

Lagging coverage for mental health services among children and adolescents through home and community-based Medicaid waivers

Jessica Keim-Malpass PhD, RN^{1,2}  | Leeza Constantoulakis PhD, RN¹ |
Emily K. Shaw MSN, CPNP-BC³ | Lisa C. Letzkus PhD, RN, CPNP-AC^{1,2}

¹Department of Acute and Specialty Care, School of Nursing, University of Virginia, Charlottesville, Virginia, USA

²Department of Pediatrics, School of Medicine, University of Virginia, Charlottesville, Virginia, USA

³Atlantic Medical Group Child Development Center, Morristown, New Jersey, USA

Correspondence

Jessica Keim-Malpass, PhD, RN, Department of Acute and Specialty Care, School of Nursing, University of Virginia, P.O. Box 800782, Charlottesville, VA, USA.
Email: Jlk2t@virginia.edu

Funding information

Lucile Packard Foundation for Children's Health

Abstract

Problem: Many states cover mental health home and community-based services (HCBS) for youth through 1915(c) Medicaid HCBS waivers that allow states to waive certain Medicaid eligibility criteria and define high-risk populations based on age, medical condition(s), and disability status. We sought to evaluate how States are covering children and adolescents with mental health needs through 1915(c) waivers compared to other youth waiver populations.

Methods: Data elements were extracted from Medicaid 1915(c) approved waivers applications for all included waivers targeting any pediatric age range through October 31, 2018. Normalization criteria were developed and an aggregate overall coverage score and level of funding per person per waiver were calculated for each waiver.

Findings: One hundred and forty-two waivers across 45 states were included in this analysis. Even though there was uniformity in the Medicaid applications, there was great heterogeneity in how waiver eligibility, transition plans, services covered, and wait lists were defined across group classifications. Those with mental health needs (termed serious emotional disturbance) represented 5% of waivers with the least annual funding per person per waiver.

Conclusions: We recommend greater links between public policy, infrastructure, health care providers, and a family-centered approach to extend coverage and scope of services for children and adolescents with mental health needs.

KEYWORDS

children with medical complexity, data standards, economic evaluation, family-centered care, health policy, Medicaid, waivers

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

© 2022 The Authors. *Journal of Child and Adolescent Psychiatric Nursing* published by Wiley Periodicals LLC.

1 | INTRODUCTION

Children and adolescents with a diagnosis representing those with a “serious emotional disturbance” (SED) have both a diagnostic and statistical manual of mental disorders-based psychiatric or mental health condition and concurrent symptoms that impair functioning in school, home, or the community, and represent 8%–12% of all youth in the United States (Costello et al., 2005; Williams et al., 2018). Children and adolescents with SED are at increased risk for school drop-out, increased risk of substance use, criminal justice involvement, and the potential to harm themselves or others (Graaf & Snowden, 2018; Graaf et al., 2021). Further, families and caregivers are also significantly impacted by children and adolescents with SED with reports of significant strain in the family, particularly in anxiety, depression, and distress (Corliss et al., 2008).

Among children and youth with co-existing medical complexity or multimorbidity, the prevalence of children and adolescents with concurrent SED is estimated to be between 30% and 50% (Einfeld et al., 2011). Children and adolescents with severe impairments either from SED alone or SED along with medical complexity need access to intensive services to be able to remain in home and community-based settings (Graaf & Snowden, 2019; Graaf et al., 2021). Care delivered in the home and community-based setting is a critical place of treatment for many SED, children with medical complexity (CMC), and other developmental disabilities (Barnert et al., 2018). Due in part to the advancements in technology in the intensive and acute care setting, CMC and children with co-existing CMC/SED are increasing in numbers and represent the majority of all pediatric health care expenditures (Berry et al., 2014; Breneol et al., 2017). CMC/SED have multiple transitions between hospital and home and rely on home and community-based health services (HCBS) to keep them out of the hospital or institutional-based settings (Breneol et al., 2017; Coller et al., 2017; Leyenaar & O'Brien, 2017). Numerous states cover these services through 1915(c) Medicaid HCBS waivers that allow states to waive certain income-based eligibility criteria and the flexibility to design services based on high-risk definitions, ages, medical conditions, and disability status (Friedman et al., 2015; Keim-Malpass, Constantoulakis, et al., 2019; Keim-Malpass, Letzkus, et al., 2019). They also get to establish the types of services included in each waiver, limits to waiver enrollees, the amount of time a child or adolescent can be on a waiver, and the total amount allocated toward each waiver type. All 1915(c) Medicaid waiver programs must be cost-neutral in design—in essence they must cost the government no more than if the state did not have the waiver (Keim-Malpass, Constantoulakis, et al., 2019). Cost-neutrality is usually accomplished through individual cost limits, limits in services offered, enrollment caps, and waiting lists (Keim-Malpass, Constantoulakis, et al., 2019; Keim-Malpass, Letzkus, et al., 2019). Many of the frameworks for service structure, reimbursement, and eligibility of HCBS are often based on adult models of care and health delivery and there is a dearth of research focused on the coverage of these services for children and adolescents with CMC and SED.

