Statement for the Record
Senate Finance Committee
Youth Residential Treatment Facilities: Examining Failures and Evaluating Solutions

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The National Health Law Program (NHeLP) is a public interest law firm working to protect and advance the health rights of low income and underserved individuals. Founded in 1969, NHeLP advocates, litigates, and educates at the federal and state levels. Consistent with its mission, NHeLP works to ensure that all people in the United States have access to affordable, quality health care, including comprehensive behavioral health services. We submit the following statement as long-time advocates for children with significant mental health needs, based on our extended experience advocating for the needs of children with mental health conditions administratively, legislatively, and in the federal courts.

We appreciate the Committee's careful and thorough documentation of the overuse of residential treatment facilities, and its many devastating consequences. The conditions reported in the Committee's Staff Report reflect an ongoing failure to develop robust, community-based youth behavioral health care services. Residential treatment facilities are neither designed nor equipped to meet the needs of youth with complex behavioral health conditions, or to deliver intensive, individualized therapeutic interventions that enable youth to succeed upon discharge or avoid readmission. Overutilization of residential treatment facilities therefore deprives youth with complex behavioral health conditions of integrated, developmentally appropriate, individualized therapeutic interventions that meaningfully treat their conditions. Overutilization of residential treatment creates conditions that are ripe for neglect, abuse, and unsafe and unsanitary conditions children the Committee has documented.

Furthermore, segregation, in and of itself, is harmful -- particularly the prolonged segregation described in the Committee's report. Children do best with families, and when they cannot be with their family of origin, they should be in the least restrictive, most family-like setting.[1] The segregation of youth in residential treatment facilities separates them from their families and communities.. When segregated for long periods, youth's existing coping and social skills and their behavioral health can

[1] American Acad. of Pediatrics et al., *The Path to Well-being for Children and Youth in Foster Care Relies on Quality Family-Based Care* (Jan. 2022), https://familyfirstact.org/resources/path-well-being-children-and- youth-foster-care-relies-quality-family-based-care-what%E2%80%99s.

deteriorate as a result of being separated from their families and friends. Segregation in residential treatment facilities often deprives youth of opportunities to develop their strengths and pursue age-appropriate interests, both of which can help them constructively manage their behavioral health conditions. Finally, prolonged segregation in residential treatment facilities deprives youth of the opportunity to build coping and other skills to manage their behavioral health conditions in the community-based settings in which they will eventually be expected to function successfully – at home, at school, in the community, and in the workplace. As the U.S. Department of Health and Human Services (HHS) explained in the preamble to the regulation implementing Section 504 of the Rehabilitation Act states, "[C]ongregate care is virtually never the most appropriate long-term placement for children."[2]

Expanding the Availability of Quality Intensive Home and Community-Based Behavioral Health Services Can Correct the Overreliance on Residential Treatment Facilities

For over two decades, experts have recognized the clinical benefit and cost effectiveness of intensive home and community-based services to meet the needs of youth with complex behavioral health conditions.[3] "These services enable children with complex mental health needs – many of whom have traditionally been served in restrictive settings like residential treatment centers, group homes and psychiatric hospitals – to live in community settings and participate fully in family and community life."[4]

In many states, the array of services available to youth with complex behavioral health conditions remains woefully inadequate and often disjointed.[5] As a result, these youth frequently experience cyclical and protracted placements in residential treatment facilities that do not provide them the intensive therapeutic interventions that they need.

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[2] U.S. Dep't of Health & Human Servs., *Discrimination on the Basis of Disability in Health and Human Service Programs or Activities*, 89 Fed. Reg. 40106 (May 9, 2024), https://www.federalregister.gov/documents/2024/05/09/2024-09237/nondiscrimination-on-the-basis-of-disability-in-programs-or-activities-receiving-federal-financial.

