Services in Support of Community Living for Youths with Serious Behavioral Health Challenges: Respite Care

Kelly English, PhD, Children's Behavioral Health Knowledge Center, Massachusetts Department of Mental Health

Rebecca Bertell Lieman, MSW, Suzanne Fields, MSW, and Melissa Schober, MPM
The Institute for Innovation and Implementation**,** School of Social Work**,** University of Maryland, Baltimore

Evidence from the Psychiatric Residential Treatment Facility (PRTF) demonstration program and the Children's Mental Health Initiative (CMHI) program has consistently found that the availability of home- and community-based services (HCBS) has improved the quality of life for children with serious behavioral health challenges and their families (e.g., improved school attendance and performance, improved clinical and functional outcomes, more stable living situations). HCBS that support families so children can live in their own homes are a fundamental component of the children's system of care.

Respite care, which offers support to a child while providing temporary relief to a child's parent/caregiver so they can have time to attend to other "life activities," is one such HCBS service. In addition to quality-of-life benefits, HCBS such as respite care are cost-effective alternatives to high-cost, out-of-home settings such as psychiatric hospitals or residential treatment centers whose efficacy is limited.[1,2] A 2013 report from the Parent/Professional Advocacy League and the Massachusetts Department of Mental Health estimated the cost of three months of respite care as $3,000,[3] while three months of care in a group home was estimated to cost $29,000.[4]

In a recent review of children's behavioral health service utilization and expenditures, use of residential treatment/congregate care and inpatient psychiatric hospitalization among children in Medicaid using

behavioral health care increased between 2005 and 2011, from 3.6 percent to 4.2 percent and from 3 to 5 percent, respectively, with residential and group care constituting the single-highest expenditure item for children using behavioral health services in Medicaid. The same analysis found that while spending on home- and community-based services such as Wraparound, peer support, respite, and multisystemic therapy increased, each service still constituted only about 2 percent of total behavioral health expenditures for youths on Medicaid, compared to residential and inpatient psychiatric hospitalization, which consumed nearly 28 percent of all Medicaid child behavioral health spending.[5]

As a recent investigation exploring the financing of systems of care approaches for children with behavioral health challenges found, HCBS including respite care are prudent investments of public funds for which policymakers receive significant return on investment in terms of improved clinical and functional outcomes for youths as well as financial savings.[6]

Caring for a child with a behavioral health challenge places unique demands and stresses upon parents that can impact critical life domains such as employment, relationships with family and friends, physical health, emotional well-being, and the ability to attain and maintain stable housing.[7,8,9]

Parents of children with behavioral health challenges must attend frequent meetings with their child's doctors, teachers, therapists, and other helping professionals, which can make it difficult to participate in the workforce and attend to their needs or the needs of other family members. In addition, they have to perform other activities to support their child to live at home and attend school. For example, they must engage in highly specialized parenting approaches to support their child's treatment plan, coordinate numerous meetings, work with doctors to monitor side effects of psychotropic medications, and respond to crises or other critical issues that emerge for their child as they grow. Moreover, parents of a child with a behavioral health challenge often cannot make use of typical child care arrangements because caregivers need special training or skills to manage the child's emotional and behavioral issues.[10] Thus, parents of children with behavioral health challenges have little time to attend to other responsibilities such as going to their own medical appointments, tending to the needs of other family members, getting the car repaired, or visiting friends or relatives. The sustained effort it takes to parent a child with behavioral health challenges can be emotionally, financially, and physically taxing, placing the child at increased risk of an out-of-home placement. Respite can play an essential role in reducing caregivers' stress and improving quality of life.[11,12] For many caregivers, simply having time to "restore and renew" can be critically important to helping them maintain their child with a behavioral health challenge at home.

The benefits of respite are not reserved solely for the parent but also extend to the entire family. Respite can allow siblings uninterrupted time with their parent(s) and give them an opportunity to "recharge" from the stress of living with a sibling who has a behavioral health challenge. For the child with a behavioral health challenge, it can give them a safe and supportive environment to calm down and prevent a crisis, offer them an opportunity to develop a hobby or practice a new skill, and, most important, help them remain in their home and community, preventing the need for an out-of-home placement.