The demand for HCBS is increasing, yet there are many barriers to achieving these services which impact the overall continuity of care for families of children with SED (Cohen et al., 2012; Simpser & Hudak, 2017). There are an inadequate number of providers or services that offer HCBS for children in particular, due in part to the inadequate payment structures and reimbursement (Simpser & Hudak, 2017). Additionally, there are many restrictions of waiver benefits in terms of limits of scope of services offered and eligibility caps, which often result in long wait lists and fragmented care (Cady & Belew, 2017). As such, many families either go without accessing these services or attempt to provide the services themselves which leads to increase financial and psychological burdens on the entire family (Thomson et al., 2016). Beyond the difficulty experienced by families attempting to navigate the complicated HCBS terrain, we have found that pediatric providers are also left with similar feelings of confusion and frustration (Keim-Malpass, Constantoulakis, et al., 2019; Keim-Malpass, Letzkus, et al., 2019).

With general historical movements away from institutional settings and toward engagement with home-and community-based services, Medicaid waivers are an important piece of this model of care coverage. Specifically, among youth with SED, Graaf et al. (2021) found that youth that lived in a state with Medicaid waiver coverage had reduced odds of unmet mental health needs. There is very limited data on the scope of services offered for 1915(c) waivers targeted toward children, generally, and particularly children and adolescents with SED. Further, there is no current best practice standard highlighting norms for the types of services offered and the duration of those services that are covered on through the waiver. Therefore, the purpose of this study was to evaluate the scope of coverage for waivers covering children with SED compared to waivers covering CMC, generally. Further, we sought to determine annual expenditures per person per waiver based on waiver type.

2 | METHODS

We conducted a cross-sectional comparative policy analysis using Medicaid 1915© waiver applications. Medicaid waiver applications are initiated by the State Medicaid offices to the Center for Medicare & Medicaid services for each individual waiver they are applying for and are generally approved for 5-year periods. These documents are freely accessible on government CMS websites. Approved 1915(c) waivers are uniform in application structure and are over 300 pages in length. Relevant waivers were included if: they were nonexpired from December 31, 2017, to October 31, 2018, and included children (ages 0–21) in their eligibility. As part of the larger parent study, the authors developed a systematic search and data extraction template to abstract key elements from the Medicaid applications (Keim-Malpass, Constantoulakis, et al., 2019; Keim-Malpass, Letzkus, et al., 2019). A systematic extraction template was used to classify the elements included in the waivers, including dollars allocated per individual, time an individual can remain on the waiver, use of cost containment strategies (capitation or individual cost limits), the

possibility that a child could transition as an adult within the same waiver without a reapplication, range of pediatric ages covered, and the scope of the service type allowed on the waiver (Keim-Malpass, Constantoulakis, et al., 2019; Keim-Malpass, Letzkus, et al., 2019). Scope of coverage could be further defined as the following: (1) case management/care coordination; (2) education services offered to family or school about the care of the child; (3) environmental/home/vehicle modifications; (4) specialized equipment/supplies; (5) counseling/psychological support/behavioral support for the child; (6) caregiver/parental/family counseling or support; (7) personal care/day habilitation; (8) respite; (9) therapies (physical therapy, occupational therapy, speech, vision, auditory); (10) skilled nursing/private duty nursing; (11) treatment (pharmaceutical, dietary, dental services) (Keim-Malpass, Constantoulakis, et al., 2019).