[3] CMS and SAMHSA*, Informational Bulletin: Coverage of Behavioral Health Services for Children, Youth, and Young Adults with Significant Mental Health Conditions* (May 7, 2013), https://www.medicaid.gov/federal-policy-guidance/downloads/cib-05-07-2013.pdf [hereinafter "2013 Informational Bulletin"]; *see also* CMS, *Informational Bulletin: Leveraging Medicaid, CHIP, and Other Federal Programs in the Delivery of Behavioral Health Services for Children and Youth* (Aug. 18, 2022), https://www.medicaid.gov/sites/default/files/2022-08/bhccib08182022.pdf

[4] CMS & SAMHSA, 2013 Informational Bulletin, *supra* note 3, at 1.

[5] Medicaid & CHIP Payment & Access Comm'n, Chapter 3: Access to Behavioral Health Services for Children and Adolescents Covered by Medicaid and CHIP, REPORT TO CONGRESS ON MEDICAID AND CHIP 105 (June 2021) https://www.macpac.gov/wp-content/uploads/2021/06/June-2021-Report-to-Congress-on-Medicaid-and-CHIP.pdf (noting that states have an obligation to cover these intensive home and community-based services, many children have families have difficulty accessing them).

Focused expansion of quality intensive home and community-based Medicaid services, including 1) intensive care coordination, 2) intensive in-home behavioral services, 3) mobile crisis response and stabilization services, and 4) therapeutic foster care (also sometimes referred to as "treatment foster care"), would meaningfully address the needs of youth with complex behavioral health conditions and prevent harmful out-of-home placements in residential treatment facilities. These services are essential to a functional youth behavioral health system. Expansion of these services would work to rebalance utilization of community-based services and institutional behavioral health treatment, and with it, begin to correct the overreliance on residential treatment facilities that is so harmful for the youth trapped in them.[6]

Intensive Care Coordination. Because youth with complex behavioral health conditions typically have high needs, and need multiple services to meet those needs, intensive care coordination is essential.[7] Intensive care coordination—particularly the form of intensive care coordination specifically designed for youth with complex behavioral health conditions known as Wraparound intensive care coordination—is a critical component of an effective system of care. Wraparound intensive care coordination is a robust, comprehensive form of care coordination that involves a "team-based, collaborative process for developing and implementing individualized care plans for children and youth with complex needs and their families" that "focuses on all life domains and includes clinical interventions and formal and informal supports."[8] Wraparound intensive care coordination plans for a range of services to meet the multiple needs of youth and their families, individualizes those services, coordinates and monitors their delivery, and modifies youth's treatment plans to address their evolving needs.[9] Intensive care coordination has long been recognized as a critical – and highly effective – service for youth with complex behavioral health conditions.[10]

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[6] *See generally* Jocelyn Guyer et al., Manatt & The Commonwealth Fund, *Leveraging Medicaid to Support Children and Youth Living with Complex Behavioral Health Needs: Framework and Strategies* (Nov. 2023), https://www.manatt.com/Manatt/media/Documents/Articles/The-Commonwealth-Fund-Report_2023-11_c.pdf; Jennifer Lav & Kim Lewis, Nat'l Health Law Prog., *Children's Mental Health Services: The Right to Community-Based Care* (Aug. 2018); https://healthlaw.org/wp-content/uploads/2018/09/NHeLP-Issue-Brief_Children%E2%80%99s-Mental-Health-Services.pdf [hereinafter "The Right to Community-Based Care"].

[7] *Rosie D. v. Romney*, 410 F. Supp. 2d 18, 31 (D. Mass. 2006).

[8] *See* CMS & SAMHSA, *2013 Informational Bulletin*, *supra* note 3, at 3; *see also* Lav & Lewis, *The Right to Community-Based Care*, *supra* note 6 at 12.

[9] *Cf. Rosie D.*, 410 F. Supp. 2d at 31, 45 ("Most prominent in th[e] evidentiary landscape [at trial] was the absence of adequate recognition that the named Plaintiffs' serious emotional disturbances constitute chronic conditions that require continuous monitoring, coordination, and modification of services."), 52-53.