While parents consistently identify respite as a need,[13,14] its availability is not widespread. In May 2013, the Center for Medicaid and CHIP Services (CMCS) and the Substance Abuse and Mental Health Services Administration (SAMHSA) issued a joint informational bulletin that provides guidance to states on designing HCBS, including respite care, to help them meet their obligations under Title II of the Americans with Disabilities Act[15] (ADA) and Medicaid's early periodic screening, diagnostic, and treatment[16] (EPSDT) requirements. As the federal government encourages more states to include respite services in their Medicaid benefit/service designs, there is a need to better understand what these services look like from an operations perspective. Information on service definitions, rate-setting methodology, provider qualifications, financing strategies, and quality measures for performance management is needed by states and localities to improve the availability of respite services and help them implement respite in their jurisdictions.

This TA Network brief is intended for use by multiple stakeholders engaged in the design, implementation, and/or expansion of Medicaid-covered respite services, including state and local family- and youth-run organizations, state Medicaid and other public child-serving agencies, Medicaid-managed care organizations, providers, and others. Respite can and does look different from state to state, with variability dependent on the purchaser, financing environment, and population served. This resource provides examples of the way respite is operationalized in certain states, including Connecticut, Indiana, Louisiana, and Montana, to help guide planning, design, and implementation efforts in other states and jurisdictions across the country.

Respite defined

In their joint informational bulletin, CMCS/SAMHSA described respite as a service intended to "assist children to live in their homes in the community by temporarily relieving the primary caregivers." Respite services provide safe and supportive environments on a short-term basis for children with mental health conditions when their families need relief."[17] Respite can take many different forms. It can be planned or provided on an emergency basis to de-escalate a crisis situation and offered in a variety of settings, including the family's home or an out-of-home location such as a respite provider home, group home, or day care center. Respite also could include a provider taking the child out into the community for a few hours, to a park or playground or to a special activity like an art or music class. This offers the child an opportunity to participate in pro-social activities under the supervision of a caring adult and supports other goals the child may be working on as part of a comprehensive treatment plan, such as developing appropriate behaviors in the community or social skills.[18] Respite may occur overnight or could be limited to a few hours during the day. The availability of a diverse array of respite options allows care to be individualized to the unique needs of a child and family, an approach consistent with the guiding principles of the children's system of care.[19]

Short-Term Respite Care Service Definition – Louisiana Coordinated System of Care

Developing a clear definition of the service being purchased is an important first step when implementing a new service. This helps purchasers, service providers, family members, and other system partners understand what the service is supposed to look like "on the ground."

"Short-term respite care provides temporary direct care and supervision for the child/youth in the child's home or a community setting that is not facility-based (e.g., not provided overnight in a provider-based facility). The primary purpose is relief to families/caregivers of a child with a serious emotional disturbance (SED) or relief of the child. Respite services help to de-escalate stressful situations and provide a therapeutic outlet for the child. Respite may either be planned or provided on an emergency basis. Normal activities of daily living are considered to be included in the content of the service when providing respite care and cannot be billed separately. These include support in the home, after school or at night, transportation to and from school/medical appointments or other community-based activities and/or any combination of the above. The cost of transportation is also included in the rate paid to providers of this service. Short-term respite care can be provided in an individual's home or place of residence or provided in other community settings, such as at a relative's home or in a short visit to a community park or recreation center. Respite services provided by or in an Institution of Mental Disease (IMD) are not covered. The child must be present when providing short-term respite care. Short-term respite care may not be provided simultaneously with crisis stabilization services and does not duplicate any other Medicaid State Plan service or service otherwise available to recipient at no cost. The Medicaid rate does not include costs for room and board. Other funding sources reimburse for room and board, including the family or legally responsible party (e.g., Office of Juvenile Justice and Department of Children and Family Services)."