Normalization criteria were developed to be able to draw comparisons across waivers and to calculate an overall coverage score for each waiver. Full methodological details of the data extraction process and normalization calculation can be retrieved from previous publications (Keim-Malpass, Constantoulakis, et al., 2019; Keim-Malpass, Letzkus, et al., 2019). In summary, an individual coverage score was calculated for each waiver based on the summation of each criteria. For this analysis, summaries were then aggregated by the target groups defined by the Centers for Medicare & Medicaid Services (CMS) and include: (1) disabled—physical; (2) autism/intellectual disability (ID)/developmental disability (DD); (3) disabled—sub-groups including medical fragility, technology dependence, HIV/AIDS, brain injury; (4) mental illness—SED. Descriptive statistics were used to calculate (1) the mean overall coverage score and (2) the mean dollar spent per person per year for each waiver target group.

3 | RESULTS

A total of 142 waivers across 5 states included children and adolescent age ranges. The majority of waivers target individuals with autism/ID/DD with only 5% of the waivers toward those with SED (Figure 1). The mean dollar spent per person per year was also highest for autism/ID/DD waivers at nearly \$37,000 compared to those with SED where the annual cost per person per year was under \$7000 (Figure 2). The calculated overall coverage score ranged from 0 to 11.68 and the autism/ID/DD waivers had the highest mean score (5.47, SD 2.64) followed by disabled—physical (5.06, SD 1.77), medical fragility/tech dependence/HIV/brain injury (4.02, SD 1.93), and mental illness/SED (2.7, SD 1.36) (Table 1).

When individual levels of service were assessed, there were several key differences in the scope of coverage for waivers of children with SED compared to the other waiver types. The mean number of services covered on SED waivers was 9.6 services compared to 14.8 services for other waiver types. Similarly, SED waivers only covered 38.6% of different types of services while other types on averaged covered 51.2% of the following types: (1) case management/care coordination; (2) education services offered to family or school about

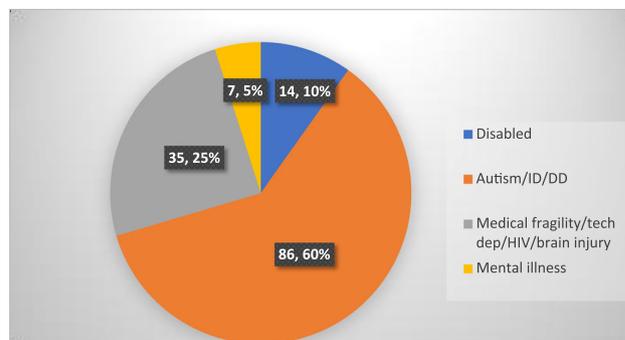


FIGURE 1 1915(c) waivers by target group $n = 142$ across 45 states [Color figure can be viewed at wileyonlinelibrary.com]

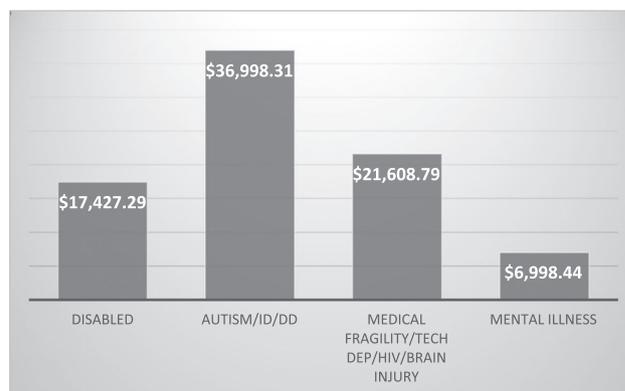


FIGURE 2 Annual mean expenditures per person per waiver

care of the child; (3) environmental/home/vehicle modifications; (4) specialized equipment/supplies; (5) counseling/psychological support/behavioral support for the child; (6) caregiver/parental/family counseling or support; (7) personal care/day habilitation; (8) respite; (9) therapies (physical therapy, occupational therapy, speech, vision, auditory); (10) skilled nursing/private duty nursing; (11) treatment (pharmaceutical, dietary, dental services). Most commonly, SED waivers covered counseling or psychological support; caregiver counseling or psychological support; and respite care. None of the SED waivers covered personal care/day habilitation; physical therapy/occupational therapy/speech; skilled nursing/private duty nursing; or treatment/dietary services. None of the included SED waivers had any provisions for the transition of care either within the same waiver with max ages ranging from 17 to 21 years of age. The majority (88%) of the SED waivers had individual cost limits per year, so once that limit was reached for the year for that child or adolescent, they would not be eligible for any remaining services.