[10] *See, e.g.,* Jonathan R. Olson et al., *Systematic Review and Meta-Analysis: Effectiveness of Wraparound Care Coordination for Children and Adolescents*, 60(11) J. AM. ACAD. OF CHILD & ADOLESCENT PSYCHIATRY 1353-1366 (2021); Jennifer S. Coldiron, et al., *A Comprehensive Review of Wraparound Care Coordination Research, 1986-2014*, 26(5) J. OF CHILD & FAMILY STUD., 1245-1265 (2017); Oswaldo Urdapilleta, et al., IMPAQ Int'l, *National Evaluation of the Medicaid Demonstration Home and Community Based Alternatives to Psychiatric Residential Treatment Facilities* (2012); Kirsten Painter, *Outcomes for Youth with Severe Emotional*

Intensive In-Home Services. Intensive in-home services are highly individualized therapeutic interventions delivered to youth and families in their homes and other community settings, designed to improve youth and family functioning and prevent out-of-home placement.[11] These services offer a critical combination of individualized therapy, skills training for the youth and family or caretaker, and behavioral interventions, delivered by a team of professionals and paraprofessionals.[12] The services are tailored to address the particular and evolving needs of youth and their families in the natural environments where the challenging behaviors arise. Providers work with youth and their families to identify symptoms and triggers, develop skills needed to respond constructively to them, and build youth's capacity to effectively navigate family life, school settings, and relationships with peers and others in the community. The effectiveness of intensive in-home services to meet the needs of youth with complex behavioral health conditions and avoid residential treatment facility placements has been widely acknowledged.[13]

Mobile Crisis Response and Stabilization Services. Mobile crisis response and stabilization services (MCRSS) "are instrumental in defusing and de-escalating difficult mental health situations and preventing unnecessary out-of-home placements."[14] They are an essential component of a functioning mental health system, and can help youth experiencing acute crises avoid the need for inpatient services.[15] MCRSS are available

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Disturbance: A Repeated Measures Longitudinal Study of a Wraparound Approach of Service Delivery in Systems of Care, 41(4) CHILD & YOUTH CARE FORUM 407 (2012).

[11] *See* CMS & SAMHSA, *2013 Informational Bulletin*, *supra* note 3, at 4.

[12] *Id*.

[13] CMS & SAMHSA, *2013 Informational Bulletin*, *supra* note 3, at 3; *see also* Eric J. Bruns et al., *Defining Quality Standards for Intensive Home-Based Behavioral Treatment Programs for Youth with Serious Emotional Disorders*, 48(6) ADMIN. AND POLICY IN MENTAL HEALTH AND MENTAL HEALTH SERVS. RESEARCH 1065-1088 (2021); Samantha Moffett et al., *Intensive Home-Based Programs for Youth with Serious Emotional Disturbances: A Comprehensive Review of Experimental Findings*, 85 CHILDREN AND YOUTH SERVS. REV. 319-25 (2018).

[14] *See* CMS & SAMHSA, *2013 Informational Bulletin*, *supra* note 3, at 5; *see also* SAMHSA, *National Guidelines for Child and Youth Behavioral Health Crisis Care* at 20 (2022) (best practices for mobile crisis response for youth); Jennifer Lav & Kim Lewis, Nat'l Health Law Prog., *Children's Behavioral Health Mobile Crisis Response and Stabilization Services*, National Health Law Program Issue Brief (Jan. 31, 2022), https://healthlaw.org/wp-content/uploads/2022/02/Mobile-Response-and-Stabilization-Services-publication.pdf.

[15] *See* Jeffery Vanderploeg et al., *Mobile Crisis Services for Children and Families: Advancing a Community-based Model in Connecticut*, 71 CHILD. & YOUTH SERVS. REV. 103 (2016) (Rapid mobile response with face-to-face crisis stabilization in the home, school, and community can improve functioning and reduce utilization of emergency departments and juvenile justice facilities); Priyanka Vakkalanka, et al., *Mobile Crisis Outreach and Emergency Department Utilization: A Propensity Score-matched Analysis*, 22 WEST J. EMERG. MED. 5 (Sept. 2, 2021) (mobile crisis outreach patients were less likely to have family and social support and yet were less likely to require hospitalization for each visit); Michael Fendrich et al., *Impact of Mobile Crisis on Emergency Department Use Among Youths with Behavioral Health Service Needs*, 70 PSYCH. SERVS. 881 (Oct. 1, 2019) (youth who received mobile crisis services had a significant