Louisiana Behavioral Health Partnership Service Definitions Manual, Version 9, Aug. 15, 2014
http://new.dhh.louisiana.gov/assets/docs/BehavioralHealth/LBHP/2014_RFP_Procurement_Library/LBHP_Service_Definitions_Manual_8.15.14.pdf

Implementation essentials

Oversight and purchasing

Purchasers of respite care for youths with serious behavioral health challenges range from state Medicaid, child welfare, mental health, and public welfare agencies to departments of education and public health. For example, Connecticut's Department of Children and Families, a consolidated children's agency that oversees children's mental health, substance abuse, juvenile justice, and child welfare, purchases respite on behalf of youths involved with its child welfare division as well as those who participate in the local system of care initiative. The Montana Department of Public Health and Human Services' Children's Mental Health Bureau purchases respite services using Medicaid funds for youths with SED. In Louisiana, respite care is purchased through the Coordinated System of Care (CSOC), using Medicaid and non-Medicaid funds.[20] The CSOC is managed by the Louisiana Office of Behavioral Health, which contracts with Magellan Health Services of Louisiana. Magellan manages the behavioral health services for Medicaid and non-Medicaid children who are at risk of out-of-home placement under the CSOC.

These entities typically purchase respite from a variety of providers. Respite can be delivered by an individual working for a community mental health center, at a licensed child care center, in a foster home, an emergency shelter, or even by a relative, friend, or neighbor of the child/family as long as they meet requirements to be a respite care provider. Indiana, for example, allows respite to be provided in the child's home, another private residence, or any facility licensed by the Indiana Family and Social Services Administration's Division of Family Resources or the Indiana Department of Child Services. Indiana permits relatives to provide respite as long as they are not the child's legal guardian, do not live in the home with the child, and meet other requirements, including certification as a respite provider by the Indiana Division of Mental Health and Addiction.

As mentioned, respite can take different forms — overnight, planned, emergency/crisis, in home or out of home — with the length of time varying by the type of respite being delivered. Given that respite is intended to be temporary or short term in nature, states typically place limits on the duration a child may receive respite care. For

Population Served – Connecticut Department of Children and Families

Understanding who the service is intended to help will ensure that the right children and families have access to the service. It also assists service providers to develop awareness of the skills and competencies their staff should possess to meet the needs of the children for whom they are caring. Defining the "who" also assists family members and other referral sources as they consider if the service is the right one for the child.

Connecticut's Short-Term Family Integrated Treatment (S-FIT) service is a brief, one- to 15-day residential treatment option providing stabilization and assessment for DCF involved youth experiencing an immediate behavioral health crisis that precludes them from remaining in their existing placement. Rapid crisis resolution and transition back into the home environment is the focus of this service. As such, the primary goals of the program are to: stabilize the youth and family (adoptive, biological, foster, kin, relative) and their extended social system; assess strengths and needs; identify/mobilize community resources; and coordinate services to ensure rapid reintegration into the home. … The focus of the intervention is on addressing the immediate source of the youth's behavioral dyscontrol while providing targeted assistance to caregivers that will allow them to resume caring for the child safely in the home environment. **S-FIT may also serve as a brief, temporary structured respite placement ranging from one to several hours on a daily basis for youth with behavioral health challenges who are in immediate need of a safe, therapeutically informed placement while alternative plans are made for a more permanent living arrangement [emphasis added].**

CT Behavioral Health Partnership – Child Psychiatric Level of Care Guidelines, Revised Feb. 25, 2016
http://www.ctbhp.com/providers/pdfs/Child_BHP_Level_of_Care_Guidelines.pdf

example, Louisiana pre-approves respite for up to 72 hours per episode, with a maximum of 300 hours per calendar year. In Indiana, overnight respite care cannot exceed 14 consecutive days.[21]

