandates that families opt into a managed care organization and prioritize home- and community-based services.[55] Among the states reviewed, Montana is the most inclusive, allowing families to access respite based solely on self-identified need, with no restrictions based on age, diagnosis, or income.[57]

Limits on Behavioral Health Respite Care

Being eligible for respite care is only the first step for families seeking support. Even after qualifying for services, families often encounter limitations on how much respite they can receive and the conditions under which it can be used.[20] These restrictions may include caps on the number of annual respite hours, limits on overnight stays, or specific eligibility conditions for when respite is allowed. While some states clearly define these limitations, others—such as California,[60] permit exceptions based on individual family needs, offering additional flexibility. Table 2.2 provides a summary of the maximum respite care allocations in different states.

In addition to annual or unit-based limits, some states impose restrictions on the number of consecutive hours or days respite care can be used in a single instance, reinforcing its role as a short-term relief service. In some cases, states set caps that apply without prior authorization but allow families to request additional respite hours or days if needed. For example, in Ohio, families can receive up to 90 days of behavioral health respite care per year without prior authorization; however, accessing respite beyond 90 hours requires prior authorization through OhioRISE.[61]

Some states impose specific limitations on how respite care can be used by families. These rules are designed with the intent of ensuring that respite is used for temporary relief rather than as a replacement

for other forms of care. For example, in Wyoming, respite is intended for short-term, temporary relief for an unpaid caregiver and should be primarily episodic.[69] It cannot be used to substitute care while the primary caregiver is at work or during services otherwise available through public education programs, including educational activities and after-school supervision. Similarly, in Iowa, respite care may not be provided during the hours in which the usual caregiver is employed, except when the youth is attending a camp.[70]

Table 2.2 Respite Care Allocations in Exemplar States

State	Respite Allocation
Arizona[62]	600 hours/year
California[60]	336 hours/year
Florida[63]	190 hours/year
Idaho[64]	300 hours/year
Illinois[65]	200 hours/year
Louisiana[66]	300 hours/year
Michigan[45]	4,608 15-minute units/year
New Hampshire[67]	30 full 24-hour days/year
Ohio[61]	90 calendar days/year
Texas[48]	720 cumulative hours/year
Wyoming[68]	416 15-minute units/year

Expanding Access through Innovation

States are increasingly turning to innovative technologies to improve access to behavioral health services. In response to growing demand and systemic challenges, initiatives like BEACON in Illinois[71] and the Wisconsin Wayfinder[72] are leading the way in connecting families to needed care.

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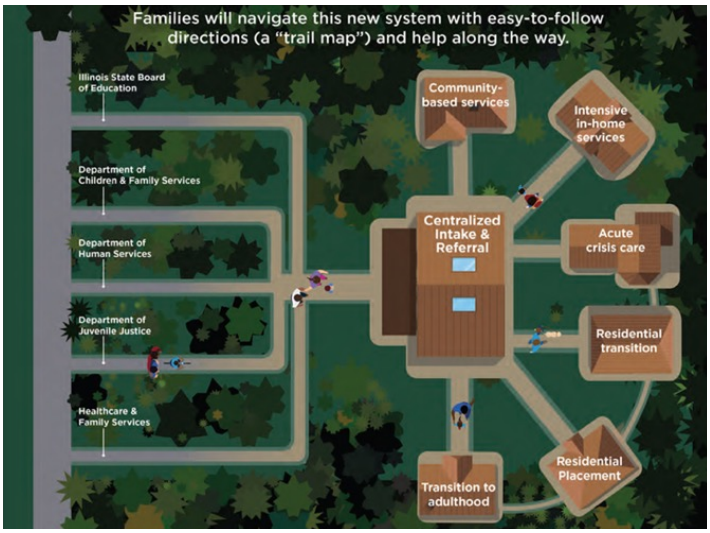


Illinois' BEACON Children's Behavioral Health Portal

In 2022 the state of Illinois partnered with the independent policy research center, Chapin Hall, to launch the Behavioral Heath Transformation Initiative. This initiative, born out of a state-wide needs assessment, aimed to provide young people with significant behavioral health needs access to necessary community and residential services and to provide resources and support to caregivers.[73]

One of the recommendations in this initiative involved implementing Resource Referral Technology aimed at better connecting families with available services.[73]

This recommendation led to Illinois and Chapin Hall announcing a partnership with Google in 2024 to lead the development of a new care portal, BEACON. BEACON went live in January 2025 and serves as "a centralized resource for Illinois youth and families seeking services for behavioral health needs." BEACON provides families with information on available state agency services and community-based programs, simplifying and streamlining the process of finding services for families. Rather than navigating through various department and agency housed resources, families now have a centralized source of information on behavioral and mental health resources, including information on accessing respite care services.

Wisconsin Wayfinder: Children's Resource Network

The Wisconsin Wayfinder: Children's Resource Network serves as Wisconsin's hub to connect families of youth with disabilities, special care needs, and mental health conditions to available programs and services.[72] The Wisconsin Wayfinder is a no-cost, one-stop-shop where caregivers can receive one-on-one direct support in navigating youth's resources. Families connect over the phone or online with a Resource Guide who assists the family in finding and engaging with services that address their youth's specific needs. Caregivers can receive assistance in understanding available health benefits, locating healthcare providers and state and community services including respite, and connecting with parent-to-parent supports.

Respite Care Registries

Respite care registries are an emerging strategy used to expand access to respite and build a more responsive and flexible care infrastructure. These registries serve as centralized directories of trained respite care providers, enabling families to identify, review, and directly contact potential providers. By connecting families with respite providers through an accessible online platform, registries can streamline the process of securing care while promoting autonomy and choice for families.

Registries typically include provider profiles that detail training history, availability, and preferences for age groups or special needs. For example, New Mexico allows providers who complete the National Respite Care Provider Training and earn a certificate to create a profile on their state registry. Providers can opt to serve in either volunteer or paid roles, and families can browse these listings to select a provider who meets their needs. Notably, New Mexico's model encourages quality by linking registry access to completion of the standardized training.

Several states—including Nevada, Wisconsin, and New York—also utilize this model, sometimes employing an independent contractor structure to maintain flexibility for both providers and families.

However, it is important to note that families are often responsible for conducting background checks on providers, which can be a barrier for some. In addition to provider listings, some registries also allow families in need of respite care to register themselves. This dual-sided approach helps programs and agencies better understand demand, facilitates more targeted outreach and support, and can inform statewide planning and workforce development.

Recommendations for Enhancing Access to Respite

Enhancing access to behavioral health respite care requires a coordinated approach that addresses the deeply interconnected barriers families face. Public awareness remains low, yet providers are often reluctant to promote services when workforce shortages—driven in part by low reimbursement rates—limit their capacity. At the same time, confusing eligibility requirements and complex access points further discourage families from seeking care. These barriers do not exist in isolation; rather, they reinforce one another in a cycle that limits both the supply and demand for respite care. Similarly, the recommendations outlined here are interconnected—improving one area, such as reimbursement or outreach, can strengthen others, like workforce recruitment or family engagement. A holistic, systems-level response is needed to ensure respite care is accessible and sustainable. Table 2.3 presents recommendations for enhancing access to behavioral health respite care.

Resources

- ARCH's tool for tracking the need for respite services
- Kansas Best Practices in Assessment for the Kansas SED Waiver
- The Collective Impact Forum's Community Engagement Toolkit
- Texas Health and Human Services Family Guide
- Michigan Department of Health and Human Services informational resources for families
- New Mexico Respite Provider Registry

Table 2.3 Recommendations and Approaches for Enhancing Access to Respite

Recommendation	Approach
Review and expand eligibility criteria	• Eligibility requirements should be reviewed to ensure they are inclusive and reflect family and youth needs. • Requiring a SED diagnosis, for example, may exclude families who still need support. • Best practices include making eligibility criteria accessible, as done in Arizona, allowing families to self-screen for services without unnecessary administrative hurdles.
Increase public awareness and outreach	• Public awareness of behavioral health respite care remains low. Outreach efforts should include brochures, digital campaigns, and direct community engagement at libraries, community centers, and healthcare centers. • Clear, consistent messaging across state and local platforms can ensure families understand the purpose and availability of respite care. • Outreach should highlight respite as a strength-based, preventive support—not a sign of failure—to reduce stigma and encourage participation.
Enhance family support and information sharing	• Families need a clear point of contact and user-friendly information about how to access services like BEACON and Wayfinder. This includes who to contact, what forms to complete, and what criteria must be met. • Adopting a "no wrong door" approach—where families can access services through helplines, referral agencies, or case managers—ensures families are supported regardless of their entry point into the system.
Address waitlists and service capacity	• To meet growing demand, programs must actively monitor waitlists and expand capacity. • Strategies include increasing funding, recruiting new providers, and ensuring geographic reach in both rural and urban areas. • If waitlists are necessary, families should have access to transparent guidelines for prioritization and regular updates on their status.
Ensure service flexibility to meet family needs	• Respite care should be available in formats that reflect caregiver preferences, including overnight care when needed.
Integrate respite care with existing community programs	• Existing after-school programs, summer camps, and community centers can serve as access points for respite care. • Marketing these programs as respite options and training staff to support youth with behavioral health needs can expand respite availability while making use of existing infrastructure.
Develop a statewide directory of respite providers and services	• A centralized directory or map of available respite should be developed and kept up to date. • County and state websites should clearly explain eligibility, service types, approved providers, and include contact information for service coordinators. • Transparency and accessibility of this information are key to reducing confusion and connecting families to care efficiently.

SECTION 3:

Behavioral Health Respite Funding, Financing, and Policies

This section provides a snapshot of current funding sources and policies that govern behavioral health respite care. We highlight exemplar states to illustrate a range of approaches; this is not intended to be an exhaustive review. Given that funding structures and policies can change rapidly, the information presented reflects the landscape at the time of writing. By describing commonly used funding strategies as well as underutilized options, we identify opportunities to enhance access and long-term sustainability in behavioral health respite care.

Behavioral Health Respite Care for Youth with Medicaid

Medicaid is one of the primary funding sources for behavioral health services for youth with SED, particularly through the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) benefit and Medicaid waivers.[74] The EPSDT ensures that youth under Medicaid access medically necessary services.[74] However, barriers limit its effectiveness in supporting respite care. First, the EPSDT benefit often supports medical and therapeutic treatments but does not typically extend to respite care, leaving families to seek alternative funding for these crucial services.[75,76] Second, many youth do not qualify for intensive supports under EPSDT due to misidentification of their needs, despite the requirement that Medicaid cover medically necessary interventions for eligible youth.[75,76]

EPSDT and Medicaid waivers both aim at improving healthcare access and services but differ in some keyways. EPSDT is a federally mandated benefit for all Medicaid-eligible youth under 21 that ensures youth receive comprehensive and preventive healthcare services, including screenings, diagnostic tests, and necessary treatments.[74] Some examples include well-visits, vision, dental, and hearing screenings. Also included are regular developmental and behavioral screenings including those for autism spectrum disorder, diagnostic evaluations to confirm diagnosis, and other treatment deemed medically necessary such as applied behavioral analysis therapy, and speech, occupational, and physical therapy if related to the autism spectrum disorder diagnosis.[74] While EPSDT does cover behavioral health services, such as therapy, psychiatric care, and crisis intervention, respite care is typically not considered a direct medical treatment.[74]

Medicaid waivers are state-specific programs that allow Medicaid to "waive" certain federal rules so states can provide additional services to specific populations who would otherwise need care in residential settings.[77] The waivers are used to expand Medicaid coverage beyond standard federal guidelines, like those outlined in the EPSDT mandate.[77] Waivers are often used to cover services like personal care, respite, home modifications, and case management.[77] Medicaid waivers have been the most common way states have covered respite for youth.[78]

California has included behavioral health respite care for youth under EPSDT via their Medi-Cal Medicaid program.[79] EPSDT mandates that Medi-Cal covers all medically necessary services for individuals under 21, which can include behavioral health services.[79] Through EPSDT, youth may access various support services without the need for a separate waiver. An initiative within Medi-Cal is the Community Supports program, which includes services like respite aimed at providing relief to caregivers of youth with complex behavioral health needs.[79] Eligibility for these services often requires that youth have a SED diagnosis and meets specific medical necessity criteria. Massachusetts is another example that does not utilize a specific Medicaid waiver to provide respite care exclusively for youth with SED and instead is provided under the EPSDT mandate through their MassHealth Medicaid program.[80]

Medicaid Waivers and Behavioral Health Respite Care

Section 1915(b) Waiver

Section 1915(b) of the Social Security Act allows states to innovate within their Medicaid programs by requesting waivers from certain federal requirements—specifically, comparability, statewideness, and freedom of choice.[81] These waivers enable states to implement managed care and other delivery system reforms as long as the program is cost-effective, meaning that overall expenditures do not exceed what they would be without the waiver.[77] While managed care can also be implemented under state plan authority, 1915(b) waivers provide states with additional flexibility to tailor services to high-need populations.[81]

Ohio has leveraged this flexibility through a 1915(b)(3) waiver to support the delivery of behavioral health respite care for all youth enrolled in its specialized managed care program—OhioRISE.[59] OhioRISE is designed to serve Medicaid-eligible children and youth with complex behavioral health and multi-system needs. Under this waiver, Ohio provides behavioral health respite care to all OhioRISE enrollees statewide.[59] The OhioRISE Plan operates behavioral health respite under a separate capitated payment structure, subject to the financial parameters set by the waiver.[59]

It is important to note that OhioRISE is currently the only managed care program in Ohio with behavioral health respite included in its defined benefit package. Additionally, CareSource is the only traditional managed care organization with behavioral health respite as an optional service through a contract with the Child and Family Health Collaborative of Ohio.