24/7 and can be provided anywhere youth experience crises. The service is provided by a team comprised of professionals and paraprofessionals trained in crisis intervention skills.[16] Crucially, the MCRSS team also works with the youth and family to identify potential triggers of future crises and develops strategies to effectively address those crises when they occur.[17] The effectiveness of MCRSS to meet the acute needs of youth with complex behavioral health needs is recognized by experts and government officials alike.[18]

Therapeutic Foster Care. For youth with complex behavioral health conditions and severely impaired family relationships, or in other situations when it is not possible to provide intensive behavioral health services in the youth's family home, therapeutic foster care is a vital alternative to residential treatment facility placements.[19] Therapeutic foster care offers a clinical intervention designed to avoid a youth's placement in congregate settings, and is delivered by specially trained foster parents who help youth learn skills in a family-like environment and also work with the family or caregiver to develop skills to more effectively intervene with the youth.

Challenges Faced by Youth Who Need Intensive Home and Community-Based Behavioral Health Services

Even where states have expanded coverage of intensive home and community-based behavioral health services—including intensive care coordination, intensive in-home services, mobile crisis response and stabilization services, and therapeutic foster care—those services often are not:

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reduction in odds of a subsequent behavioral health ED visit compared with youth who did not receive community-based mobile crisis services).

[16] *See* CMS & SAMHSA, *2013 Informational Bulletin*, *supra* note 3, at 5; SAMHSA, *National Guidelines for Child and Youth Behavioral Health Crisis Care, supra note 14* at 20 (2022).

[17] *See* CMS & SAMHSA, *2013 Informational Bulletin*, *supra* note 3, at 5; SAMHSA, *National Guidelines for Child and Youth Behavioral Health Crisis Care, supra note 14* at 22 (2022).

[18] *See, e.g.*, Melissa A. Schober et al., Nat'l Ass'n of State Mental Health Program Dirs., *A Safe Place to Be: Crisis Stabilization Services and Other Supports for Children and Youth*, Paper No. 4 in the *From Crisis to Care Technical Assistance Series* (Sept. 2022), https://innovations.socialwork.uconn.edu/wp-content/uploads/sites/3657/2023/03/Safe-Place-to-Be_Childrens-Crisis-and-Supports_NASMHPD-4.pdf; SAMHSA, *Crisis Services: Effectiveness, Cost-Effectiveness, and Funding Strategies* 10-11 (2014), https://store.samhsa.gov/product/crisis-services-effectiveness-cost-effectiveness-and-funding-strategies/sma14-4848?referer=from_search_result; SAMHSA, *National Guidelines for Child and Youth Behavioral Health Crisis Care, supra note 14.*

[19] *See* Lav & Lewis, *The Right to Community-Based Care*, *supra* note 6 at 18-20; *see also* Laura W. Boyd, SPARC, *Therapeutic Foster Care: Exceptional Care for Complex, Trauma-Impact Youth in Foster Care* 3 (July 2013), https://firstfocus.org/wp-content/uploads/2014/11/11-therapeutic-foster-care-exceptional-care-for-complex-trauma-impacted-youth-in-foster-care.pdf; Phillip A. Fisher & Kathryn S. Gilliam, *Multidimensional Treatment Foster Care: An Alternative to Residential Treatment for High Risk Children and Adolescents*, 21(2) PSYCHOSOCIAL INTERVENTION 195, 196 (Aug. 2012).

- widely available due to insufficient provider networks and wait times;[20]
- sufficiently *intensive* due to overly-restrictive time-limits for services or infrequent service delivery;
- provided in accordance with appropriate standards or guidelines designed to ensure their therapeutic effectiveness or provided with only some of the components required to meeting the needs of the youth receiving them;
- provided in a highly coordinated manner;[21] or
- Accessible to children involved in child welfare and juvenile justice systems.

These deficiencies in existing services materially contribute to unnecessary—and unnecessarily prolonged—utilization of residential treatment facilities that are often a dangerous last resort for youth with complex behavioral health needs. It is essential to address these challenges.