Eligibility and screening

Another important aspect of implementing respite is establishing clear eligibility criteria. This helps to ensure that youths who are most in need of the service can access it. States commonly use standardized screening or assessment tools to help establish eligibility for respite services or a larger program or package of services of which respite is a part. For example, the child and adolescent needs and strengths (CANS) tool is used in Louisiana to determine eligibility for enrollment in the CSOC, with respite being one of the many services an eligible youth can access. Indiana also uses the CANS tool to establish eligibility for the state's Money Follows the Person-Psychiatric Residential Treatment Facility Services Program (MFP–PRTF). In addition to meeting specific CANS ratings, youths in Indiana must be at least 6 years old but not yet 18, be eligible for Medicaid, and have been receiving Medicaid services for at least one day before discharge from a qualified institutional setting that they have resided in for at least 90 days. For youths in Montana who meet the eligibility criteria for the state's 1915(i) HCBS program (see box) as determined by the state's utilization review (UR) contractor, they must then have a face-to-face independent assessment conducted by a qualified individual[22] to determine if the child needs at least one of the 1915(i) services such as respite.

Eligibility Criteria – Montana Department of Public Health and Human Services

Access to respite care in Montana is limited to youths who meet the criteria for the state's Medicaid 1915(i) Home- and Community-Based Services State Plan Program. Only youths who are living in a "family home setting" are eligible for respite care under the 1915(i) program. In addition, a youth must meet the following criteria to be eligible for services included in the 1915(i):

1. Is age 5 through 17, or up to age 20 if the youth is still in secondary school and consents to participation in the 1915(i) HCBS State Plan Program.
2. Is Medicaid-eligible.
3. Meets the clinical criteria of SED and has at least two of the following risk factors:
    a. Has had at least one admission to a PRTF in the past 12 months; has had at least one admission to a local inpatient hospital related to behavioral health needs, not physical health needs, in the past 12 months.
    b. Has had at least one admission to a therapeutic group home in the past 12 months.
    c. In lieu of 1915(i) HCBS State Plan Program services, the youth is at risk of placement in a PRTF per an assessment of referral information.

A youth is required to meet the following needs-based eligibility criteria:

1. Resources available in the community do not meet the treatment needs of the youth as documented by at least two of the following risk factors (a–d) or at least one of risk factors (a-d) and e, below:
    a. The youth has had at least one admission to a PRTF in the past 12 months.
    b. The youth has had at least one admission to a local inpatient hospital related to behavioral health needs, not physical health needs, in the past 12 months.
    c. The youth has had at least one admission to a therapeutic group home in the past 12 months.
    d. In lieu of 1915(i) HCBS State Plan Program services, the youth is at risk of placement in a PRTF per an assessment of referral information.
    e. The youth is receiving three or more of the following types of outpatient services in the community setting and is not making progress: outpatient therapy with or without medication management; comprehensive school and community treatment; day treatment OR partial hospitalization; therapeutic family care OR therapeutic foster care; or respite.
2. The services can reasonably be expected to improve the condition of the youth or prevent further regression.

Montana Department of Public Health and Human Services, Children's Mental Health Bureau, 1915(i) Home- and Community-Based Services State Plan Program for Youth with SED Policy Manual, Oct. 1, 2015 http://dphhs.mt.gov/dsd/CMB/Manuals.aspx

Provider qualifications and training

Clearly defining the requisite skills, competencies, and experience a provider must possess to deliver respite is one way that states promote quality of care and ensure the safety and well-being of youths receiving respite services. States typically will define the types of providers who can deliver respite care (e.g., hospitals, community mental health centers, licensed foster homes, individuals) as well as the standards or qualifications the people providing the service must meet (e.g., college degree, at least 18 years old, possess a valid driver's license).

States also may establish standards for supervision, training, and limits on the number of youths an individual providing respite can serve at one time as another way to promote quality respite care. In Indiana, individuals must be approved to provide respite by the Department of Mental Health and Addiction. Individuals must be at least 21 years of age and have (1) a high school diploma or equivalent; (2) at least three years of qualifying experience working with or caring for youths with serious emotional disturbance; (3) completed a criminal history background screen; and (4) documented a safe driving record.[23]

Responsibility for ensuring that providers meet the standards and qualifications for participation as a qualified respite provider may be held by the state purchaser or licensing authority or be delegated to another entity such as a managed behavioral health care organization or an administrative services organization.