Section 1915(c) Waiver

The 1915(c) waiver allows states to develop tailored programs for youth eligible for institutional-level care.[82] These waivers allow states to provide Medicaid-funded home and community-based services (HCBS) as alternatives to institutional care for individuals with disabilities or special healthcare needs.[82] A key feature of the 1915(c) waiver is that it can expand or omit the means test (i.e., financial eligibility requirements) for Medicaid eligibility and the waiver program, and instead base eligibility on clinical need or need for institutional care.[77] While commonly used to expand access to behavioral health respite care, these waivers often include enrollment caps, which can lead to waitlists and limited availability of services.[83]

Ohio uses a 1915(c) waiver to offer out-of-home respite to a subset of OhioRISE enrollees who meet specific clinical and functional criteria.[84] This service provides short-term relief to primary caregivers and is delivered exclusively outside the youth's home.[84] Other states, such as Texas and Wyoming, also leverage 1915(c) waivers to provide behavioral health respite. Texas's Youth Empowerment Services (YES) Waiver offers respite, crisis stabilization, and therapeutic supports to help youth remain in the community.[48] Wyoming's Children's Mental Health Waiver includes respite and family support services aimed at preventing institutionalization and easing caregiver burden.[35]

Section 1915(i) State Plan Amendment

The 1915(i) State Plan Amendment (SPA), introduced under the Affordable Care Act, allows states to offer HCBS—including behavioral health respite—through their Medicaid programs without the administrative complexities of traditional waivers.[82] The 1915(i) does not require individuals to meet an institutional level of care, making it a more accessible option for youth who need intensive support in less restrictive settings.[77] A key distinction of the 1915(i) SPA is that it is only available to individuals who are financially eligible for the state's Medicaid program.[77] However, once financial eligibility is established, youth can be additionally eligible for more services under the SPA if they meet criteria.[77] Furthermore, the 1915(i) requires that HCBS be offered to eligible populations statewide.[77] Under this policy state funded services may include case management, respite care, day treatment, partial hospitalization, outpatient rehab and clinical services and other services states request.[77] This makes it a potentially powerful mechanism to deliver intensive, targeted behavioral health

services—like respite care—to children and families in the least restrictive setting possible.[77]

Several states have implemented the 1915(i) SPA to expand access to behavioral health services, including respite care. In Oregon, families access services, like respite care, through the state's Coordinated Care Organizations or the Oregon Health Authority, which oversees Medicaid programs.[85] Illinois uses the 1915(i) SPA to provide Medicaid-funded services, including respite care, to youth with SED without requiring a full waiver.[86] Indiana's 1915(i) SPA includes services such as wraparound facilitation, habilitation, respite care, caregiver training and support, and transportation.[87] In Indiana, eligible individuals must be Medicaid-eligible and have income at or below 150% of the Federal Poverty Level.[87]

Section 1115 Demonstration Waivers

Section 1115 waivers offer flexibility for states to pilot innovative programs or expand Medicaid-covered services.[82] Section 1115 of the Social Security Act gives the Centers for Medicare & Medicaid Services (CMS) the authority to approve waivers for Medicaid programs, enabling states to make changes to how they deliver Medicaid services or how they cover populations.[82] These waivers are typically used for demonstration projects that aim to test new approaches, such as expanding Medicaid eligibility, providing new services, integrating care systems or improving cost-efficiency in Medicaid services.[77] An important limitation is that these waivers only change the Medicaid program for those who are financially eligible for Medicaid.[77]

These waivers encourage creative solutions, including integrating housing, food security, and respite care into broader behavioral health initiatives. For example, Illinois recently implemented a 1115 waiver to address holistic needs for pediatric and adult populations transitioning out of institutional settings.[88] Missouri's 1115 Demonstration Waiver is designed to reduce unnecessary hospitalizations and institutional placements by offering flexible Medicaid-funded services—including behavioral health respite—that help families care for youth in home and community settings.[89]

Combinations of Waivers

Some states have utilized multiple waivers to obtain coverage for behavioral health respite care for youth on Medicaid.[78] For example, New York uses the Section 1915(c) HCBS Waiver to operate the Children's Waiver Program, which provides respite care and a range of other services for all youth with complex healthcare needs, including mental health conditions.[90] The Children's Waiver Program is designed to provide HCBS to youth who would otherwise require care in an institutional setting. It includes various services such as respite care, family support, crisis intervention, and behavioral health services to support youth and their families in maintaining care at home and in the community. Additionally, New York also uses its Health Home Program, which is supported by the 1115 Waiver, to integrate and coordinate care, including respite and other behavioral health services.[91]

Funding Sources for Behavioral Health Respite Care for Youth without Medicaid

A variety of federal, state, and private funding sources support behavioral health respite care. While Medicaid is the primary funding source, alternative funding mechanisms exist for youth who do not qualify for Medicaid. Federal grants play a crucial role in expanding access to respite care, particularly through programs like the Children's Mental Health Initiative which are federal grants designed to expand community-based systems of care.[20] Similarly, Community Mental Health Services Block grants provide states with flexible funding to address behavioral health needs, and many states have used these funds to support respite care programs.[20] Additional federal funding sources also support respite care initiatives. Title V Maternal and Child Health Services Block Grants, administered by the Health Resources and Services Administration (HRSA), provide funding to improve maternal and child health, with states able to allocate portions for

respite care services.[20] Child Abuse Prevention and Treatment Act (CAPTA) grants support programs aimed at preventing child abuse and neglect, with some states using these funds to offer respite as a preventive measure for at-risk families.[20]

Graaf and Snowden conducted a study aiming to describe alternative strategies to waivers to fund HCBS for youth who were not eligible for Medicaid due to financial reasons.[37] They collected data from 46/50 U.S. states using publicly available data, structured telephone interviews and brief email surveys with state mental health agency representatives. The results revealed that states primarily rely on two strategies to fund HCBS for youth who are not financially eligible for Medicaid.[37] The first strategy involves expanding Medicaid eligibility through the Children's Health Insurance Program (CHIP). Eight states in the study extended CHIP to cover youth in families earning up to 300% of the federal poverty level, allowing these youth to access the full Medicaid benefit package, including HCBS. The second strategy is the use of state general revenue funds, often combined with federal Community Mental Health Services Block grants.[37] Some states allocate substantial funding to ensure that all youth in need receive services regardless of their insurance status, while others acknowledge that limited funds result in unmet needs.[37]

In many cases, states supplement their behavioral health budgets by pooling resources from other child-serving agencies, such as child welfare and juvenile justice.[37] Local government contributions also play a role in some states, but this can result in regional disparities due to differences in local funding capacity and political will.[37] The study emphasized that while non-waiver strategies like CHIP expansions and general revenue funding provide important alternatives to Medicaid waivers, they vary widely in scope, eligibility criteria, and sustainability.[37] CHIP-based expansions function similarly to Medicaid waivers but are limited to families under a specific income threshold. In contrast, general revenue-funded programs are more flexible but lack uniform standards and are highly vulnerable to economic and political changes. The study also highlights that state decisions around these funding mechanisms are influenced by a complex mix of political ideology, administrative structure, and fiscal conditions.[37] States that prioritize local control or have a history of cross-system collaboration may be more likely to adopt non-waiver strategies, though this can sometimes result in uneven access across regions.[37]

Notably, Ohio supplements its behavioral health budget through the Multi-System Youth (MSY) Custody Relinquishment Prevention Program.[92] This program was developed to prevent families from having to relinquish custody of their children to the child protection system solely to access behavioral health treatment. Sponsored by the Ohio Family and Children First (OFCF) Cabinet—which includes the Ohio Departments of Children and Youth, Developmental Disabilities, Education and Workforce, Mental Health and Addiction Services, Medicaid, and Youth Services—the MSY Program supports youth with complex, multi-system needs who require creative, cross-system supports.

Eligible youth must either be at risk of custody relinquishment or have been recently relinquished (e.g., within the past 30 days) for the sole purpose of obtaining care. Families can access the MSY funding in one of two ways: through their county Family and Children First Council or through the OhioRISE Medicaid Managed Care Plan for youth enrolled in OhioRISE. All applicants must have a local or regional team that is actively coordinating care and pursuing creative solutions tailored to the youth and family's unique needs. The MSY program is considered a funder of last resort—intended to be used only when local funds, insurance, post-adoption supports, and other resources have been exhausted—and it cannot be used to supplant existing funding. MSY funds can be used for respite services, among other supports, providing a critical safety net for families navigating multiple complex systems.

State Funded Strategies for Respite

Several states allocate funds directly for respite care through dedicated budget appropriations, providing essential support for families. However, these funds are often limited and struggle to meet the growing demand or ensure long-term sustainability. One

Table 3.1 S5150 and S5151 Billing Codes and Reimbursement Rates Across States

State	15-minute unit rate	Per diem rate
Arizona[94]	$6.67 to $7.08	$336.99 to $358.04
Arkansas[95,96]	$5.00 (1:1) $3.50 (Shared staffing)	$165 (Planned) $180 (Emergency)
Colorado[97]	$7.27 to $7.59	$311.35 to $333.89
Indiana[98]		$402.97 (Planned) $408.77 (Residential) $463.42 (Unexpected)
Ohio[99]	$7.50 (1:1 Individual Provider) $20.83 (1:1 Agency)	$90.00 (1:1 Individual Provider) $250.00 (1:1 Agency)
Wisconsin[100]	1:1 Individual Provider: Care Level 1 (low): $3.15 Care Level 2 (medium): $4.20 Care Level 3 (high): $5.25 1:1 Agency: Care Level 1 (low): $7.35 Care Level 2 (medium): $8.40 Care Level 3 (high): $9.45	1:1 Individual Provider: Care Level 1 (low): $183.75 Care Level 2 (medium): $246.75 Care Level 3 (high): $304.50 1:1 Agency: Care Level 1 (low): $425.25 Care Level 2 (medium): $488.25 Care Level 3 (high): $551.25
Wyoming[101]	$5.91 (1:1 Individual Provider) $8.23 (1:1 Agency)	$212.80 (1:1 Individual Provider) $296.37 (1:1 Agency)

approach is the use of state general revenue funds, which many states designate to support respite for youth who do not qualify for Medicaid.[37] These funds are typically distributed through state health or human services departments to local agencies and nonprofit organizations that administer respite programs. Some states also provide grants to county or community-based organizations, expanding access to respite care for families in need. For example, Connecticut reports using general revenue funds to cover all HCBS for youth with significant mental health needs.[37] As a result, youth in Connecticut who present with serious behavioral health concerns are not denied access to needed care due to a lack of insurance or financial resources; the state ensures coverage by allocating public funds specifically for children's behavioral health services.[37]

A second strategy some states use to fund respite care is providing cash subsidies directly to families, allowing families to independently arrange and pay for services that best meet their youth's needs. Minnesota offers Family Support Grants through its Parent Support Outreach Program giving families flexible financial assistance to cover respite care and other supportive services for youth with significant emotional or behavioral needs.[93]

Reimbursement Rates

Billing variations across payers make it challenging to compare respite care services across states or payor sources. Purchasers of respite include state Medicaid programs, child welfare agencies, mental health departments, public welfare agencies, and departments of education and public health, each using different funding streams and billing codes. SAMHSA outlined these complexities in their report on respite care.[7]

Billing codes for respite also vary by state and payer. While S5150 (unskilled respite care, not hospice, per 15 minutes) and S5151 (unskilled respite care, not hospice) are commonly used, their application is not consistent. These inconsistencies create challenges in comparing services and funding strategies. To facilitate cross-state comparisons, Table 3.1 was developed using the S5150 and S5151 billing codes for "unskilled respite care, not hospice."

It is important to note that states like Ohio set reimbursement rates for respite care providers based on Medicaid fee schedules and specific contract arrangements within the OhioRISE program.[59] These rates are designed to cover the cost of providing respite care in home and community settings, as an alternative to institutional care. Providers must be enrolled and contracted through the OhioRISE network to be reimbursed for respite care services, and they must meet specific standards and qualifications set by Ohio's Medicaid program. Notably, Ohio allows for a specified number of service units to be billed per day before a per diem rate applies, offering additional flexibility in how respite care is delivered and reimbursed.[59]

Recommendations for Funding and Sustaining Respite Care

Sustaining and expanding access to high-quality respite care for youth with behavioral health needs requires strategic and diversified funding approaches. The recommendations in Table 3.2 highlight key strategies to support long-term sustainability, including maximizing Medicaid mechanisms, leveraging state and federal partnerships, and promoting innovative

Table 3.2 Recommendations and Approaches for Enhancing Access to Respite

Recommendation	Approach
Examine who is left out of current funding models	To improve the long-term funding and sustainability of behavioral health respite care, states should critically examine who is being left out of current funding mechanisms. Many existing models—such as Medicaid waivers, CHIP expansions, or child welfare-based funding—are only accessible to low-income families or those formally involved with public systems. This often excludes middle-income families, who may not qualify for public programs yet cannot afford to pay out of pocket.
Include respite in Medicaid and commercial insurance plans	Expand the amount of Medicaid and commercial health insurance plans that include behavioral health respite as a healthcare service.
Enhance advocacy for EPSDT and Medicaid expansion	Collaborative efforts among state health agencies, school systems, and advocacy groups can maximize the use of EPSDT benefits to fund respite care.
Expand state funded respite care and general revenue allocations	States should supplement federal funding with direct appropriations for behavioral health respite care. Developing targeted policies and line-item funding in state budgets ensures greater reliability and sustainability for respite care programs.
Innovative payment models	Value-based payment models can incentivize providers to deliver respite care while reducing costly hospitalizations and emergency services for this population. States should explore Section 1115 demonstration waivers to pilot innovative funding models that integrate respite care into holistic service delivery. This approach can address broader determinants of health while improving access to and sustainability of respite care services.
Promote partnerships between Medicaid and education systems	Given the significant number of youth with mental health challenges served through schools under the Individuals with Disabilities Education Act, states could foster stronger interagency collaboration to co-fund services like respite care.
Integrated funding streams	States should consider adopting or expanding flexible, multi-agency funding models like Ohio's MSY Program to support youth with complex behavioral health needs and prevent custody relinquishment. To maximize the impact of such programs, states should strengthen mechanisms to coordinate and leverage local funds before accessing MSY or similar state-level funds, ensuring the program remains a true funder of last resort. Additionally, aligning Medicaid funding with other state and local initiatives—such as foster care systems—can create more comprehensive, coordinated support packages that reduce system fragmentation and better serve high-need youth and their families.