Policy Recommendations

We wholeheartedly support the Senate Committee on Finance's recommendations in its report "Warehouses of Neglect."[22] Below are some specific policy recommendations to

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[20] To fully correct the overreliance on residential treatment facilities to address the behavioral health needs of these youth, each of these services must be made available to youth whenever and wherever they need them. Although waiting lists are not permitted for EPSDT services, as a practical matter, youth often are forced to wait for services due to provider capacity. For example, if a youth needs a psychiatric or psychological evaluation before developing a community-based treatment plan, shortages of psychiatrics and psychologists can delay access to care. This insufficient service capacity can exist even in a fee-for-service environment, where enrollees are free to choose their providers, If the community as a whole has a shortage of providers and a lack of capacity to serve youth with high-end needs, then access will be challenging. These problems can be compounded when dealing with a managed care system, where enrollees have to seek care within their network.

[21] While Wraparound intensive care coordination, intensive in-home services, and mobile crisis response and stabilization services can be beneficial even when provided to youth with complex behavioral health conditions in isolation, their effectiveness is greatest when they are delivered together, as needed, in a highly coordinated manner. *See* Declaration of Richard N. Shepler, Ph.D., *A.A. v. Phillips*, Civil Action No. 19-CV-770-BAJ-SDJ (M.D. La.), ECF No. 181-1 (9/14/2023), at p. 13 (¶ 36) ("When delivered together in a highly coordinated fashion, these services robustly create the conditions necessary for children and youth with significant emotional, behavioral, and mental health needs, including youth with SED, to function safely and successfully in their homes and communities); Eric J. Bruns Expert Report, *C.K. v. Bassett*, No. 2:22-cv-01791-NJC-JMW, ECF 54-2 (11/16/2023), at 7 (youth most likely to experience positive outcomes when ICC using Wraparound, Intensive In-Home Behavior Therapy, and Mobile Crisis Services are provided in coordinated fashion at state and local levels). These and other experts have emphasized the clinical shortcomings of disjointed interventions for youth with complex behavioral health conditions.

[22] United States Senate Committee on Finance, *Warehouses of Neglect: How Taxpayers Are Funding Systemic Abuse in Residential Treatment Facilities* 6 (June 2022).

support the Committee's recommendation to prioritize community-based services and placements.

1. Consider financial incentives to provide services with fidelity to the model.

Some services that youth need should be delivered through practice models that have fidelity scales that allow practitioners to assess whether services are being delivered in the way that they were designed.[23] For example, Intensive Care Coordination can (and should) be delivered via High Fidelity Wraparound; and for this service, there are scales to monitor fidelity to the practice model in service delivery and indicated ways to collect data about enrollment and outcomes.[24]

For services with well-established fidelity scales and evaluation processes, states could be required to implement such evaluations and publicly share data related to the evaluations. States could be provided additional funding to develop the data systems, high fidelity monitoring, and training that is necessary to demonstrate adherence to the model and to continuously improve these services.

2. Deem Psychiatric Residential Treatment Facilities (PRTFs) "institutional placements" for purposes of 1915(c) waivers.

Because PRTFs are not considered "institutional settings" for the purposes of § 1915(c), it can be difficult to target home and community-based waivers to this population through 1915(c) waivers.[25] However, between fiscal years 2007 and 2011, CMS conducted a successful national demonstration project, the Psychiatric Residential Treatment Facilities Demonstration ("PRTF Demonstration"), authorized by the Deficit Reduction Act of 2005.[26] Through the PRTF Demonstration, youth received high fidelity

[23] *See, e.g.*, University of Washington Wraparound Evaluation & Research Team, National Wraparound Implementation Center, and the National Wraparound Initiative Webinar, *Keeping Wrap on Track: A Panel of Leaders of Large-Scale Wraparound Evaluation Projects* (April 16, 2024), https://nwi.pdx.edu/webinars/Webinar54-keeping-wrap-on-track.pdf

[24] National Wraparound Initiative, National Wraparound Implementation Center, & Wraparound Evaluation and Research Team, *Guidance for Family First Prevention Services Act Evaluation Plans for High Fidelity Wraparound* (2022), https://nwi.pdx.edu/pdf/Guidance-FFPSA-High-Fidelity-Wraparound-Updated-02-2022.pdf.