Examples of Medicaid and state billing codes and reimbursement rates

STATE	BILLING CODES AND RATES
Connecticut[24]	• Paid by Department of Children and Families for children and youths under their care; not a Medicaid-reimbursed service. • Rates are "PSR" or provider specific. • The average rate is about $93 per day, and rates range from a minimum of $35.54 to $140.91 per day for residential beds.
Indiana[25]	• T1005 HA, respite, hourly; $4 per 15 minutes. • S5151, respite, daily; $100 for 7-24 hours. • S5151 HA U1, respite crisis, daily; $120 for 8-24 hours. • S5151 HA U2, respite daily in Medicaid Psychiatric Residential Treatment Facility, $321.52 per day.
Louisiana[26]	• S5150, individual short-term respite; $3.90 per 15 minutes, $15.60 per hour. • H0045, crisis stabilization not in the home; $180 per day.
Maryland[27]	• W5000, respite care, in-home, community-based; $25.66 per hour. • W5001, respite care, residential; $203.43 per unit (overnight).
Montana[28]	• S5150 UA, per 15 minutes; $4.74. • S5151, per diem; $200. Rate is for 24-hour, overnight respite provided in a therapeutic group home or shelter care (or similar provider settings).
Ohio[29, 30]	• S5151, per diem (12 hours or more); included in managed care capitation. • S5150, per 15 minutes; included in managed care capitation.

Conclusion

While much attention has been paid to states' continued expansion of home- and community-based services for children and youths with behavioral health needs, less attention has been given to how the shift from congregate or inpatient care affects families. The demands on the parents and caregivers of children and youths with behavioral health needs may negatively affect employment and increase family stress.[31] To ameliorate negative effects, prevent costly out-of-home placements and the use of acute care services, and improve child and family outcomes,[32] states should consider increasing the availability of high-quality respite care.