Table 3.2 Recommendations and Approaches for Enhancing Access to Respite *(Continued)*

Recommendation	Approach
Increase reimbursement rates for respite care	Establish competitive reimbursement rates, particularly for overnight care, to better reflect the true cost of services and incentivize provider participation.
Adjust service limitations to meet family needs	Review and revise state policies that impose arbitrary limits on respite hours or frequency, ensuring service availability aligns with family needs.

funding models. These approaches emphasize the importance of aligning funding with family needs, reducing administrative barriers, and ensuring adequate provider reimbursement to support the delivery and growth of flexible, family-centered respite care.

Resources

- ARCH Tools for Sustainability Financing Strategies
- ARCH Tools for Collaboration Building and Sustaining Partnerships
- ARCH State Policy Resource Guide

SECTION 4:

Best Practices and Guidelines for Behavioral Health Respite Care

Many families express hesitancy in using respite with concerns often centering around the trustworthiness and competence of respite providers, with families worried about their youth's safety, the adequacy of care and monitoring, and whether their youth will have a positive experience.[27] The flexibility of respite models, settings, and provider qualifications allows programs to be tailored to meet diverse family needs, though this adaptability can make it challenging to establish a single standardized approach. Therefore, it is essential to identify best practices and guidelines that can right size care while remaining adaptable to the family and youth's needs.

This section reviews existing guidelines, standards of care, and best practices for behavioral health respite. It will highlight exemplar programs that are innovators and leaders in providing high-quality care. Furthermore, this section will delineate features of a high-quality episode of behavioral health respite care, offering practical insights into how these principles are applied in real-world settings. For the purposes of this section, we will discuss both planned and emergency respite care (also referred to as crisis respite care), highlighting the unique considerations and best practices for each setting. This section seeks to provide a comprehensive understanding of how to deliver effective, trustworthy, and family-centered behavioral health respite care.

Overarching Principles for Behavioral Health Service Delivery

Respite care is a vital part of the broader SoC for youth with behavioral health needs. To strengthen behavioral health services in Arizona, the state held community listening sessions to establish twelve core principles that all youth mental health service providers should follow.[102] Many of these principles align with the principles of Wraparound;[103] however, respite can be provided within the Wraparound model or as a stand-alone service.

Regardless of the approach, these principles—emphasizing individualized, family-centered, and strengths-based care—apply to all respite care. Table 4.1 below presents an exemplar state, Arizona's, guiding principles for all youth's behavioral health service delivery, along with aligned practices.[102] For a detailed overview of the guiding principles, associated practices, and real-world examples illustrating their application, please see the Appendix Table 2.

4.1 Principles and Practices for Children's Behavioral Health Service Delivery[102]

Guiding Principle	Key Practices
Collaboration with the child and family	Family and youth are involved in decisions; given service options; informed to make choices
Functional outcomes	Goals defined by family; strengths-based outcomes assessed; plan revised as needed
Collaboration with others	Team includes chosen family/community members; goals are set and problems solved collectively
Accessible services	Barriers like transportation addressed; families educated on rights and processes
Best practices	Trauma-informed, person-centered, strengths-based care; provider seeks consultation
Most appropriate setting	Services provided in inclusive, least restrictive environments, like home or community
Timeliness	Services provided promptly; providers escalate if delays occur
Services tailored to the child and family	Service intensity based on strengths and needs; child/family seen as experts
Stability	Whole-person care; proactive crisis planning; consistent service delivery
Respect for child and family's unique cultural heritage	Planning incorporates cultural values, beliefs, and language
Independence	Supports encourage skill-building and decreasing reliance on formal services
Connection to natural supports	Families supported in connecting to sustainable community resources

Table 4.2 Examples of Individual Respite Settings

State	Child or relative home	Community setting	Respite providers home	Licensed foster home/ Therapeutic foster home	Crisis stabilization unit/ Crisis receiving center/ Emergency shelter	Independent living agency	Group home	Camp	Licensed mental health setting/ respite facility	Residential treatment center
Idaho[64]	✓	✓		✓					✓	
Kansas[53]	✓	✓		✓	✓					
Louisiana[53,66]	✓	✓		✓	✓	✓				
Michigan[45]	✓	✓		✓			✓	✓	✓	
Ohio[108]	✓	✓	✓	✓						
Texas[48]	✓		✓	✓				✓	✓	✓
West Virginia[55]	✓	✓								
Wyoming[51]	✓	✓								

Types of Respite Care and Providers

Respite care is provided through a variety of organizations, and its availability varies by state. Respite can be provided by trained providers through community-based programs, agency-employed staff, and/or facility-based settings (such as residential or treatment centers). Another form of respite care comes from "self-directed" programs, or in other words, the families are able to hire their respite care provider; this form of respite care is utilized by more than half of families receiving services.[104]

Despite the diversity of provider types, there is limited research comparing outcomes across these different delivery models. Caregivers often report using a mix of formal (billable, professional services) and informal (support from friends, relatives, or community members) respite care.[105] This blending of support types can complicate efforts to evaluate their distinct impacts. Still, both forms are seen as valuable in enhancing caregivers' ability to engage in self-care and sustain long-term caregiving roles. In some cases, families are unable to identify informal support networks, underscoring the critical role of formal respite.[106]

Although guidelines for delivering high-quality respite care exist, there is no consensus on the most effective model—particularly for youth with behavioral

health needs. The choice between in-home and out-of-home care is best guided by the preferences and needs of the family, in accordance with the SoC principle of family voice and choice.

Current research on respite delivery methods remains limited. Most available studies focus on the distinction between formal and informal care, while fewer explore differences between in-home and out-of-home services.[24] In one study, out-of-home and center-based care did not lead to improvements in youth mental health.[107] Conversely, another study found that using both formal and informal supports together yielded significantly better results than either approach alone.[24] Regardless of the model, families consistently identify timely and reliable access to respite care as a major barrier.[12] Expanding all forms of respite—across settings and provider types—will be essential to reducing caregiver burden and improving family well-being.[21,29,33]

In-home respite typically involves care provided either in the youth's home or the home of a trained respite provider. Out-of-home respite may take place in community spaces or institutional settings. Table 4.2 summarizes sample state guidelines outlining where respite can occur for youth, including both in-home and out-of-home options. Most commonly, services are delivered in family homes, relatives' homes, or community settings, while residential treatment centers are less frequently utilized. It is important to note that the examples in Table 4.2 are not exhaustive and may vary by state.

Guidelines for Planned Respite

Numerous guidelines for planned respite are available from various organizations and state-level authorities, providing comprehensive frameworks for delivering quality respite care (see Resources). The ARCH National Respite Network and Resource Center established National Respite Guiwdelines that serve as overarching best practices for high quality respite.[109] While they are not specific to behavioral health, these guidelines serve as a foundational resource for respite providers, healthcare professionals, human service agencies, and policymakers. The guidelines presented below offer a summary of guiding principles applicable to all respite models and services, functioning as a checklist for providers to evaluate and enhance their service delivery.[109]

Components of Planned Respite Checklist

Family Involvement

- ☐ Inclusion of family caregivers in all aspects of respite service delivery.
- ☐ Regular needs assessments and informal discussions to identify caregiver needs or preferences.
- ☐ Active participation of caregivers in service design, planning, and evaluation of respite services.
- ☐ Clear definition of family roles and responsibilities within respite services.
- ☐ Family-centered approach that builds on the strengths and resources of families and considers the needs of all family members (including siblings).
- ☐ Emotional support and reassurance for caregivers regarding the safety and well-being of their child in care.
- ☐ Respite services are designed to be accessible early on in the caregiving journey and provided at regular, therapeutic intervals to support the caregiver's health and well-being.
- ☐ Caregivers maintain the ability to check in with their loved ones during respite care to ensure peace of mind.
- ☐ Family caregivers are encouraged to make the most of their respite time by engaging in activities that promote relaxation, personal growth, and overall well-being.
- ☐ Respect for caregiver preferences related to service delivery, including location, hours, and activities are accommodated as appropriate.

Components of Planned Respite Checklist
(continued)

Family Diversity

- ☐ Recognition and respect for each family's unique characteristics, including race, ethnicity, language, composition, socio-economic status, and religious beliefs.
- ☐ Incorporation of cultural and linguistic needs into respite services.
- ☐ Support for diverse family structures such as grandfamilies, foster and adoptive families, single-parent households, and LGBTQ+ families.

Privacy and Confidentiality

- ☐ Strict adherence to privacy and confidentiality standards, including HIPAA regulations.
- ☐ Limit information requests to what is necessary for service provision and evaluation.
- ☐ Respect for the care recipient's personal space and possessions.

Safety

- ☐ Ensure a clean, safe, and hazard-free environment that allows the child to explore the respite setting.
- ☐ Children are continuously supervised.
- ☐ Adherence to protective services requirements to prevent abuse.
- ☐ Secure exits to prevent wandering and ensuring the safety of all individuals.

Individualized Care

- ☐ Treat each child as an individual, recognizing unique strengths and needs.
- ☐ Avoid grouping based solely on disability or diagnosis unless necessary for medical supervision.
- ☐ Respect for family routines and preferences.
- ☐ Support for social development within the context of the individual's cultural and family background.

Components of Planned Respite Checklist
(continued)

Appropriate Activities

- ☐ Provide activities that enhance physical, cognitive, emotional, cultural, spiritual, and social well-being.
- ☐ Encourage self-expression and participation in developmentally appropriate physical and social activities
- ☐ Minimize passive activities like television viewing and promoting interactive, creative engagements.
- ☐ Maintain structured schedules and routines to create a secure environment.
- ☐ Ensure that individuals in mixed-age groups engage in activities suited to their developmental level, offering challenges and opportunities that foster self-esteem and prevent boredom.

Flexibility of Care

- ☐ Offer a flexible continuum of care to meet varying family needs.
- ☐ Availability of care during different times (day, evening, overnight, extended periods).
- ☐ Provide both in-home and out-of-home care options as well as planned and emergency.
- ☐ Ensure families can choose and, if necessary, change providers.
- ☐ Accommodate siblings when appropriate and allowing personal items (e.g., stuffed animal) in out-of-home settings to createa familiar environment.

Respite Care Activities

There are few specific guidelines on activities that should be conducted during respite. While many states regulate the duration of respite (e.g., no overnight stays) and provider qualifications, there are limited directives regarding the activities and structure of respite care. Table 4.3 presents a sample of states that provides guidance on the types of content and activities that are allowed during respite.

Table 4.3 Behavioral Health Respite Care Activities from Exemplar States

State	Respite Content
Kansas[53]	Normal activities of daily living, such as in-home support, after-school or nighttime care, and transportation to and from school, medical appointments, or other community-based activities.
Louisiana[66]	Communication and coordination with the family or legal guardian. Additionally, collaboration with other child-serving systems should occur as needed to support treatment goals.
Ohio[108]	Assistance with activities of daily living, transportation, and support in home and community-based settings.
West Virginia[55]	Facilitate participation in age-appropriate community activities, such as shopping, volunteering, and attending concerts.
Wyoming[69]	Focus on social and behavioral skill-building, such as learning how to interact with others, engaging in positive recreation, and practicing following directions.

Guidelines for Emergency or Crisis Respite

Crisis or emergency respite care plays a critical role in providing immediate support to families and youth experiencing behavioral health crises. This type of care is designed to stabilize situations quickly, prevent unnecessary hospitalizations, and support the long-term well-being of youth and their families. SAMHSA envisions crisis services encompassing three core components to address the full spectrum of behavioral health crises:[110]

Someone to Contact: 988 Lifeline and Other Behavioral Health Lines
Someone to Response: Mobile Crisis and Outreach Services
A Safe Place for Help: Emergency and Crisis Stabilization Services

SAMHSA outlines national guidelines and overarching principles to guide the development and sustainment of Behavioral Health Coordinated System of Crisis Care.[110] For a summary of the guidelines and associated practices illustrating their application, please see the Appendix Table 3.

Innovative Respite Programs

Highlighted below are innovative respite programs from across the country that are addressing critical community needs in creative and effective ways. Each of the featured organizations has presented their programs at the ARCH National Respite Network and Resource Center's annual conference, showcasing promising practices in respite care.