[25] *See* 42 U.S.C. § 1396n(c)(2)(B) (permitting states to target waivers to those "entitled to medical assistance for inpatient hospital services, nursing facility services, or services in an intermediate care facility." We recognize that states have other options to target services to youth with specific needs, but such mechanisms, like 1915(i) state plan services, are underutilized. *See* Molly O'Malley Watts et al*.,* KFF, Medicaid Home And Community-Based Services: Medicaid Home & Community-Based Services: People Served and Spending During COVID-19 (2022), https://www.kff.org/report-section/medicaid-home-community-based-services-people-served-and-spending-during-covid-19-issue-brief/#endnote_link_548723-23 (Thirteen states have 1915(i) state plan amendments, constituting less than 1% of all spending on HCBS, and of those, only six states use 1915(i) to target individuals with mental health disabilities).

[26] Deficit Reduction Act of 2005, Pub. L. No. 109-171, § 6063, 120 Stat. 4, 99 (2006).

wraparound services (the form of ICC discussed above), and their families received respite services, and to a lesser extent in select states, peer services. These services were targeted to youth currently in PRTFs and/or youth currently in the community but at risk of PRTF placement.[27] The PRTF Demonstration served over 4,000 youth nationally, and found that providing community-based alternatives to youth meeting the PRTF level of need improved or maintained the their functional status.[28] Youth with the highest level of need consistently showed improvement in mental health status.[29] Furthermore, the waivers were cost effective: waiver services cost only 32% of comparable services provided in PRTFs.[30]

While the EPSDT mandate requires states to cover all necessary services for youth under age 21, and each of the services discussed above fall within this mandate, there are certain advantages to also utilizing a 1915(c) waiver for this population to provide services that are not otherwise covered (or coverable) as medical assistance, such as respite services. A state may also utilize a 1915(c) waiver to provide services for youth with slightly higher income levels, which can limit the harmful practice of "custody relinquishment" by families with higher incomes desperate to access community-based services for youth with complex behavioral health conditions. Last, as noted above, the fact that states have a federal obligation to cover such services does not always result in robust access to services. As the PRTF Demonstration found, use of the waiver increased participant enrollment in services and provider recruitment and enrollment.[31] Therefore, legislation that would deem a PRTF an institutional level of care for purposes of HCBS waivers may be a successful strategy to supplement essential State Plan services.

If Congress pursues this path, safeguards must be put in place to ensure that these waivers do not in any way curtail or limit a state's EPSDT obligations or State Plan services. The Medicaid Act provides for coverage of all medically necessary services that are included within the categories of mandatory and optional services listed in § 1905(a), regardless of whether such services are covered under the State Plan.[32] CMS has emphasized that, pursuant to EPSDT, states should not rely on waivers to provide services that can be authorized under a State Plan, but may use waivers to

[27] Oswaldo Urdapilleta et al., IMPAG International, LLC, *National Evaluation of the Medicaid Demonstration Waiver Home-and Community-Based Alternatives to Psychiatric Residential Treatment Facilities* (May 30, 2012), https://nwi.pdx.edu/pdf/nationalevaluationPRTF.pdf
[28] Kathleen Sibelius, Secretary of Health and Human Services, *Report to the President and Congress: Medicaid Home and Community-Based Alternatives to Psychiatric Residential Treatment Facilities Demonstration* (July 2013), https://www.medicaid.gov/sites/default/files/2019-12/prtf-demo-report.pdf.
[29] *Id.*
[30] *Id.*
[31] Oswaldo Urdapilleta, et al., IMPAG International, LLC, *National Evaluation of the Medicaid Demonstration Waiver Home-and Community-Based Alternatives to Psychiatric Residential Treatment Facilities* 51 (May 30, 2012), https://nwi.pdx.edu/pdf/nationalevaluationPRTF.pdf
[32] 42 U.S.C. §§ 1396a(a)(10)(A), 1396a(a)(43), 1396d(a)(4)(B); 1396d(r).

supplement the EPSDT benefit. [33] Thus, any waivers for PRTF levels of care should be used to help develop service structures, recruit providers, extend coverage to families with slightly higher incomes, and to supplement youth's existing entitlement.