4 | DISCUSSION

To our knowledge, this is the first study to systematically evaluate coverage of Medicaid 1915(c) waivers for children with SED compared to other pediatric/adolescent waivers. The overall

Component	Medical complexity (non-SED)	Mental illness/SED
Mean # of services covered	14.8	9.6
Percent of types of services covered ^a	51.2%	38.6%
Calculated mean overall coverage score	5.1	2.7

Abbreviation: SED, serious emotional disturbance.

^aPercent of services that cover the following domains: (1) case management/care coordination; (2) education services offered to family or school about care of the child; (3) environmental/home/vehicle modifications; (4) specialized equipment/supplies; (5) counseling/psychological support/behavioral support for the child; (6) caregiver/parental/family counseling or support; (7) personal care/day habilitation; (8) respite; (9) therapies (physical therapy, occupational therapy, speech, vision, auditory); (10) skilled nursing/private duty nursing; (11) treatment (pharmaceutical, dietary, dental services).

Medicaid coverage score takes into account access and scope of services in the face of cost neutrality. Autism/ID/DD waivers 1915(c) waivers are the most common and most comprehensive in coverage with waivers targeting children with mental health needs (here, representing SED) severely lagging in both dollars allocated per person per year and overall calculated coverage score. Additionally, none of the waivers allowed for transition to adult services beyond the age of 21, which represents a remarkable gap in care. The state-by-state examination of all waivers for children allows for comparison of SED waivers to other waiver types and can establish a benchmark to set policy priorities for children and adolescents with SED or mental health needs.

We wish to discuss several key areas highlighting policy recommendations:

- (1) Synergy across financing strategies for mental health needs in the context of children with multimorbidity

Pediatric HCBS covering children and adolescents with SED are currently financed and supported through a complex, multifaceted system of sometimes overlapping Federal and State provisions, regulations, and legislation that do not always work in coordination with one another. Many states cover HCBS through 1915(c) Medicaid HCBS waivers that allow states to waive certain income eligibility criteria and define high-risk populations based on age, medical condition(s), and disability status (Perrin, 2012). All waiver programs must cost the federal government no more than if the states did not have the waiver (i.e., cost-neutrality) which often means enrollment limits, waiting lists, or individual cost limits that can result in gaps of care (Ng et al., 2015; Rosenthal et al., 2012).

There are other models of financing including the Tax Equity and Responsibility Act (TERFA)/Katie Beckett pathway that allows any state to extend Medicaid to a child with a significant disability or life-limiting illness, but often this approach extends the regular Medicaid state plan and often does not include additional HCBS (Catalyst Center, 2011; Keim-Malpass et al., 2013; Rosenthal et al., 2012; Simpser & Hudak, 2017). Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) benefits provide essential medical services, some personal care, and hospice care to various high-risk populations (Catalyst

TABLE 1 1915(c) waiver comparisons highlight mental illness/SED compared to medical complexity (non-SED) waiver types

Center, 2011; Farrall et al., 2011; Simpser & Hudak, 2017). Following the Affordable Care Act, some states will continue to opt to apply for 1115 demonstration waiver applications for HCBS (Drake et al., 2016). States can interpret demonstration waivers widely and they are intended to broaden out services and connect social services along with health services (Drake et al., 2016; Revere et al., 2016). Other states have moved toward Medicaid managed care which some believe will broaden eligibility to more people, but may limit the type of services offered (Hall et al., 2013). Additional study is required to comparing access to services for SED across all financial payers because when assessing all pediatric/adolescent 1915(c) waivers, we are only evaluating one limited financial model. Despite this limitation, within this “snapshot” of the 1915 waivers, we find that SED waivers are dramatically underfunded compared to other pediatric waiver types.