Children's Home Network Caregiver Support Services (Florida)

The Children's Home Network in Tampa, Florida, runs a comprehensive Caregiver Support Services (CSS) program that uses respite care as a key prevention tool to reduce child abuse and neglect—particularly among families raising youth with disabilities or behavioral challenges.[111] CSS provides short-term support (typically 3–6 months, with possible extensions) through a Wraparound approach that includes clinical assessments, family navigation, aftercare, support groups, and practical tools such as budgeting support and skill-building for caregivers of youth up to age 14.[111] A unique feature of the program is that caregivers are integrated into the organization itself—supporting intake, outreach, and continuity of care—which helps build trust and consistency.

Families can identify trusted individuals to serve as respite providers, who are then vetted, trained, and hired as 1099 contractors. In addition to these community-based supports, full- and part-time staff offer in-home or center-based respite, with oversight from supervisors who shadow providers and match families based on cultural and linguistic needs (staff speak languages including Spanish, Greek, Vietnamese, and American Sign Language). Since December 2024, families have reported[112]:

97.7% reduction in parental stress

98% increase in family support

92% increase in family protective factors

Notably, no youth in the program have required removal from their families, underscoring the model's strong potential as an evidence-based approach to family preservation.

Claude Moore Precious Time (Virginia)

Claude Moore Precious Time partners with James Madison University's College of Health and Behavioral Studies to connect nursing and health and human service students with families of youth with special healthcare needs including youth with behavioral health challenges.[113] Since 2005, the program has supported 237 families and provided nearly 40,000 hours of free respite care—all with the goal of promoting healthy outcomes for families and preparing future healthcare professionals.[113] Each semester, students provide up to twenty hours of individualized, trust-based respite care, offering caregivers a break while youth engage in play, socialization, and personal attention. The program extends its impact to underserved rural communities, ensuring families in need have access to support.[113] The program reports that:[114]

95% of caregivers reported feeling like they had a break

95% felt their youth benefited from student visits

100% said students showed openness to learning from their families

Caregiver to Caregiver Respite Network (Massachusetts)

The Caregiver to Caregiver Respite Network (C2C) is an innovative, community-driven model designed specifically for families of youth and youth with mental and physical disabilities, extending support through age 26.[115] Rooted in shared experience, C2C uniquely offers respite care provided by parent peers. Caregivers are matched based on the youth's needs, family location, and cultural and language background, ensuring tailored and

culturally responsive support. C2C staff conduct background checks, orient families, and manage an online learning platform to support safe and informed participation. Central to the C2C model is the principle of reciprocity—caregivers are encouraged to exchange care by watching one another's youth for a set number of hours. While private pay and personal care attendant hours are accepted, this reciprocal model strengthens caregiver networks and exemplifies a highly innovative approach to peer-based respite.

Sibshops (Oklahoma)

Sibshops is a research-based, family-centered program designed to meet the often-overlooked needs of siblings of youth with disabilities.[116] Recognizing that siblings frequently share the longest-lasting relationships—and may eventually take on caregiving roles—Sibshops fills a critical gap in family support services. Sibshops provides engaging, peer-driven workshops for siblings of youth with emotional, behavioral, and developmental needs, serving families with youth from birth through age 21. While the program offers essential respite care for the youth with a disability, its signature focus is on supporting neurotypical siblings through structured, fun, and emotionally affirming experiences.

Sibshops can operate using a trifecta model of support: while siblings receive peer support, the youth with a disability benefit from respite, and parents engage in community support groups—ensuring that the entire family unit is cared for. In addition, they offer a unique sibling camp, where siblings attend alongside their sibling with a disability, fostering inclusive bonding experiences and family connection. They report that:

95% of youth report a positive shift in how they feel about their siblings

95% of youth learn new coping strategies

Innovative Respite Programs in Ohio

In Ohio, the Child and Family Health Collaborative of Ohio developed an innovative respite care program in partnership with CareSource, an Ohio Medicaid plan. A 6-month pilot in 2021 showed the following results:[32]

88% reduction in acute service usage

54% decline in emergency department visits, resulting in a 59% decrease in ED spending

67% reduction in inpatient services, leading to 77% drop in inpatient costs

36% decrease in day treatment services, with 35% reduction in associated expenses

The Child and Family Health Collaborative of Ohio has since expanded the respite program statewide. To gain a deeper understanding of how respite care is implemented on the ground, interviews were conducted with three providers in Ohio: Quality Moments, Cadence Care Network, and the National Youth Advocate Program.

Quality Moments

Founded in 2022, Quality Moments is an Ohio-based community mental health agency dedicated to serving some of the state's most vulnerable families. Initially created in response to helping foster care agencies access timely mental health services, Quality Moments provides comprehensive support—including case management, therapy, and respite. A key differentiator of Quality Moments is their rapid response—every referred youth is seen within a week, ensuring families get the immediate support they need. Respite providers take youth into the community for individualized outings, fostering positive experiences while giving caregivers a much-needed break.

The organization emphasizes a relational approach—not only in their work with youth and families but also in their employee culture. Quality Moments is

deeply responsive to community needs, demonstrated by their development of group respite. When Franklin County Juvenile Court saw a troubling rise in young boys getting into legal trouble, Quality Moments pioneered a boxing-based group respite program. This initiative provided structured, positive engagement for youth, successfully preventing arrests over the summer. Now expanding in partnership with Franklin County Juvenile Court, the program exemplifies how community-driven respite can stabilize placements and strengthen families.

Cadence Care Network

Cadence Care Network has provided behavioral health respite in Ohio for nearly a decade, focusing on planned, community-based support for youth with high behavioral needs and caregivers lacking natural supports. Serving about 200 youth annually—typically once per week per youth—the program is in high demand and often maintains a waitlist. Cadence has built a strong workforce by engaging college students in related fields, offering them valuable hands-on experience that frequently leads to full-time roles in behavioral health.

A key to their success is its thorough training model and commitment to quality. New staff undergo extensive training and shadow experienced workers before working independently. A detailed respite manual and group supervision foster consistent, high-quality care. Cadence collaborates closely with care management entities and partners with local organizations to help families build lasting community connections beyond respite.

National Youth Advocate Program (NYAP)

The National Youth Advocate Program (NYAP) launched its behavioral health respite program in 2021, initially focusing on youth with SED and later expanding under OhioRISE to serve a broader population. This expansion allowed NYAP to provide both hourly respite care, offering short-term relief for caregivers, and overnight respite, allowing for more extended relief. One of the program's key innovations is its use of treatment foster homes for overnight respite care, ensuring that youth with complex behavioral health needs are cared for by trained families. These homes are selected based on the specific needs, preferences, and routines of the youth, and the program includes a structured intake process to ensure smooth transitions for the youth.

NYAP stands out for its adaptive, inclusive approach—recruiting and training staff based on the specific needs of the youth they serve, including youth with co-occurring behavioral and developmental challenges. The program emphasizes trauma-informed care, crisis de-escalation, and cultural humility, with robust supervision and on-call support. NYAP also prioritizes data-driven improvement through continuous quality improvement, tracking outcomes such as family preservation, reduced need for higher-level care, and prevention of abuse or neglect, ensuring both quality and accountability in service delivery. In 2024, they report that over 96% of families are free of substantiated abuse and neglect and over 85% of youth remain or reunify with family or kin.[117]

Resources to Enhance Best Practice Uptake

The challenge with best practices is effectively increasing their uptake and implementation. We must focus on proven methods that support adoption and integration into real-world settings. The three resources reviewed below—support from the Family-Run Executive Director Leadership Association, communities of practice, and the Extension for Community Healthcare Outcomes (ECHO) model—offer valuable strategies for achieving this goal.

FREDLA Reinforcing the Family Mosaic

The Family-Run Executive Director Leadership Association (FREDLA) offers a comprehensive suite of tools to support high-quality respite care. This includes technical assistance for program development, training based on nationally recognized best practices, a step-by-step process for matching providers with families, and a best-practice checklist.[118] Modeled after SoC principles, FREDLA's training integrates with team-based planning, including High Fidelity Wraparound. Their resources—

shaped by insights from youth, parents, providers, and policymakers—are adaptable to state-specific service descriptions and policies.

Communities of Practice

Establishing a Community of Practice (CoP) for behavioral health respite care can enhance collaboration, knowledge sharing, and service improvement among key stakeholders. A CoP is a group of individuals who share a common interest or profession and come together to learn, problem-solve, and innovate.[119] Through regular interactions, members can exchange best practices, address common challenges, and develop strategies that enhance the quality of respite.

The CoP should focus on creating actionable resources such as training materials, toolkits, and policy recommendations that can be used to improve respite care practices. By forming a CoP, stakeholders can build a strong network of support, foster innovation, and improve service delivery for youth and families in need.[119] This collaborative approach will not only strengthen professional development but also contribute to the advancement of policies and resources that enhance respite care on a broader scale.

ECHO Model (Extension for Community Healthcare Outcomes)

Organizations can adopt the ECHO Model to build a CoP. ECHO is a structured tele-mentoring approach that connects experts with practitioners to disseminate best practices, enhance professional learning, and improve service outcomes. Originally developed to expand hepatitis C treatment,[120] the model has since been widely applied in healthcare, education, and behavioral health. Unlike telemedicine, which facilitates direct provider-to-patient interactions, ECHO fosters an "all teach, all learn" environment where participants engage in case-based learning, peer mentorship, and ongoing collaboration.[121]

Key principles of the ECHO Model include leveraging technology to create virtual learning communities, sharing best practices to improve service delivery, using case-based learning to address complex issues, and monitoring outcomes to assess impact.[121] Inspired by medical residency rounds, ECHO sessions involve participants presenting real, anonymized cases to specialists and peers for discussion and recommendations. This interactive format helps refine knowledge through a local lens and supports continuous learning beyond traditional webinars or one-time trainings. Studies indicate that participation in ECHO Networks enhances professional knowledge, reduces isolation, and improves retention among practitioners.[122]

Recommendations for Enhancing Best Practices in Respite Care

Ensuring access to high-quality, flexible respite care is essential for supporting youth with emotional and behavioral challenges and their families. Effective respite provides relief for caregivers while fostering positive experiences for youth. The following recommendations highlight key strategies to improve respite care, emphasizing family voice and choice, trust-building, early intervention, diverse care models, collaboration, and quality assurance. By implementing the approaches in Table 4.4, respite providers can better meet the needs of families, reduce crises, and create a more supportive care network.

Resources

- Adopt US Kids Creating and Sustaining Effective Respite Services: Lessons from the Field
- Arch National Respite Guidelines: Guiding Principles for Respite Models and Services
- Children Now Reimagining Respite Care for Children and Youth in Foster Care
- Family-Run Executive Director Leadership Association Reinforcing the Family Mosaic
- Project ECHO
- SAMHSA National Guidelines for Child and Youth Behavioral Health Crisis Care
- Texas Building Safety and Environmental Health Checklist
- Youth Respite Policy in Oregon

Table 4.4 Recommendations and Approaches for Best Practice Uptake

Recommendation	Approaches
Choice and flexibility[36]	• Youth and families emphasize the need for flexibility in respite care. • Youth desire more agency in selecting programs that suit their circumstances, preferring either solo settings or group environments with peers facing similar challenges. • Families should have a wide array of respite options, including in-home and out-of-home care, with culturally competent providers available to meet diverse needs.
Building trust and relationships[21]	• If using a known provider isn't possible, agencies should facilitate meetings between youth, caregivers, and new providers to build familiarity. • Maintain open communication to ensure providers understand the youth's routines, needs, and preferences.
Early and preventative use of respite[21]	• Encourage families to use respite care before they reach a crisis point, fostering familiarity with the process and providers. • Increased programming for drop-in centers, peer supports, and mentorship can expand youth-initiated respite opportunities.
Expanding respite models and accessibility[123]	Broaden the delivery models of respite care, incorporating innovative approaches such as: • **Host family respite** – Families in the community provide respite care in their homes, offering a safe and supportive environment. Can be short-term or recurring, building relationships between the respite provider and the youth. • **Mobile respite care** – Brings respite directly to families in rural or underserved areas. Staffed vans or mobile units travel to different locations to provide structured activities and caregiving support. • **Shared respite care** – Parents and caregivers form cooperative respite groups, taking turns caring for each other's youth. • **Respite embedded in schools** – After-school programs incorporating respite care. Provides structured, supervised environments with social engagement opportunities.

Table 4.4 Recommendations and Approaches for Best Practice Uptake *(continued)*

Recommendation	Approaches
Strengthening systems and collaboration[21]	• Establish collaboratives (e.g., CoP, ECHO) to share best practices and address common challenges. • Maintain a centralized resource hub with guidance on respite care and examples of effective practices. • Respite systems must address service gaps and barriers, incorporating feedback from families to drive program improvements. • Collaboration among families, stakeholders, agencies, and community partners is essential for effective respite systems.
Ensuring quality and safety[109]	• Respite providers should receive case plans to ensure safety, allowing providers to understand a youth's needs, anticipate risks, and provide individualized support. • Caregivers should be empowered to select, hire, and train competent providers, with support mechanisms in place to assist in this process. • All respite must be high quality, ensuring the safety and well-being of youth, with continuous evaluation and improvements based on family feedback.
Coordinate respite with broader family support services	• Respite programs should serve as gateways to a comprehensive network of caregiver supports, extending beyond short-term relief to include connections to vital services such as transportation, therapy, early intervention, education, and financial assistance. • The Tennessee Caregiver Coalition offers a wide array of supports including caregiver support groups—both general and culturally specific groups such as one tailored for Black caregivers—along with educational events, emergency respite, and community-building activities.