3. **Improve Access to Services by Requiring Additional Rate Analysis.**

As noted above, although formal waitlists are not permitted for State Plan services, youth often wait for services due to poor access and provider shortages. Recently, CMS finalized the Ensuring Access to Medicaid Services rule, in part to rectify this lack of access.[34] Laudably, CMS will require comparative payment rate analysis for outpatient mental health and substance use disorder services, and this analysis must measure Medicaid fee for service rates against Medicare payment rates for the same time period (and track rates for the pediatric population separately).[35] However, for various reasons, many of the services needed to serve this population of youth may not be adequately addressed in the rate analysis.[36]

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[33] *Id.*; CMS, EPSDT – A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents 26 (2014), https://www.medicaid.gov/sites/default/files/2019-12/epsdt_coverage_guide.pdf; ("Children under age 21 who are enrolled in an HCBS waiver program are also entitled to all EPSDT screening, diagnostic, and treatment services. Because HCBS waivers can provide services not otherwise covered under Medicaid, waivers and EPSDT can be used together to provide a comprehensive benefit for children with disabilities who would otherwise need the level of care provided in an institutional setting. . . .The HCBS waiver services essentially "wrap-around" the EPSDT benefit."). CMS, Application for a § 1915(c) Home and Community-Based Waiver [Version 3.6, January 2019] Instructions, Technical Guide and Review Criteria 131-132 (2019), https://wms-mmdl.cms.gov/WMS/help/35/Instructions_TechnicalGuide_V3.6.pdf ("States have an affirmative responsibility to ensure that all child waiver participants (including children who become eligible for Medicaid by virtue of their enrollment in a HCBS waiver) receive the medically necessary services that they require, including Medicaid coverable services available under EPSDT. Because the HCBS waiver can provide services not otherwise covered under Medicaid and can also be used to expand coverage to children with special health care needs, EPSDT and HCBS waivers can work well in tandem. However, a child's enrollment in an HCBS waiver cannot be used to deny, delay, or limit access to medically necessary services that are required to be available to all Medicaid-eligible children under federal EPSDT rules.").

[34] CMS, Medicaid Program; Ensuring Access to Medicaid Services, 89 Fed. Reg. 40542 (May 10, 2024).

[35] *Id*. at 40872; 42 C.F.R. §§ 447.203(b)(2), (b)(3)(i)(B) (effective July 1, 2026).

[36] *Id.* at 40733. CMS has already stated that to narrow the analysis, it will exclude certain codes. In order to be included as a mental health service, the service must have an E/M CPT/HCPCS code that was in effect for calendar year 2023, the code must be on the Berenson-Eggers Type of Service (BETOS) code list for the same period, and it must fall into the E/M family grouping for outpatient mental health and substance use disorder services. Examples CMS gives of services that will be excluded in include peer support, psychosocial rehab, and assertive community treatment. The final list of CPT/HCPCS codes that are subject to comparative rate analysis will be published no later than July 1, 2025, and are subject to change. However, it seems likely that core services essential to support children with intensive mental health needs may not be included in this analysis.

While we appreciate that CMS has an enormous task ahead to effectively implement the Access Rule, we are concerned that payment rates for services for this population may not be adequately examined. Additional funding directed towards studying payment rates and access to the core community-based services outlined above (1) intensive care coordination, 2) intensive in-home behavioral services, 3) mobile crisis response and stabilization services, and 4) therapeutic foster care) would help inform future rulemaking to address these gaps.

Conclusion

We thank the Committee for its extensive work on behalf of youth with complex behavioral health needs, and for its steadfast commitment to improving services for these youth, and in turn, their lives. We look forward to partnering with the Committee as it continues to pursue solutions to this urgent problem.