Statement for the Record

Senate Finance Committee

Youth Residential Treatment Facilities: Examining Failures and Evaluating Solutions

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Submitted by the Long Term Services and Supports Task Force Co-Chairs
Consortium for Constituents with Disabilities

820 First Street NE, Suite 740
Washington, DC 20002

The undersigned co-chairs of the Consortium for Constituents with Disabilities (CCD) Long Term Services and Supports (LTSS) Task Force appreciate the opportunity to submit a statement for the record for the hearing, *Youth Residential Treatment Facilities: Examining Failures and Evaluating Solutions,* held on June 12, 2024. We thank the Committee for holding a hearing on the grave abuses that children and youth have suffered in residential treatment facilities, and appreciate the focus on building solutions through expanding and improving intensive home and community-based services.

CCD is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration, and inclusion of children and adults with disabilities in all aspects of society free from racism, ableism, sexism, and xenophobia, as well as LGBTQ+ based discrimination and religious intolerance. The CCD LTSS Task Force advocates for the services and supports that enable individuals with disabilities of all ages to live in their own homes and communities.

One of the Task Forces' priorities is to reduce the use of long-term institutional care for children with disabilities, and to advocate for robust implementation of children's right to community-based mental health services pursuant to the Early and Periodic Screening,

Diagnostic, and Treatment (EPSDT) mandate, the Americans with Disabilities Act, and Family First Prevention Services Act.

Several days ago, we celebrated the 25th anniversary of the *Olmstead v. Lois Curtis and Elaine Wilson*, where the Supreme Court held that segregation of people with disabilities is a form of discrimination under the Americans with Disabilities Act. As Justice Ginsberg explained: "[C]onfinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."[1] What was true in 1999 is still true today: prolonged segregation of youth in residential treatment facilities deprives them of the all the benefits of that come with community living—including opportunities to be with their families and friends, to learn in school, and to develop strengths and pursue their interests.

Instead of long-term stays in residential facilities, children with disabilities belong with families, receiving high quality, intensive home and community-based mental health services when necessary.[2] As the U.S. Department of Health and Human Services' (HHS) regulation implementing Section 504 of the Rehabilitation Act states, "[C]ongregate care is virtually never the most appropriate long-term placement for children."[3]

Focused expansion of quality intensive home and community-based Medicaid services would meaningfully address the needs of youth with complex behavioral health conditions and prevent harmful out-of-home placements in residential treatment facilities. Such services include: 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,"). 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.[4]

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[1] 527 U.S. 581, 583.

[2] American Academy of Pediatrics, Children's Defense Fund, Foster Club, Think of Us, and Youth Law Center (Jan. 2022), The Path to Well-being for Children and Youth in Foster Care Relies on Quality Family-Based Care, https://familyfirstact.org/resources/path-well-being-children-and- youth-foster-care-relies-quality-family-based-care-what%E2%80%99s.

[3] 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.

[4] *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)

Pursuant to Medicaid's Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit, all of these services can (and must) be available to Medicaid-enrolled youth when necessary.[5] However, this care is often not widely available, due in part to underinvestment in community-based care and insufficient provider networks, leading to long wait times or complete denial of access. When the services are available, they are often not provided in a highly coordinated manner, nor in accordance with appropriate standards or guidelines designed to ensure their therapeutic effectiveness.

To help remedy these issues, we offer the following recommendations:

1) **Support states in ensuring services are provided 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.[6] For such services, we suggest requiring states to implement these evaluations and publicly share data. 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. For example, Intensive Care Coordination delivered via High Fidelity Wraparound, includes scales to monitor fidelity to the practice model in service delivery and indicated ways to collect data about enrollment and outcomes.[7] Additional funding can support states to effectively implement this service and carry out these evaluations.

2) **Allow 1915(c) waivers for youth with a Psychiatric Residential Treatment Facilities (PRTF) level of care.**

Because PRTFs are not a designated institutional setting for the purposes of §1915(c), it can be difficult to target home and community-based waivers to this population through 1915(c) waivers.[8] While the EPSDT mandate requires states to cover all

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(hereinafter "The Right to Community-Based Care"), https://healthlaw.org/wp-content/uploads/2018/09/NHeLP-Issue-Brief_Children%E2%80%99s-Mental-Health-Services.pdf.

[5] 42 U.S.C. §§ 1396a(a)(10)(A), 1396a(a)(43), 1396d(a)(4)(B); 1396d(r).

[6] *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

[7] 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.

[8] *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 and that 1915(c)s are used to target some individuals with mental

necessary services for youth under age 21, there are also certain advantages to 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 children and youth with slightly higher income levels, which can also be utilized to limit the practice of "custody relinquishment" just to access community-based services for families with higher incomes.[9] Last, as noted above, even though states have a federal obligation to cover such services, this does not always result in robust access. Given these challenges, legislation that would deem a PRTF an institutional level of care for purposes of HCBS waivers may be a successful strategy. Such a strategy could help develop service structures, recruit providers, extend coverage to families with slightly higher incomes, and to supplement children's existing entitlement.

We ask that if this policy is pursued, safeguards are put in place to ensure that waivers do not in any way curtail or limit a state's EPSDT obligation to provide youth with all medically necessary services that are included within the categories of mandatory and optional services, regardless of whether such services are covered under the State Plan.[10]

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health needs, but to do so the individual would still have to meet an inpatient hospital, nursing facility, or intermediate care facility level of care.

[9] HHS recently amendment Section 504 regulations to clarify that the practice of requiring children, on the basis of disability, "to be based outside the family home through custody relinquishment, voluntary placement, or other forfeiture of parental rights in order to receive services" is prohibited. 42 C.F.R. § 84.60 (effective July 8, 2024), 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. 40189 (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.

[10] 42 U.S.C. §§ 1396a(a)(10)(A), 1396a(a)(43), 1396d(a)(4)(B); 1396d(r). 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

3) Require additional rate analysis for intensive home and community-based mental health services

As noted above, although formal waitlists are not permitted for State Plan services, and waivers cannot be used to circumvent EPSDT entitlements, youth still all too 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.[11] 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).[12] However, for various reasons, many of the services needed to serve this population of youth may not be adequately addressed in the rate analysis.[13] Thus, 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 core community-based services for youth with complex behavioral health conditions and significant needs could address these gaps and help inform future rulemaking.

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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.").

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

[12] *Id*. at 40872. 42 C.F.R. 447.203(b)(2), (b)(3)(i)(B).

[13] 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.[13] Examples CMS gives of services that will be excluded in include peer support, psychosocial rehab, and assertive community treatment.[13] 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.[13] However, it seems likely that core services essential to support children with intensive mental health needs may not be included in this analysis. CMS, Medicaid Program; Ensuring Access to Medicaid Services, 89 Fed. Reg. 40680, 40733 (May 10, 2024).

Thank you for your attention to these important issues. The Task Force looks forward to continued partnership as the committee works to move forward legislation that would support people with disabilities and improve access for Medicaid services. Please feel free to contact Jennifer Lav at lav@healthlaw.org with any questions or comments.

Dan Berland
National Association of State Directors of Developmental Disabilities Services (NASDDDS)

Tory Cross
Caring Across Generations

Lydia Dawson
American Network of Community Options and Resources (ANCOR)

Jennifer Lav
National Health Law Program (NHeLP)

Michael Lewis
American Association of People with Disabilities

Gelila Selassie
Justice in Aging