SECTION 5:

Training, Recruitment, and Qualifications for Respite Care Providers

Respite care can take different forms depending on the needs of the youth and family, as well as the available resources in the community. It may be delivered by natural supports, such as extended family members or trusted individuals in the youth's network, or it may be provided in structured settings, such as licensed facilities or specialized respite programs. Each model of respite care has strengths and presents unique challenges and considerations for recruitment, training, and provider qualifications.

Effective training and recruitment strategies must recognize the diversity of respite care delivery and ensure that providers—whether they are family members, community-based caregivers, or facility staff—are equipped with the skills and knowledge needed to support youth with behavioral health needs. This section outlines key recommendations for strengthening the workforce by establishing appropriate qualifications, improving training programs, and implementing effective recruitment strategies tailored to the different types of respite care.

Provider Qualifications

Minimum qualifications for behavioral health respite providers vary by state, but several common elements emerge. Most states require providers to be at least 18 years old and have a high school diploma or GED, though some states allow equivalent experience or education. Background checks—including screenings through youth and adult abuse registries—are commonly required and typically conducted on a regular schedule, ranging from monthly to annually, depending on program policies and state regulations. States such as Michigan require providers to have specific training or demonstrated competencies in areas like first aid, recipient rights, or working with individuals with disabilities or SED.[45]

Some states include unique criteria. For example, Louisiana require providers to be a certain number of years older than the youth they serve[124] and Michigan mandates providers be trained in individual service plans and be affiliated with a certified agency or family-directed voucher program.[45] New York specifies different age requirements for daytime (18+) and overnight (21+) care and emphasizes experience with youth with SED.[125] Wyoming additionally requires valid auto insurance for those transporting youth.[68] These varying standards reflect differing priorities around provider preparedness, safety, and alignment with state systems. Appendix Table 4 presents publicly available minimum qualifications for a sample of states.

Referral Process and Matching Families with Providers

There is a lack of updated recommendations for best practices in recruiting respite care providers.[126] Some states, such as Delaware, have created state-wide organizations to assist in the coordination of respite for families, including recruitment, training to improve quality and retention of providers, and connecting providers to families in need of services.[127] To identify a respite care provider for a family, referrals for respite care services may be secured from some type of social service delivery system (e.g., mental health agency, social and rehabilitation services, medical services, public schools), or from families themselves.[20] It is paramount that program administrators equip the provider with the training required to meet the needs of specific families receiving the respite care.[20]

The Technical Assistance Center for Lifespan Respite recommends that families first match with a provider on paper based on shared values and training relevant to the family and youth's needs. Second, it is recommended that the potential respite provider spend time with the youth on a trial basis to gauge

the success of the match. Third, based on the trial experience and the perceptions of the caregivers, the provider is formally matched to the family.[20]

Variability in Training Requirements

Training requirements for respite providers vary widely but generally include CPR and first aid certification, crisis management, and specialized training in working with youth with behavioral health needs. Most states require CPR and first aid certification, and a growing number require crisis intervention training. Several states emphasize trauma-informed care, de-escalation strategies, and safety planning to ensure providers are equipped to support youth in crisis. Some states, including New York[125] and Wyoming[68], require providers to complete specific respite training programs approved by the overseeing agency. Additionally, states like Texas and West Virginia incorporate training on Wraparound services, cultural competency, and compliance with policies like HIPAA and abuse reporting.[55] Table 5.1 provides the minimum training requirements from a selection of states.

Table 5.1 Selected States Respite Provider Minimum Training

State	Minimum Training
Idaho[64]	• Respite training by Magellan Healthcare • CPR certification
Kansas[53]	• CPR certification • First aid training • Crisis prevention/Management (example: Crisis Prevention Institute, Mandt, etc.) • Population online training for community-based services or child support services • Respite care online training (curriculum approved by operating agency) • Community based services or child support services core online training
New York[125]	• Complete the Office of Mental Health's (OMH) Respite Curriculum or one of the following approved training programs: Rest A Bit, Parenting Skills Training, Model Approach to Partnerships and Parenting (MAAP), or Therapeutic Crisis Intervention. Individuals who completed an OMH-approved alternative curriculum, including the Individualized Care Model before January 2008, are not required to complete the OMH Respite Curriculum • Respite workers must receive training in safety in the home and community provided through their agency • Respite staff must be trained in the implementation of the Plan by the licensed professional
Ohio[108]	• First aid certification • Trauma-informed care practice training • De-escalation strategy training (only applies if serving youth with behaviors that pose safety concerns to themselves or others)

Table 5.1 Selected States Respite Provider Minimum Training *(continued)*

State	Minimum Training
New York[125]	• CPR certification • First aid certification • Crisis and safety planning • Critical incident reporting • Health insurance portability and accountability act (HIPAA) • Introduction to Wraparound • Reporting of abuse, neglect, and exploitation • Restraint and restrictive intervention • Service documentation • YES waiver training
West Virginia[55]	• Crisis intervention • Emergency procedures • Trauma-informed care • Cultural competency and person-centered planning • Wraparound facilitation principles • CPR • Infectious disease control • Member rights
Wyoming[68]	• CPR certification • First aid certification • Wraparound training • Magellan Healthcare's respite learning path training • Other trainings required by care management entity

Best Practices in Training

Currently, there are no federal training requirements for respite care providers, and only a few states have specific training mandates.[128] ARCH outlines essential competencies for respite providers,[20] including:

- Overview of respite services and family caregiving issues
- Caregiver stress management
- Confidentiality and communication skills
- Disability awareness and respect for care recipient independence
- Youth and adolescent development
- Conditions commonly encountered by respite providers
- Effective ways to work with families of youth with mental health challenges and/or families in crisis
- Family diversity (cultural, ethnic, racial, linguistic, family composition)
- Planning developmentally appropriate activities and maintaining routines
- Program policies, emergency procedures, and infection control
- Medication administration and health-related tasks
- Crisis intervention and behavior management

More specific training materials have been produced nationally and domestically. The National Academy for State Health Policy in collaboration with ARCH and the Respite Care Association of Wisconsin developed a competency-based online respite provider training curriculum, called the "National Respite Care Provider Training".[129] This free training is completely online and completed at the learner's own pace. It was designed for providers ranging from entry level to experienced providers. The training is based on the National Respite Care Provider Training Core Competencies.[130] There are two key resources:

- National Respite Care Provider Training (NRCPT) Toolkit - an agency or organization-level guide to recruitment, hiring, and training respite care providers.
- National Respite Care Provider Training - an individual-level training for respite care providers. The training is asynchronous and available online in English or Spanish.

There are additional trainings for consideration. For example, Magellan Healthcare is a behavioral healthcare agency which provides training on respite care.[131] Another program example, which has developed an abundance of strategies for workforce retention and training is Maine's program "Respite for Me".[132] Other recommended models include Idaho's Respite Care Provider Training Manual, Safeguards Respite Training Certificate,[133] and the Family-Run Executive Director Leadership Association (FREDLA)'s "Reinforcing the Family Mosaic" respite care training.[118]

Recommendations for Strengthening the Respite Care Workforce

To build and sustain a high-quality respite care system for youth and families, intentional strategies are needed to strengthen the respite workforce. Table 5.2 outlines key recommendations across several domains, including provider training and support, recruitment and workforce development, partnerships with educational institutions, cultural competency, provider compensation, and administrative processes. These recommendations emphasize the importance of preparing respite providers with the necessary skills, ensuring diverse and family-centered care, and creating supportive systems that promote workforce retention and quality service delivery.

Resources

- Administration for Community Living Direct Care Workforce Strategy Center
- ARCH A guide for using the cultural and linguistic competence assessment for respite organizations
- Magellan Healthcare Short-Term Respite Training
- Maine's "Respite For Me" Care Partner Supports
- Louisiana's Respite Care Provider Training Manual
- SafeGuards Respite Services Training Certificate
- FREDLA's "Reinforcing the Family Mosaic" training
- National Respite Care Provider Training (NRCPT) Toolkit
- National Respite Care Provider Training
- National Direct Service Workforce Resource Center's Direct Service Workforce Training Resources Toolkit: A Companion Resource
- National Academy For State Health Policy's Respite Care Provider Training Webinar: Lessons from the States
- Respite Care Association of Wisconsin Student Respite Toolkit

Table 5.2 Recommendations and Approaches to Support the Respite Workforce

Recommendation	Approaches
Provider training & support	• Consider adopting or adapting a developed national training for the respite workforce (e.g., ARCH, FREDLA, Magellan). • Ensure that respite providers meet essential qualifications, including age requirements, background checks, and relevant experience to deliver high-quality care and promote safety for children and families. • Ensure all respite providers, whether paid or volunteer, receive ongoing supervision, support, and feedback on their performance. • Include shadowing opportunities for potential respite providers to ensure a good fit before committing to the role. • Conduct group supervision for peer-to-peer learning and support. • Provide comprehensive training in key competency areas, including crisis intervention, trauma-informed care, cultural competency, client rights and confidentiality, and behavioral health issues. • Integrate both behavioral health professionals and family members in the design and facilitation of training programs to ensure providers understand both general behavioral health needs and specific child/family dynamics.
Recruitment & workforce development	• Build the workforce through innovative recruitment strategies and partnerships, including outreach to a diverse array of professionals such as behavioral health providers, school staff, youth and families, colleges and universities, and childcare providers. • Incentivize recruitment and retention with sign-on and retention bonuses. • Recruit providers from diverse cultural, racial, and linguistic backgrounds, including various family structures (e.g., grandfamilies, foster/adoptive families, LGBT families). • Recruit providers to offer diverse role models for children and youth. • Target recruitment efforts in areas with high demand for respite care services or address transportation issues to ensure accessibility. • Promote professional development through learning collaboratives and peer support networks, fostering career growth and resource-sharing among respite care providers.
Formal partnerships with colleges and universities	• Organizations may elect to establish formal partnerships with colleges and universities. These partnerships can create structured clinical or practicum opportunities for students in fields such as social work, nursing, psychology, and counseling to gain hands-on experience. • Collaborations can include service-learning placements, internships, credit-bearing fieldwork, and training partnerships. Programs should ensure that students receive appropriate supervision, trauma-informed training, and opportunities for reflection and learning.

Table 5.2 Recommendations and Approaches to Support the Respite Workforce *(continued)*

Recommendation	Approaches
Cultural competency & family-centered care	• Encourage family caregivers to identify their own respite providers, leveraging both formal and informal supports. • Ensure that respite providers are trained to meet specific family and care recipient needs, such as fluency in the family's first language or expertise in working with children.
Financial support & provider compensation	• Standardize and ensure consistency in respite reimbursement rates and worker pay, particularly to reflect the experience and type of care provided (e.g., community care vs. crisis care). • Provide respite providers with benefits like health insurance, paid sick and vacation days, and retirement packages, when possible.
Reducing administrative barriers	• Simplify and reduce the administrative burden associated with certification, paperwork, and unnecessary trainings to minimize delays and costs. • Streamline the certification process to ensure clarity and efficiency, avoiding overwhelming administrative costs that may deter respite organizations from providing services.

SECTION 6:

Evaluating Behavioral Health Respite Care

Effective evaluation is essential for ensuring that behavioral health respite programs provide high-quality support to youth and families while maintaining alignment with best practices. By systematically collecting and analyzing data, programs can drive continuous quality improvement, measure outcomes, and strengthen the program's overall impact.[134] A well-structured evaluation plan allows decision-makers to refine services, advocate for funding, and make informed choices about staffing, operations, and partnerships.[134]

While a respite care program may function smoothly on a daily basis, it may still fall short of delivering meaningful, long-term benefits. For example, a program might efficiently coordinate intakes, yet if staff do not collect data on participant needs, services provided, or follow-up outcomes, they may overlook gaps in care, unmet community needs, or deviations from evidence-based practices. Further, respite evaluation should assess staff training and performance. Routine staff evaluations help identify training needs, ensure adherence to best practices, and enhance service quality.[110] High operational efficiency or high satisfaction alone do not guarantee improved well-being for those served.[135] This section focuses on evaluating respite care services and their broader, long-term impact on individuals, families, and systems. While this is not a deep dive into the science of program evaluation, it offers key considerations for program leaders, such as defining measurable goals, selecting meaningful indicators, and establishing data collection methods.