- (2) Enhanced data harmonization requirements can lead to further economic analyses

Despite progress in rebalancing long-term care for children over the past decade, there is significant variation in spending and service provision across states and across waiver types, as we also find in our present analysis with allocation to children and youth waivers targeting mental illness/SED severely lacking in both quantity of services and direct financial provisions. Additionally, there is a lack of empirical or economic evidence which supports the effectiveness of different approaches, waiver components, or scope of services offered (Frimpong et al., 2018; Segelman et al., 2017; Velott et al., 2015). One of the barriers to date has been in harmonizing the variability in how waivers are operationalized and the lack of data standards that exist (Higdon et al., 2013). As an example, we conducted a recent comparative analysis assessing all 142 1915(c) waivers targeting children and despite having HCBS-centered taxonomy, there was great variability in how states described services and eligibility criteria (Keim-Malpass, Constantoulakis, et al., 2019). Profound variation makes it incredibly difficult to draw comparisons across states or offer guidance for best practices. To address this barrier, we created a normalization calculation that assesses overall coverage per waiver which can then be aggregated to the state level. While this approach can allow for systematic assessment, it

still only addressed 1915(c) waivers, which are only one piece of the financing puzzle. To date, there is no standardization in 1115 demonstration waiver applications which makes the same approach nearly impossible at this point in time. Further, the specific assessment of coverage for youth with SED represents a significant gap in the literature.

(3) Family-centered models of care for children with mental health needs in clinical settings

Due to the extensive caregiving burden on families of CMC, policy and financing structure should take a family-centered approach to provide services, including mental and behavioral health (Kuhlthau et al., 2011; Lor et al., 2016). Children with SED have very specific developmental, physical, social, and psychological needs that can be addressed through a tailored approach across the care trajectory (Barnert et al., 2018; Olson, 2017). For instance, there are several waivers that target only pediatric age ranges (i.e., 0–21) that include provisions such as caregiver/parental/family counseling, bereavement or sibling support as a key service offered, which recognizes the child embedded in the context of the entire family. Additionally, there are specific developmental milestones and points in time where intensive therapy may be most beneficial. Finally, there is early evidence that supporting the entire family through services such as respite care has positive economic impacts for the family and society (Leslie et al., 2017).

A larger point of discussion is the general lack of advocacy supporting the implementation of models of care that we know are beneficial for children and adolescents with SED. More study is also needed to discover the coverage elements are the most beneficial for youth with SED and co-occurring medical complexity, as it appears through this study that the medical complexity components are prioritized over mental and emotional components of coverage. As such, sustained research is needed in this area to demonstrate effectiveness in implementation, monetary programmatic support, and translation to policy of beneficial family-centered models of care. Child adolescent psychiatric nurses can play a key role in establishing research priorities in this regard as they are the experts in demonstrating short- and long-term health outcomes for both the child and family that can be used to demonstrate effectiveness.

(4) Interprofessional integration to learn how to support families

Navigating HCBS alongside families of children and adolescents with SED is complicated and ever-evolving. Psychiatric-mental health nurse practitioners have a unique opportunity to work alongside families as they transition from intensive care to ambulatory care to home and back to the hospital. Psychiatric-mental health nurses are also in a position to continue to advocate for enhanced family-centered supports for HCBS (Perkins & Agrawal, 2018; Unicef, 2010). To be more effective in our own understanding, there is an opportunity for enhanced collaboration with our social work and physician colleagues in an interprofessional way for continued education, support, and advocacy (Bainbridge et al., 2014). Researchers and policymakers are wise to include

clinicians at the point of care in their research teams and policy guidance because there is much to be learned about experiences on the ground and an inherent knowledge of daily challenges children, adolescents, and families of SED face. Clinicians at the point of care bring inherent knowledge about care trajectories and therapeutic approaches that may be the most beneficial. Currently, most of the waiver applications are made by Medicaid state administrators with limited clinical involvement or expertise in care coverage decisions and sustained engagement across different stakeholder groups offers an opportunity to advocate for evidence-based community supports.