[1] Burns, B.J., Hoagwood, K., and Maultsby, L.T. (1998). *Improving outcomes for children and adolescents with serious emotional and behavioral disorders: Current and future directions.* Epstein, M., Kutash, K., and Duchnowski, A. (Eds.), *Outcomes for children and youth with behavioral and emotional disorders and their families: Programs and evaluation best practices*. Austin, TX: PRO-ED.
[2] U.S. Public Health Service. (2000). *Report of the Surgeon General conference on children's mental health: A national action agenda.* Washington, D.C. Author.
[3] This estimate was based on a rate of $25 per hour for 10 hours of care per week.
[4] Parent/Professional Advocacy League and Massachusetts Department of Mental Health. (2013). *Respite care: What families say.* Boston, MA: Author.
[5] Pires, S., Gilmer, T., Allen, K., and McLean, J. *Faces of Medicaid: Examining children's behavioral health service utilization and expenditures*, 2005-2011. Center for Health Care Strategies.
[6] Stroul, B., Pires, S., Boyce, S., Krivelyova, A., and Walrath, C. (2014). *Return on investment in systems of care for children with behavioral health challenges.* Washington, D.C.: Georgetown University Center for Child and Human Development, National Technical Assistance Center for Children's Mental Health.
[7] Parent/Professional Advocacy League. (2010). *Overcoming barriers in our community: How are we doing?* Retrieved on Aug. 11, 2014, from: http://ppal.net/wp-content/uploads/2011/01/Overcoming-Barriers-in-our-Community.pdf
[8] Evercare and the National Alliance for Caregiving. (2009). *The economic downturn and its impact on family caregiving: Report of findings.* Minnetonka, Minn.: Evercare; Bethesda, Md.: NAC. Retrieved on Aug. 11, 2014, from: http://www.caregiving.org/data/EVC_Caregivers_Economy_Report FINAL_4-28-09.pdf
[9] Bruns, J., and Burchard, J. (2000). *Impact of respite care services for families with children experiencing emotional and behavioral problems.* Children's Services: Social Policy, Research, and Practice, 3(1), 39-61.
[10] Parent/Professional Advocacy League and Massachusetts Department of Mental Health. (2013). Op cit.
[11] Supra note 1.
[12] Supra note 4.
[13] AdoptUSKids (2012). *Creating and sustaining effective respite services.* Linthicum, Md.: Author. Retrieved on Aug. 3, 2014, from: http://adoptuskids.org/_assets/files/AUSK/respite-program/creating-and-sustaining-effective-respite-services.pdf
[14] Supra note 4.
[15] http://www.ada.gov/ada_title_II.htm
[16] http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-and-Periodic-Screening-Diagnostic-and-Treatment.html
[17] U.S. Department of Health and Human Services, Center for Medicaid and CHIP Services, and the Substance Abuse and Mental Health Services Administration. (2013). *Coverage of behavioral health services for children, youth, and young adults with significant mental health conditions.* Retrieved on June 20, 2014, from: http://medicaid.gov/Federal-Policy-Guidance/Downloads/CIB-05-07-2013.pdf
[18] Funding for extra activities such as an art or music class may be provided by the family, a flexible fund account that is available to the provider, or through a scholarship or philanthropic organization.
[19] Stroul, B., Blau, G., and Friedman, R. (2010). *Updating the system of care concept and philosophy*. Washington, D.C.: Georgetown University Center for Child and Human Development, The National Technical Assistance Center for Children's Mental Health.
[20] The LBHP partner agencies include the Louisiana Office of Behavioral Health, Medicaid, Office of Juvenile Justice, Department of Children and Family Services, and the Department of Education.
[21] Indiana Health Coverage Program, Division of Mental Health and Addiction. Child Mental Health Wraparound Services. Version 1.3, Feb. 13, 2017. Retrieved Sept. 18, 2017, from: http://provider.indianamedicaid.com/media/155601/dmha cmhw.pdf
[22] A qualified individual is defined as a licensed mental health professional employed by the state's UR contractor who has the education and professional qualifications to enable them to complete an assessment that is specific to the 1915(i) HCBS State Plan program.
[23] Supra note 24.
[24] Connecticut Department of Social Services. Residential Home Care Services Rates. Retrieved Sept. 18, 2017, from: http://www.ct.gov/dss/lib/dss/pdfs/ratesetting/rch/residential_care_home_schedule_08-01-2014.xlsx
[25] Supra note 24.
[26] Magellan of Louisiana. (n.d.) Short-Term Respite Care. Retrieved Sept. 18, 2017, from: http://sites.magellanhealth.com/media/1371100/informational_sheet_-_short_term_respite.pdf
[27] Code of Maryland Regulations 10.09.89.11. Retrieved Sept. 18, 2017, from: http://www.dsd.state.md.us/comar/comarhtml/10/10.09.89.11.htm:
[28] Montana 1915(i) Codes, Modifiers, and Fees, Effective July 1, 2016. Retrieved Sept. 18, 2017, from: http://medicaidprovider.mt.gov/Portals/68/docs/feeschedules/2016/July2016Finalized/fsprov28_1915July 2016.pdf
[29] Ohio Medicaid and CareSource MyCare Ohio Health Partners. Behavioral Health Respite Care Services for Children. July 17, 2017. Retrieved Sept. 18, 2017, from: https://www.caresource.com/documents/behavioral-health-respite-care-services-for-children/
[30] Ohio Administration Code, 5160-26-03 Managed Health Care Programs: Covered Services. Retrieved Sept. 18, 2017, from: http://codes.ohio.gov/oac/5160-26-03
[31] Rosenzweig, J.M., Brennan, E.M., and Ogilvie, A. M. (2002). *Work-family fit: Voices of parents of children with emotional and behavioral disorders*. Social Work, 47(4), 415-424. doi:10.1093/sw/47.4.415
[32] Pilapil, M., Coletti, D.J., Rabey, C., and DeLaet, D. (2017). *Caring for the Caregiver: Supporting Families of Youth with Special Health Care Needs*. Current Problems in Pediatric and Adolescent Health Care 47(8): 190-199.