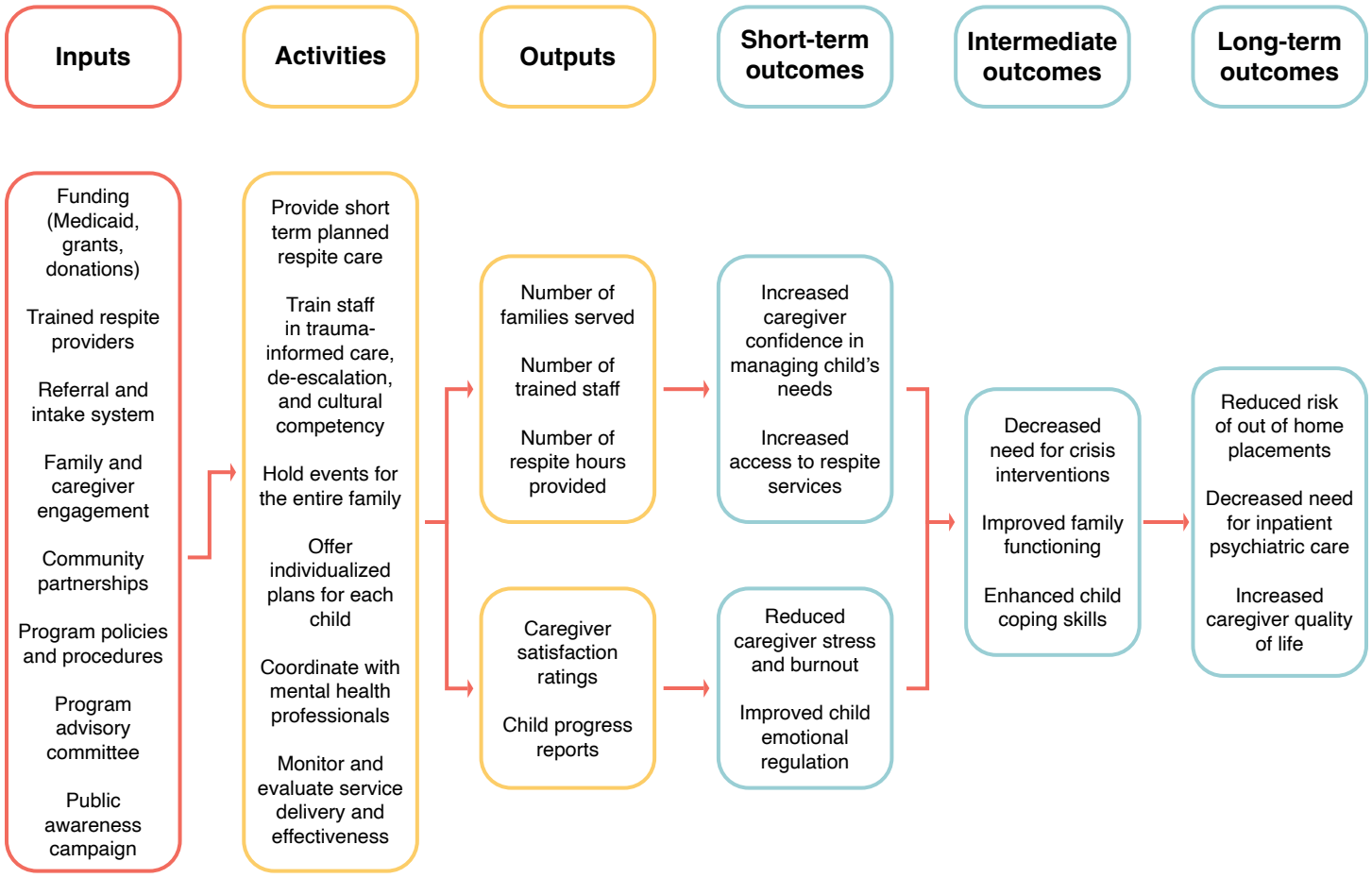
Overview of Program Evaluation

Program evaluation is a systematic process used to determine the effectiveness and efficiency of programs, policies, and organizations in achieving their intended outcomes.[134] By regularly collecting and analyzing data, program evaluation provides critical insights that inform decision-making, guide improvements, and ensure accountability. Program evaluation helps answer essential questions such as:[134]

- Are activities being carried out as planned?
- Is the program achieving its intended goals?
- Did the program directly lead to the observed outcomes?
- What other factors might be influencing the results?
- Are the appropriate resources being used effectively?

The CDC's Program Evaluation Framework provides a structured approach for designing and conducting evaluations across diverse programs and settings.[134] A cornerstone of program evaluation is a logic model which depict the relationships between a respite program's resources, activities, and outcomes.[134] The logic model provides a framework for tracking progress and measuring success. Below displays a sample logic model for respite care.

Sample Behavioral Health Respite Program Logic Model

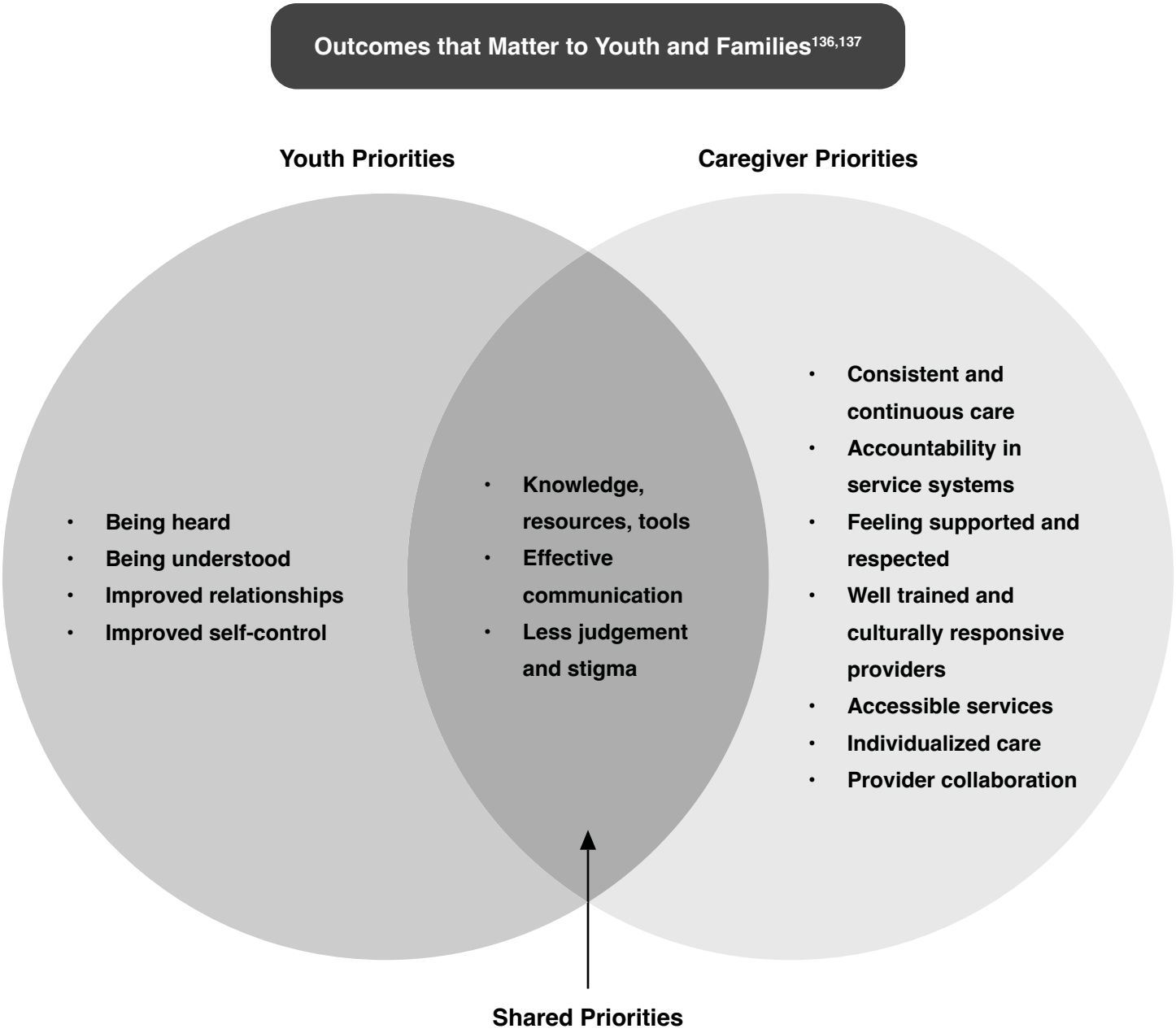


In addition, the Program Evaluation Framework Action Guide[134] serves as a practical tool for novice evaluators, offering guidance on applying the framework across various programs and settings. By following this structured approach, organizations can conduct effective, ethical, and impactful evaluations that drive program improvement and enhance public health outcomes. For a summary of program evaluation steps and activities, please see the Appendix Table 5.

Priority Outcomes for Youth and Families

A recent project funded by the Patient-Centered Outcomes Research Institute (PCORI) aimed to support the development of behavioral health services that deliver outcomes valued by families by identifying what youth, young adults, and caregivers consider most important.[136,137] The project team engaged 34 youth and young adults with behavioral health needs and 42 caregivers from six U.S. regions in two rounds of one-hour virtual focus groups.

In the initial round, participants discussed what they hoped to gain from behavioral health services for personal, familial, and parental or youth well-being, as well as the attributes of positive service experiences. While these findings are not specific to respite care, they highlight priorities that may be relevant when determining which outcomes to evaluate. Understanding and addressing these priorities can help shape services that better meet the needs of youth and their caregivers.[136,137]



Common Data Elements in Respite Evaluation

To ensure consistency and comparability across respite programs, the Common Data Elements (CDE) approach is recommended.[135] This method standardizes data collection using predefined questions and response options, allowing programs to track trends, assess effectiveness, and make data-driven improvements.[135] While primarily designed for research, CDEs can enhance respite program evaluation by enabling long term assessment and comparisons across respite models.[135]

ARCH identified CDEs for benchmarking and cross-program comparisons that broadly encompass caregiver factors, care receiver factors, respite factors and outcomes.[138] Key metrics that influence the effectiveness of respite care include service type, model specifics, frequency and intensity of respite, and implementation fidelity.[19] The amount and frequency of respite may significantly impact caregiver and youth outcomes. Additionally, the timing of initial

respite access plays a crucial role; respite received earlier in the caregiving journey may yield more lasting benefits compared to respite accessed later when caregivers are already experiencing significant stress or crisis.[19] Program evaluators should measure the amount, frequency, timing, and specific outcomes to better understand its impact on long-term well-being.[19]

Table 6.1 contains CDEs as recommended by ARCH,[138] along with reliable and valid family-focused measures. To ensure meaningful evaluation of respite care, it's important to disaggregate data—breaking it down by factors like service type, access, and outcomes across different groups. This approach helps uncover disparities, assess effectiveness for diverse populations, and improve how programs are delivered. Additionally, all the tools listed in Table 6.1 are free and easily accessible, making them practical options for integrating into program evaluations.

Table 6.1 Suggested Common Data Elements and Disaggregated Data

Domain Assessed	Measures Name	Description	Description
Family function	McMaster Family Assessment Device[139]	Measures healthy and problematic aspects of family functioning.	60 or 12 for the general functioning scale
Caregiver stress	Parental Stress Scale[140]	Measures caregivers' feelings about their caregiving role exploring both negative and positive perceptions.	18
	Zarit Burden Interview[141]	Measures the subjective burden among caregivers, particularly related to emotional, social, and financial strain.	22, 12 or 4
	Caregiver Strain Questionnaire[142]	Measures objective and subjective strain among caregivers of youth with emotional and behavioral disorders.	21
Caregiver self-efficacy	Parenting Sense of Competence Scale[143]	Measures caregivers' self-esteem, satisfaction, and efficacy in their caregiving role.	16
Caregiver well being	Family Quality of Life Scale[144]	Measures satisfaction with various aspects of family life including emotional well-being, family interaction, parenting, physical/material well-being, and disability-related support.	25

Table 6.1 Suggested Common Data Elements and Disaggregated Data *(continued)*

Domain Assessed	Measures Name	Description	Description
Caregiver mental health	Patient Health Questionnaire-4[145]	Measures symptoms of anxiety and depression.	4
	Brief Resilient Coping Scale[146]	Measures the caregivers' tendency to cope with stress in a resilient way.	4
Demographics[138]		• Age • Race and ethnicity (to identify disparities in access and outcomes) • Gender and gender identity • Socioeconomic status (income level, insurance type, employment status) • Geographic location (rural, urban, suburban) • Primary language spoken	
Caregiver and care receiver characteristics[138]		• Relationship between caregiver and care receiver (e.g., parent-youth) • Caregiver health status (physical and mental health conditions) • Care receiver primary and comorbid diagnoses (e.g., ADHD and autism) • Caregiving burden level (measured by stress, time spent caregiving, etc.) • Stage of caregiving (early vs. crisis-stage caregiving)	

Table 6.1 Suggested Common Data Elements and Disaggregated Data *(continued)*

Domain Assessed	Measures Name	Description
Service utilization data[138]		• Type of respite provided (in-home, center-based, crisis respite, etc.) • Dosage of respite (frequency, duration, intensity) • Source of respite funding (Medicaid, private pay, grants, informal supports) • Waitlist times and access barriers
Program quality and satisfaction[138]		• Caregiver and care receiver satisfaction with services • Service provider experience and retention • Fidelity of service model implementation

Exemplar Evaluation: Measuring the Impact of Respite on Families

Researchers from Vermont evaluated the short-term effectiveness of respite care for families caring for youth with emotional and behavioral disturbances through a controlled, longitudinal design.[10] Over a six-month period, researchers compared 33 families who received respite care to 28 families on a waitlist, measuring several key outcomes. Results indicated that moderate amounts of respite care led to significant improvements in key areas, such as reduced out-of-home placements, increased caregiver optimism, and lower negative youth behaviors in community settings. Outcomes and indicators are presented in Table 6.2 and may be beneficial when designing evaluation plans.

Table 6.2 Outcomes and Indicators of Behavioral Health Respite in Vermont[10]

Outcome	Indicator
Out-of-Home Placement	Measured by the number of days the child spent in out-of-home care over the six-month period.
Crisis Intervention	Tracked by the number of times families required crisis intervention from an external source.
Perceived Need for Future Support	Caregivers' optimism about managing their child's care at home was assessed using two Likert scale questions about the likelihood of needing OHP or CI in the next six months. Lower scores indicated greater confidence in continuing care at home.
Family Function	Measured using the General Functioning Subscale of the Family Assessment Device (FAD) to assess overall family health.
Caregiving Stress	Evaluated using the Impact on Family Scale, which examines financial strain, social stress, personal strain, and a sense of mastery.
General Parental Stress	Measured through an abbreviated version of the Hassles and Uplifts Scale.
Child Behaviors	Assessed using the Quarterly Adjustment Indicator Checklist, a 21-item measure of behavioral adjustment.
Respite and Mental Health Services Utilization	Parents reported on the number of respite hours received and the types of respite and mental health services accessed during the six-month evaluation period.