There are several limitations of our analysis. We only included spending and coverage assessment from 1915(c) waivers, and as we note there are numerous other ways to finance mental health coverage. Because of this, further study is needed to expand beyond 1915(c) waivers to assess all services that cover a child with SED on a state-by-state comparison level. This type of analysis could then be expanded to demonstrate the impact of service coverage on longitudinal mental health outcomes for both patients and families. There were limited ways to be able to characterize mental health components of other waiver types that were not classified as mental health/SED because waivers do not report spending by program type within a waiver, just the overall waiver type. Finally, due to the variation in reporting, we were not able to include 1115 demonstration waiver spending into this present analysis. Even so, we recognize numerous gaps in spending and coverage for children with mental health needs. We must advocate for innovative models of care that are evidence-based, family-centered, and developmentally appropriate as well as setting implementation priorities. Medicaid waivers, and other models of home- and community-based services, are in need of enhanced attention, policy surveillance, and financial attention.

ACKNOWLEDGMENT

This study was funded through the Lucile Packard Foundation for Children's Health (J. K.-M., PI).

CONFLICT OF INTEREST

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

We have our data published online and freely accessible.

ORCID

Jessica Keim-Malpass  <http://orcid.org/0000-0002-7035-8556>

REFERENCES

- Bainbridge, D., Brazil, K., Krueger, P., Ploeg, J., Taniguchi, A., & Darnay, J. (2014). Measuring horizontal integration among health care providers in the community: An examination of a collaborative process within a palliative care network. *Journal of Interprofessional Care*, 29(3), 245–252. <https://doi.org/10.3109/13561820.2014.984019>
- Barnert, E. S., Coller, R. J., Nelson, B. B., Thompson, L. R., Klitzner, T. S., Szilagyi, M., Breck, A. M., & Chung, P. J. (2018). A healthy life for a