Measuring Cost and Economic Value of Respite

Cost savings in behavioral health systems often result from reduced reliance on high-cost services, such as inpatient psychiatric care, residential treatment, out-of-home care placements, juvenile justice involvement, and emergency medical services.[147] Respite care can demonstrate value by tracking reductions in service use, increased cost savings, and return on investment.

SAMHSA outlines key cost-utilization indicators that while designed for youth and adults in crisis, are also applicable to respite settings:[110]

- Use of emergency department, emergency medical service, and fire department services
- Inpatient hospitalization, residential treatment, group home, and other placements
- Arrests, detention, and incarceration
- School suspensions and expulsions
- Youth protection investigations, removals from the home, and foster care placement disruptions
- Decreased severity of behavioral challenges

Despite ample evidence of respite's benefits, measuring its economic value presents challenges due to inconsistent definitions, workforce shortages, and limited data collection.[135] Traditional economic evaluation methods—return on investment (ROI), cost-benefit analysis (CBA), and cost-effectiveness analysis (CEA)—each provide different insights into respite's value.[135]

To justify continued funding, cost-effectiveness and cost-benefit studies must account for context and measurable outcomes.[135] Research should evaluate whether respite prevents or reduces hospital stays, improves both caregiver and care receiver health, and ultimately lowers overall healthcare costs.[135] Since policymakers and funders prioritize economic analyses when allocating resources, a robust evaluation framework is essential to sustaining and expanding respite care services.

Return on Investment (ROI)

ROI calculates the direct financial return by comparing the net financial gain from an intervention to its cost. While useful for many financial decisions, ROI has limitations in public health contexts, where many benefits are non-monetary. For respite care, focusing solely on financial returns may undervalue its broader societal impact.

Cost-Benefit Analysis (CBA)

CBA takes a broader approach by assigning monetary values to both costs and benefits, including direct, indirect, and intangible impacts. This allows policymakers to assess whether respite's total benefits–such as improved caregiver well-being, reduced stress-related health issues, and lower institutional care costs–justify its costs. However, monetizing these benefits can be complex and may lead to underestimations.

Cost-Effectiveness Analysis (CEA)

CEA compares the cost of an intervention to its effectiveness in achieving specific health outcomes. Instead of focusing on financial returns, this method assesses the value of respite by measuring its impact on health improvements, such as reduced caregiver stress, improved mental health, and delayed institutionalization. CEA helps determine which services provide the best outcomes for their cost, even if they do not generate direct financial savings.

Dissemination of Findings

Disseminating the results of a program evaluation is critical for ensuring that findings are not only understood but also used to inform decision-making, improve services, and advocate for continued support. Transparent and accessible reporting helps stakeholders—including funders, policymakers, service providers, and families—see the impact of respite care and identify areas for growth. To reach diverse audiences, findings should be shared in multiple formats that cater to different levels of expertise and interest. Common methods include data visualizations, social media content, briefs, success stories or testimonials, newsletters, presentations and evaluation reports.[134]

Wyoming uses a unique approach to dissemination in the form of a quarterly scorecard.[148] The scorecard is an effective benchmarking tool that ensures transparency and continuous program evaluation. Their color-coded system provides a clear and immediate understanding of performance. The score card includes metrics such as: minimum contacts per family, average length of stay, engagement and implementation, and improved youth functioning. By adopting diverse dissemination strategies and ensuring transparency through tools like scorecards, program evaluation findings can drive better services, informed policy, and sustained funding for respite care.

Recommendations for Advancing Respite Evaluation

Effective respite evaluation is essential for improving service delivery, justifying funding, and strengthening support for families. By standardizing evaluation methods, addressing methodological challenges, and expanding access, respite programs can better demonstrate their impact and improve outcomes. Through rigorous evaluation and data-driven decision-making as demonstrated throughout this section and in Table 6.3, respite programs can enhance their effectiveness and long-term sustainability.

Table 6.3 Recommendations and Approaches for Respite Evaluation

Recommendation	Approaches
Standardize evaluation	• Include at least one measurable outcome for caregivers, and where possible, assess impacts on the child, families, and society. • Utilize standardized measures to ensure consistency in evaluation. • Use Common Data Elements to enhance consistency and comparability across respite programs. • Measure both short- and long-term outcomes to understand broader life-course impacts.
West Virginia[55]	• Develop strategies to measure avoided negative outcomes, such as crisis prevention and reduced out-of-home placements. • Ensure evaluations prioritize caregivers as primary beneficiaries, not just care recipients. • Implement methods to isolate the specific benefits of respite when it is part of a broader support program. • Establish consistent measures of respite “dose”, including frequency, duration, and service model.

Table 6.3 Recommendations and Approaches for Respite Evaluation *(continued)*

State	Minimum Training
Understand and expand access	• Assess how individuals learn about respite to improve outreach and accessibility. • Track units of respite provided to analyze outcomes for high vs. low utilizers. • Identify gaps in service accessibility and implement targeted outreach to underserved populations. • Consider contextual factors affecting respite effectiveness, including insurance coverage, family support, and accessibility of respite.
Cost-effectiveness and justification for funding	• Ensure cost evaluations are context-specific by considering the overall cost, costs likely to occur without respite, cost burdens on different stakeholders, and outcomes for both respite users and non-users. • Examine cost-saving outcomes such as decreased emergency room visits and inpatient hospitalizations. • Investigate whether respite care alone, or combined with other services, leads to improved outcomes.
Dissemination of findings	• Implement a public-facing system for easy benchmarking and transparency. • Highlight program innovators to foster a culture of sharing and improvement. • Use diverse dissemination methods to reach different audiences, including dashboards, infographics, newsletters, presentations, and evaluation reports.

Resources

- ARCH Evaluation Form for Planned Respite
- ARCH Evaluation Form for Crisis Respite
- ARCH Caregiver Experience with Respite Tool
- ARCH Common Data Elements for Respite Research Worksheet
- ARCH Measuring the Value of Respite
- ARCH Recommended Common Data Elements for Respite Research
- Centers for Disease Control Program Evaluation Framework Action Guide
- Measuring System Change and Consumer Outcomes: Recommendation's for Developing Performance Metrics for State Lifespan Respite Programs
- SAMHSA National Guidelines for Crisis Respite (includes evaluation metrics)
- University of Kansas Community Toolbox Introduction to Evaluation
- Wyoming's Scorecard Specification Manual
- Youth Empowerment Services Program Evaluation Executive Summary

Conclusion

Behavioral health respite care is a vital, yet underutilized, component of a comprehensive system of care for youth and families navigating emotional and behavioral health challenges. As this white paper has demonstrated, respite care offers far more than temporary relief—it is a preventative, family-centered intervention that supports caregiver well-being, promotes youth stability, and has the potential to reduce reliance on high-cost, restrictive services. Across the country, innovative models and policy strategies are emerging to expand access, improve quality, and ensure sustainability of respite. Yet, significant barriers remain, including inconsistent funding, workforce shortages, and limited public awareness.

To meet the growing behavioral health needs of youth and families, stakeholders must act with urgency and coordination. This includes expanding Medicaid and commercial insurance coverage, investing in provider training and recruitment, integrating respite into community-based settings, and embedding evaluation into every stage of service delivery. Most importantly, respite care must be designed and delivered in partnership with families—honoring their voices, respecting their choices, and building systems that reflect their lived experiences.

The recommendations outlined in this report provide a roadmap for advancing high-quality behavioral health respite care. By embracing these best practices and fostering cross-sector collaboration, states and communities can transform respite from a fragmented service into a cornerstone of family preservation and youth well-being. The time to act is now—because every family deserves the opportunity to rest, recover, and thrive.

We close this white paper with the voices of those who matter most—the youth, families, and providers who have experienced the impact of behavioral health respite firsthand. Their words reflect both the profound need for these services and the potential they hold when delivered with compassion, respect, and partnership.

Cadence Care Network

The following was written by an 18-year-old respite client:

> "My respite provider. Terra is one of my favorite person on this planet, she's one of my strong support system, once a week she brings me to places, I choose to go to the mall most of the time because I love to window shop at stores, or sometimes me and Terra go to park to spend time with nature or play tennis, I confide to her with my problems she just listens to my rants she doesn't judge me I think she try her best to understand me I'm so grateful to have her in my life, yesterday we went to Mill Creek flower park, I told her that hugging a tree will give you healing and she laughs at me and I convinced her with all my might that it works."

Pathway Caring for Children

> "We provided BH Respite to a young person in a rural community with very limited resources. This gave him, and his family, an opportunity to have experiences that would not otherwise have been possible. The respite worker was able to connect with him and give him a voice. He said that he never had anyone actually listen to him and try to understand him like his respite worker did."

The following is from a care coordinator:

> "I just want to acknowledge the amazing work you have been doing with HJ. H had many changes in her providers recently, but the one thing that's been consistent is that she absolutely loves being involved with respite. She enjoys her outings with you so much, and H is truly doing amazing!! If she hasn't told you yet, I won't spoil it for her, but she won several awards at school and currently has 4.0 GPA for this last quarter. Her grades were so poor last year we set a goal of her maintaining a C average, and she has risen above and beyond that expectation! Many of the other awards she was given were to recognize her attendance and respectful behavior at school, which is the complete opposite of how she had been performing the previous year. Her connection with you is definitely a big part of her success, so I just wanted to express my gratitude to you. I think the work you are doing with her will bear a positive influence on her for many years to come. Thanks again."

Adriel School

> "Although we have always offered respite services through our continuum of care the number of respites we are currently providing has substantially increased. Our foster families that have adopted special needs children are finding it as a huge resource. We have also been able to provide respite through these programs for youth that have reunified from our foster care program. This offers many families an extra support to help preserve the family upon reunification (and a plus the youth is able to respite with their previous foster family)."

Appendix

Table 1 Exemplar Eligibility Criteria

State and Considerations	Eligibility Criteria
Illinois; Criteria is for the Family Support Program (FSP)[58]	• The parent or guardian resides in Illinois • The youth is under the age of 18 • The youth is not under the guardianship/legal custody of any unit of the federal, State or local government • The parent/guardian agrees to meet the terms of the Program's Parent or Guardian Responsibilities • The youth demonstrates a severe emotional disturbance • The youth demonstrates a severity of need indicating that his or her clinical needs are not being met through active participation in traditional outpatient mental health services • The youth demonstrates sufficient cognitive capacity to respond to psychiatric treatment and intervention • The youth's history of mental health challenges and treatment efforts demonstrate a chronic condition rather than an acute episode • The youth demonstrates behaviors or symptoms that are likely to respond to the treatment services available in the FSP
Kansas; Criteria is for their SED waiver[53]	• Youth is between the ages of 4 to 18 years old • Youth is diagnosed mental health condition which substantially disrupts the ability to function socially, academically, and/or emotionally • Youth is at risk of inpatient psychiatric treatment • Meet CAFAS assessment and CBCL threshold for eligibility • Be financially eligible for Medicaid
Montana[57]	• Families and youth identify a critical need for relief, regardless of age, income, race, ethnicity, special need or situation.
Kansas; Criteria is for their SED waiver[53]	• Youth is between the ages of 4 to 18 years old • Youth is diagnosed mental health condition which substantially disrupts the ability to function socially, academically, and/or emotionally • Youth is at risk of inpatient psychiatric treatment • Meet CAFAS assessment and CBCL threshold for eligibility • Be financially eligible for Medicaid

Table 1 Exemplar Eligibility Criteria *(continued)*

State and Considerations	Eligibility Criteria

Ohio; Criteria for OhioRISE behavioral health respite[59,108]	• Youth meets criteria for enrollment in OhioRISE including
	  • Youth is eligible for Ohio Medicaid (either managed care or fee-for-service)
	  • Youth is age 0-20
	  • Youth requires significant behavioral health treatment needs, measured using the Ohio Child and Adolescent Needs and Strengths (CANS) assessment or a recent inpatient behavioral health hospital/psychiatric residential treatment facility admission.
	• Youth is an enrolled OhioRISE member
	• Youth must have behavioral health needs for the behavioral health respite service as determined by the OhioRISE Child and Family Centered Plan
	• Youth resides in one of the following:
	  • With their primary caregiver in a home that is not owned, leased, or controlled by a provider of any health-related treatment or support services
	  • In a foster home licensed by the Ohio Department of Job and Family Services (ODJFS)
	  • In the home of kin
	  • In a medically fragile or treatment foster home

Texas; Criteria for the Youth Empowerment Services waiver[48]	• Youth is aged 3 to 18 years old • Youth has a SED • Qualifying mental health diagnosis • Have attempted other outpatient services such as counseling and continue to need a higher level of care • Reside in a qualified setting (e.g., service area, non institutional setting, own home if emancipated) • Youth is at risk of being placed outside the home due to mental health needs • Youth meets the criteria to be in a psychiatric hospital • Youth is eligible for Medicaid • Youth currently lives in a home setting with a legal guardian or on their own if legally emancipated
West Virginia; Criteria is for waiver[55]	• Youth is between the ages of 3 and 20 • Youth is a resident of West Virginia • Meet the program eligibility (e.g., CAFAS) • Choose home and community-based treatment services instead of services in a medical facility or group home. • Choose to sign up with the identified managed care organization. • Currently or at any time during the past 12 months, have been diagnosed with a mental, behavioral or emotional disorder for a period of time that is satisfactory to meet standards that are in the most current edition of the Diagnostic and Statistical Manual (DSM).
Wyoming; Criteria is to enroll in the CME/Wraparound[68]	• Youth between the ages of 4 and 21 • Meets the definition of SED or SMI • Scores within range on the CASII or ECSII • Display SED or severe and persistent mental illness • Respite supports a specific goal in the youth's plan of care