- child with medical complexity: 10 domains for conceptualizing health. *Pediatrics*, 142(3), e20180779. <https://doi.org/10.1542/peds.2018-0779>
- Berry, B. J. G., Hall, M., Neff, J., Goodman, D., Cohen, E., Agrawal, R., & Kuo, D. (2014). Children with medical complexity and medicaid: Spending and cost savings. *Health Affairs*, 33(12), 2199–2206.
- Breneol, S., Belliveau, J., Cassidy, C., & Curran, J. A. (2017). Strategies to support transitions from hospital to home for children with medical complexity: A scoping review. *International Journal of Nursing Studies*, 72, 91–104. <https://doi.org/10.1016/j.ijnurstu.2017.04.011>
- Cady, R., & Belew, J. (2017). Parent perspective on care coordination services for their child with medical complexity. *Children*, 4(6), 45. <https://doi.org/10.3390/children4060045>
- Catalyst Center. (2011). *Financing Pediatric palliative and hospice care programs*. Health Care. Retrieved Sept 4, 2022, from <https://ciswh.org/resources/financing-pediatric-palliative-and-hospice-care-programs/>
- Cohen, E., Lacombe-Duncan, A., Spalding, K., MacInnis, J., Nicholas, D., Narayanan, U. G., Gordon, M., Margolis, I., & Friedman, J. N. (2012). Integrated complex care coordination for children with medical complexity: A mixed-methods evaluation of tertiary care-community collaboration. *BMC Health Services Research*, 12, 366. <https://doi.org/10.1186/1472-6963-12-366>
- Coller, R. J., Nelson, B. B., Klitzner, T. S., Saenz, A. A., Shekelle, P. G., Lerner, C. F., & Chung, P. J. (2017). Strategies to reduce hospitalizations of children with medical complexity through complex care: Expert perspectives. *Academic Pediatrics*, 17(4), 381–388. <https://doi.org/10.1016/j.acap.2017.01.006>
- Corliss, B. A., Lawrence, E. C., & Nelson, M. A. (2008). Families of children with serious emotional disturbances: Parent perceptions of family resources and stressors. *Child and Adolescent Social Work Journal*, 25(4), 271–285. <https://doi.org/10.1007/s10560-008-0126-0>
- Costello, E. J., Egger, H., & Angold, A. (2005). 10-year research update review: the epidemiology of child and adolescent psychiatric disorders: I. Methods and public health burden. *Journal of the American Academy of Child and Adolescent Psychiatry*, 44(10), 972–986. <https://doi.org/10.1097/01.chi.0000172552.41596.6f>
- Drake, M., Gevorgyan, A., & Hetterich, C. (2016). Lessons from a Medicaid Section 1115 waiver program. *Healthcare Financial Management*, 70, 86–94.
- Einfeld, S. L., Ellis, L. A., & Emerson, E. (2011). Comorbidity of intellectual disability and mental disorder in children and adolescents: A systematic review. *Journal of Intellectual & Developmental Disability*, 36(2), 137–143. <https://doi.org/10.1080/13668250.2011.572548>
- Farrall, K., Hess, C., & Justice, D. (2011). *The Affordable Care Act and Children with Special Health Care Needs: An analysis and steps for state policymakers*. Retrieved October 1, 2017 from <http://www.nashp.org/sites/default/files/aca.children.special.hcneeds>
- Friedman, C., Lulinski, A., & Rizzolo, M. C. (2015). Mental/behavioral health services: Medicaid home and community-based services 1915(c) waiver allocation for people with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, 53(4), 257–270. <https://doi.org/10.1352/1934-9556-53.4.257>
- Frimpong, E. Y., Kuang, J., Wang, R., & Radigan, M. (2018). Medicaid cost trajectories for children with serious emotional disturbance: The HCBS waiver program versus targeted case management. *Psychiatric Services*, 69(11), 1160–1166. <https://doi.org/10.1176/appi.ps.201700537>
- Graaf, G., & Snowden, L. (2018). Medicaid waivers and public sector mental health service penetration rates for youth. *The American Journal of Orthopsychiatry*, 88(5), 597–607. <https://doi.org/10.1037/ort0000295>
- Graaf, G., & Snowden, L. (2019). State approaches to funding home and community-based mental health care for non-medicare youth: Alternatives to medicaid waivers. *Administration and Policy in Mental Health*, 46(4), 530–541. <https://doi.org/10.1007/s10488-019-00933-2>
- Graaf, G., Snowden, L., & Keyes, L. (2021). Medicaid waivers for youth with severe emotional disturbance: Associations with public health coverage, unmet mental health needs & adequacy of health coverage. *Community Mental Health Journal*, 57, 1449–1463. <https://doi.org/10.1007/s10597-020-00759-5>
- Hall, A. G., Landry, A. Y., Lemak, C. H., Boyle, E. L., & Duncan, R. P. (2013). Reported experiences with medicaid managed care models among parents of children. *Maternal and Child Health Journal*, 18, 544–553. <https://doi.org/10.1007/s10995-013-1270-5>
- Higdon, R., Stewart, E., Roach, J. C., Dombrowski, C., Stanberry, L., Clifton, H., Kolker, N., van Belle, G., Del Beccaro, M. A., & Kolker, E. (2013). Predictive analytics in healthcare: Medications as a predictor of medical complexity. *Big Data*, 1(4), 237–244. <https://doi.org/10.1089/big.2013.0024>
- Keim-Malpass, J., Constantoulakis, L., & Letzkus, L. C. (2019). Variability in states' coverage of children with medical complexity through home and community-based services waivers. *Health Affairs (Project Hope)*, 38(9), 1484–1490. <https://doi.org/10.1377/hlthaff.2018.05413>
- Keim-Malpass, J., Hart, T. G., & Miller, J. R. (2013). Coverage of palliative and hospice care for pediatric patients with a life-limiting illness: A policy brief. *Journal of Pediatric Health Care*, 27(6), 511–516. <https://doi.org/10.1016/j.pedhc.2013.07.011>
- Keim-Malpass, J., Letzkus, L. C., & Constantoulakis, L. (2019). Publicly funded home and community-based care for children with medical complexity: Protocol for the analysis of medicaid waiver applications. *JMIR Research Protocols*, 8(7), e13062. <https://doi.org/10.2196/13062>
- Kuhlthau, K. A., Bloom, S., Van Cleave, J., Knapp, A. A., Romm, D., Klatka, K., Homer, C. J., Newacheck, P. W., & Perrin, J. M. (2011). Evidence for family-centered care for children with special health care needs: A systematic review. *Academic Pediatrics*, 11(2), 136–143. <https://doi.org/10.1016/j.acap.2010.12.014>
- Leslie, D. L., Iskandarani, K., Velott, D. L., Stein, B. D., Mandell, D. S., Agbese, E., & Dick, A. W. (2017). Medicaid waivers targeting children with autism spectrum disorder reduce the need for parents to stop working. *Health Affairs*, 36(2), 282–288. <https://doi.org/10.1377/hlthaff.2016.1136>
- Leyenaar, J. K., & O'Brien, E. R. (2017). Families' priorities regarding hospital-to-home transitions for children with medical complexity. *Pediatrics*, 139(1), 33. <https://doi.org/10.1542/peds.2016-1581>
- Lor, M., Crooks, N., & Tluczek, A. (2016). A proposed model of person, family, and culture centered nursing care. *Nursing Outlook*, 64(4), 352–366. <https://doi.org/10.1016/j.outlook.2016.02.006>
- Ng, T., Stone, J., & Harrington, C. (2015). Medicaid home and community-based services: How consumer access is restricted by state policies. *Journal of Aging & Social Policy*, 27(1), 21–46. <https://doi.org/10.1080/08959420.2015.969078>
- Olson, K. (2017). After the visit: An overview of government and community programs supporting children with medical complexity. *Children*, 4(5), 35. <https://doi.org/10.3390/children4050035>
- Perkins, J., & Agrawal, R. (2018). Protecting rights of children with medical complexity in an era of spending reduction. *Pediatrics*, 141(Suppl 3), S242–S249. <https://doi.org/10.1542/peds.2017-12841>
- Perrin, C. O. (2012). *Home and community-based 1915 (c) Medicaid waivers for respite support state-by-state tables of Medicaid waiver information*. Network (Vol. 1915). Retrieved from October 1, 2017, <http://www.lifespanrespite.memberlodge.org/Resources/Documents/Home>
- Revere, L., Semaan, A., Lievsay, N., Hall, J., Wang, Z. M., & Begley, C. (2016). Collaborative learning in the Texas medicaid 1115 waiver program. *Journal for Healthcare Quality*, 38(6), e52–e63. <https://doi.org/10.1097/JHQ.0000000000000058>

- Rosenthal, J., Hendersen, M., Dolatshahi, J., Hess, C., Tobias, C., Bachman, S., & Comeau, M. (2012). *Public insurance programs and children with special health care needs*. National Association for State Health Policy. National Association for State Health Policy. Retrieved August 15, 2014, from <http://www.nashp.org/public-insurance-programs-and-children-special-health-care-needs-tutorial-basics/>
- Segelman, M., Intrator, O., Li, Y., Mukamel, D., Veazie, P., & Temkin-Greener, H. (2017). HCBS spending and nursing home admissions for 1915(c) waiver enrollees. *Journal of Aging & Social Policy*, 29(5), 395–412. <https://doi.org/10.1080/08959420.2017.1319714>
- Simpser, E., & Hudak, M. L. (2017). Financing of pediatric home health care. *Pediatrics*, 139(3), e20164202. <https://doi.org/10.1542/peds.2016-4202>
- Thomson, J., Shah, S. S., Simmons, J. M., Sauers-Ford, H. S., Brunswick, S., Hall, D., Kahn, R. S., & Beck, A. F. (2016). Financial and social hardships in families of children with medical complexity. *Journal of Pediatrics*, 172, 187–193. <https://doi.org/10.1016/j.jpeds.2016.01.049>
- Unicef. (2010). *Advocacy toolkit. A guide to influencing decisions that improve children's lives*.
- Velott, D. L., Agbese, E., Mandell, D., Stein, B. D., Dick, A. W., Yu, H., & Leslie, D. L. (2015). Medicaid 1915(c) home- and community-based services waivers for children with autism spectrum disorder. *Autism*, 20(4), 473–482. <https://doi.org/10.1177/13623613155590>
- Williams, N. J., Scott, L., & Aarons, G. A. (2018). Prevalence of serious emotional disturbance among U.S. children: A meta-analysis. *Psychiatric Services*, 69(1), 32–40. <https://doi.org/10.1176/appi.ps.201700145>

How to cite this article: Keim-Malpass, J., Constantoulakis, L., Shaw, E. K., & Letzkus, L. C. (2022). Lagging coverage for mental health services among children and adolescents through home and community-based Medicaid waivers. *Journal of Child and Adolescent Psychiatric Nursing*, 1–7. <https://doi.org/10.1111/jcap.12392>