Table 2 Twelve Principles for Children's Behavioral Health Service Delivery, Arizona[102]

Guiding principle	Practices	Example in action
Collaboration with the child and family		
The child and family are treated as partners, including in assessment, service planning and delivery, and evaluation of the effectiveness of behavioral health services.	The child and family are given choices and options for services, service providers and any other decisions to be made regarding their treatment. The choices and preferences of the family are prioritized in service plans. Providers give the family information needed for them to make informed decisions about all aspects of treatment.	Jasmine, a 10-year-old with anxiety, and her family choose a trauma-informed respite provider with quiet spaces after discussing their preferences with the care team. Regular feedback is encouraged, and adjustments are made based on the family's input.
Functional outcomes		
The family vision defines success from the child and family's perspective.	Functional outcomes focused on strengths and assets are assessed rather than deficits. The service plan needs to be monitored for effectiveness and revised to meet changing needs or if any strategies are determined to be ineffective.	Ethan, a 12-year-old with ADHD, enjoys strategy games and building activities. His respite care plan includes small group activities that focus on his strengths, and adjustments are made to support his social confidence.
Collaboration with others		
Teams may include the child, family, and individuals important in the child's life who are chosen by the child and family to participate.	Working collaboratively is a dynamic process where individuals come together, share knowledge, experiences, resources, and strengths to promote growth and development. Team collaboration creates opportunities to set goals and objectives, establish plans to implement those goals, monitor progress, and solve problems collectively.	Liam, a 9-year-old with autism, benefits from a collaborative team that includes his teacher, speech therapist, respite provider, and uncle. Strategies from different people in his life are integrated to support his transitions.
Accessible services		
The child and family have access to developmentally appropriate services that are individualized and meet their unique needs.	Barriers to services including transportation should be identified during service planning and the child and family are supported in overcoming those barriers to care. Providers educate the family about their rights, required timeframes, grievance and appeals processes, and escalation processes.	Sophia, an 8-year-old with severe anxiety, lives in a rural area with limited transportation. The team arranges for transportation to and from Sophia's home.

Table 2 Twelve Principles for Children's Behavioral Health Service Delivery, Arizona[102] *(continued)*

Guiding principle	Practices	Example in action
Best practices		
Competent individuals who are adequately trained and supervised to provide behavioral support to children and caregivers.	These practices shall include, but are not limited to: trauma informed care, person-centered service delivery, addressing social determinants of health (SDOH), and strengths-based approaches. Providers seek clinical consultation as appropriate.	Maria, a respite care provider, supports 10-year-old Liam, who has anxiety stemming from past trauma. Maria uses trauma-informed care techniques, speaks in person-first language, and collaborates with Liam's family to create a strengths-based plan focusing on his love for art. When Liam shows signs of increased anxiety, Maria consults with a supervisor to adjust strategies, ensuring best practices are followed.
Most appropriate setting		
Children and caregivers are provided services in their home, community, school, or the most suitable environment of choice.	Services and support are provided in the most inclusive, responsive, accessible, and least restrictive setting. The team prioritizes services that are provided in the family home and community.	Jordan is a 12-year-old who struggles with behavioral challenges at school. Her care team coordinates in-home support and community programs like after-school art classes, helping Jasmine feel secure in familiar environments while addressing her needs.
Timeliness		
The child and family's need for services and supports are assessed and tailored to a child and family's unique needs.	Providers work collaboratively with the family to ensure timely service delivery. Providers escalate as appropriate when assistance is needed with securing services in a timely manner.	When 12-year-old Max experiences a sudden increase in suicidal ideation, his respite care provider immediately contacts Max's parents and the mental health team to expedite an appointment. When an appointment isn't available within the necessary timeframe, they escalate the issue, ensuring Max receives the care he needs promptly.
Services tailored to the child and family		
The unique needs and strengths of the child and family determine the different types and intensity of services provided.	The child and family are treated as experts in their life and current situation; in how they would like things to be and what do they feel is the best way for them to get there. The service plan is created with a strength-based approach that incorporates the unique strengths of the child and family.	17-year-old Alex, who has ADHD, wants to pursue a culinary career. His respite provider works with him and his family to develop a plan that includes cooking classes and mentorship opportunities. The service plan emphasizes Alex's strengths and passion, helping him build confidence and skills for the future.

Table 2 Twelve Principles for Children's Behavioral Health Service Delivery, Arizona[102] *(continued)*

Guiding principle	Practices	Example in action
Stability		
Behavioral healthcare teams utilize whole person care to wrap the child and family in a supportive environment that provides access to care in a way that minimizes risk in the least restrictive setting.	The team encourages the identification processes to support consistent and stable delivery of services. The team anticipates potential crises and addresses those situations through crisis and safety planning.	14-year-old Mia, diagnosed with bipolar disorder, has experienced multiple foster placements. Her new care team creates a comprehensive plan that includes consistent therapy, a crisis plan, regular respite care, and family support meetings. By anticipating potential crises and ensuring consistent care, Mia remains stable in her current foster home.
Respect for the child and family's unique cultural heritage		
Behavioral health services are provided in a manner that respects their culture. These include but are not limited to traditions, heritage, belief systems, social, racial, or ethnic family of origin.	The child and family's cultural heritage is treated as a strength-based resource and is incorporated into all planning processes. Aspects of the child's individual cultural identity, separate from that of the family, are validated and given consideration, particularly as the child ages into adolescence.	11-year-old Amina's family practices traditional Somali customs. Her care team ensures communication in the family's primary language and incorporates cultural traditions into her care plan. Amina's love for traditional dance is encouraged as a strength, helping her connect with her heritage while receiving support.
Independence		
All services and supports are individualized based on the child and family needs to ensure growth and encourage self-management.	The child and family are able to obtain a realistic desired level of independence. As a child and family makes progress toward their goals, the amount of formal services decreases and the family's use of natural and community supports increases.	16-year-old Jordan, diagnosed with autism, wants to live independently after high school. His respite provider helps him develop life skills, like budgeting and cooking.
Connection to natural supports		
Providers shall support the child and family in identifying and encouraging a broad spectrum of natural supports.	Natural support is sustainable and available to children and families even after formal behavioral health services are no longer needed. Natural support can be individuals, organization, or community resources.	9-year-old Lily has anxiety and struggles with making friends. Her respite provider transports her to a local Girl Scouts troop, where she builds friendships and gains confidence. Even after formal behavioral health services end, Lily continues to thrive with the support of her troop and community connections.

Table 3 SAMHSA Overarching Principles for Behavioral Health Coordinated System of Crisis Care[110]

Overarching Principle	Description
Comprehensive, integrated, coordinated systems-based approach	Crisis services must work across multiple systems (e.g., healthcare, education, justice) with clear oversight to ensure seamless, connected care for individuals.
Person-centered, family-focused, right level of care at the right time	Services should be responsive to individual and family needs, allowing people to define their own crises and access care appropriate to their acuity level.
Prioritize safety	Crisis services should ensure emotional and physical safety for help seekers, staff, and the public, through protocols, training, and trauma-informed environments.
Equitably accessible and responsive	Services must be culturally and linguistically appropriate, non-discriminatory, and designed to eliminate disparities across diverse populations.
Prioritize quality and effectiveness	Use data-driven evaluation and continuous improvement to ensure services are effective, equitable, and improve user experiences and outcomes.
Developmentally appropriate	Crisis services should be tailored to the specific needs of children, youth, transition-age individuals, and older adults, including coordination with appropriate systems.
Resiliency- and recovery-oriented	Services should focus on individual strengths and recovery goals, and include peer support as a key component of care.
Trauma-informed	All services should recognize the impact of trauma and deliver care that emphasizes safety, trust, empowerment, and cultural sensitivity.
Continuity of care, follow-up, and linkage	Care should span from the initial crisis through stabilization and include proactive follow-up and linkage to ongoing supports.
Evidence-based, evidence-informed, and/or reflect best, promising, and emerging practices	Crisis care must be grounded in current scientific evidence or informed by emerging, promising, or best practices.
Responsive to wholistic needs	Crisis services should address the full range of behavioral, physical, and social needs—including housing, employment, and social support.

Table 4 Selected States Respite Provider Qualifications

State	Minimum Qualifications
Idaho[64]	• At least 18 years of age • Earned a high school diploma or GED • Employed by a credentialed Idaho Behavioral Health Plan network provider • Be no less than 36 months older than the member to which they are rendering services
Kansas[53]	• At least 21 years of age • Earned a high school diploma or GED • Pass a background check • Pass a child abuse and adult abuse registry check • Pass a motor vehicle screen
Louisiana[124]	• At least 18 years of age • Earned a high school diploma, GED, or trade school diploma in the area of human services, or demonstrated competency, or verifiable work experience in providing support to persons with disabilities • The provider must be at least three years older than an individual under the age of 18
Michigan[45]	• At least 18 years of age • Be able to practice prevention techniques to reduce transmission of any communicable diseases from themselves to others in the environment where they are providing support • Have a documented understanding and skill in implementing the individual plan of services and report on activities performed • Be in good standing with the law (i.e., not a fugitive from justice, a convicted felon, etc) • Be able to perform basic first aid and emergency procedures • Be trained in recipient rights • Be an employee of the community mental health services program or its contract agency, or an employee of the parent who is paid through a Choice Voucher arrangement.
New York[125]	• At least 18 years of age for daytime service and 21 years of age for overnight • Some high school education (a high school diploma or G.E.D. is preferred) • Experience working with children (preference given to those with experience in the children's mental health field/working with children with SED)

Table 4 Selected States Respite Provider Qualifications *(continued)*

State	Minimum Qualifications

Ohio[108]	• Eligible providers for OhioRISE behavioral health respite must be one of the following:
	  • Individuals employed by an Ohio Mental Health and Addiction -certified and Medicaid enrolled agency providers
	  • Department of Developmental Disabilities certified providers of informal respite
	  • Family who do not also meet the definition of legally responsible family member and who do not reside in the home with the member
	  • Natural supports
	  • Foster settings that are not currently fostering other youth or if foster other youth, the foster caregiver has determined that the youth in need of behavioral health respite services can be safely served together with the youth residing in the home.
	  • Additional criteria for foster caregivers include: 1) Has a relationship, established via a face-to-face meeting, a telephone call, or a video call, with the youth who will receive respite services in the foster home; 2) is fostering siblings or kin of the youth who will receive respite services in the foster home; or 3) Is fostering the child of a parenting youth who will receive respite services in the foster home.
	• Pass a background check

Texas[48]	• At least 18 years of age • Current Texas drivers license • Pass a background check • Pass a child abuse and adult abuse registry check
Wyoming[51]	• At least 21 years of age • Pass a background check • Two years of work/personal experience with children (preference given to individuals who have worked with a child with SED) • Maintain current auto insurance if transporting youth • Enrolled as a Wyoming Medicaid Provider through the State's Fiscal Agent

Table 5 Overview of the CDC's Program Evaluation Framework[134]

Step	Description	Activities
Assess the context	Evaluations are influenced by the context in which the evaluation is situated. This can include the various features of an evaluation's setting, such as location and environment, people and their cultural values, historical circumstances, roles that power and privilege play, and other pertinent characteristics.	• Review program goals and materials • Identify available data and tools • Observe the program in action determining if differences in program in action vs intended implementation • Identify program training and partnership needs • Determine if a program is ready for evaluation.
Describe the program	In this step of the evaluation process, it is essential to clearly describe the program by identifying key activities and expected outcomes. A well-defined program roadmap enhances understanding and sets the stage for a successful evaluation. Taking the time to accurately detail the program ensures a strong foundation for planning and implementation.	• Develop a logic model or a program road map of the program that will be evaluated • Develop an accompanying narrative description of the program
Focus the evaluation questions and design	Collaboratively engage with interest holders to focus the evaluation efforts and develop the most appropriate evaluation design.	• Clearly state why the evaluation is being conducted, how the findings will be used, and who will benefit from them. • Determine whether the evaluation will focus on process, outcomes, or another approach. • List stakeholders who will use the evaluation findings and how they will apply the information. • Create key questions that will guide the evaluation based on program priorities and stakeholder needs. • Outline the overarching evaluation framework, ensuring it aligns with the logic model, program context, and available resources. • Integrate culturally appropriate evaluation methods that reflect program context and stakeholder diversity. • Use stakeholder priorities and the logic model to determine which program aspects are most critical to evaluate.

Table 5 Overview of the CDC's Program Evaluation Framework[134] *(continued)*

Step	Description	Activities
Gather credible evidence	Identify the evidence needed to answer the evaluation questions. This step involves selecting appropriate data sources, defining key measures, and determining data collection methods. A well-planned data collection strategy ensures that credible and relevant evidence is gathered to support meaningful evaluation findings.	• Engage key stakeholders to align on data collection expectations, ensuring that the strategy meets the evaluation's purpose and priorities. • Determine what specific data is needed to answer evaluation questions, considering both qualitative and quantitative measures. • Choose appropriate methods based on the evaluation needs (e.g., surveys, interviews) • Identify who or what will provide the necessary information, such as program participants, staff, records, or external data sources. • Define how, when, and from whom data will be collected, ensuring alignment with evaluation goals and resources. • Establish clear indicators and measures to assess reliability and validity, ensuring collected evidence supports meaningful conclusions.

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