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2021-2022 Cohort of New Hampshire-Maine Leadership Education in Neurodevelopmental and Related Disabilities (NH-ME LEND) Program Trainees.

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The Role of Medicaid for Children with Special Health Care Needs and Disabilities

Produced by the 2021-2022 Cohort of New Hampshire-Maine Leadership Education in Neurodevelopmental and Related Disabilities (NH-ME LEND) Program Trainees.

Medicaid is a federal-state partnership that provides health care coverage to low-income children, senior citizens, and people with disabilities.ⁱ More than 39 million children 0-18 years old were enrolled in Medicaid and CHIP by December 2021. Among Black, Hispanic, and American Indian/Alaska Native (AI/AN) infants under one year, more than 6 in 10 rely on Medicaid coverageⁱ. Children of color are disproportionately poor and, as a result, more likely to have Medicaid coverage. More than half of all Black, Hispanic, and AI/AN children under 18 are covered by Medicaid.ⁱⁱ

The child health benefit package under Medicaid is known as Early, Periodic, Screening, Diagnostic, and Treatment (EPSDT). The goal of EPSDT is to assure that all children get the health care they need whenever they need it. It mandates that coverage must be early and must be sufficient to correct or ameliorate any physical and mental conditions identified. Medicaid focuses on optimal child development, which EPSDT ensures. For children with disabilities, Medicaid covers many services they need which would not be covered under private insurance.^{iv}

Children with special health care needs (CSHCN) have ongoing physical, developmental, behavioral, or emotional conditions that require health and related services of a type or amount beyond that required by children generally.^v Medicaid is a primary source of financing for services to CSHCN and disabilities. About one in five US children under 18 have special health care needs - with nearly half being covered by Medicaid.^{vi}

Home and Community Based Services Policy

Medicaid plays a significant role in financing home and community-based services (HCBS) which help to ensure that children can live at home with their families rather than living in more costly institutions. This began with the Katie Beckett Medicaid option, signed into law in 1981 by President Ronald Reagan, that enables HCBS for children up to age 19 who would otherwise have required institutionalization to become Medicaid eligible.^{vii}

With the Olmstead Supreme Court decision in 1999, states were required to provide HCBS to people of all ages as a matter of disability rights, usually with HCBS waivers in Medicaid. The result was that more beneficiaries were served in the community and children with severe disabilities were kept with their families instead of in institutions.

The goals of policy changes for HCBS are to make Medicaid equitable across states and disabilities, by 1) putting HCBS into Medicaid state plans instead of waivers, 2) increasing access to services, 3) offering expanded and consistent benefits, and 4) eliminating waiting lists. In addition, federal funding through grants is needed to strengthen support for the workforce. Providing adequate financing to states is essential. Ensuring a workforce, services, and financing to support families, who deliver most HCBS and coordinate care, is paramount.

Toward these goals, the American Rescue Plan Act (ARPA) made important changes including an increased Medicaid Federal Medical Assistance Percentage (FMAP) matching for states to strengthen the direct care workforce, eligibility, and quality of HCBS. While not enacted, the Build Back Better Act aimed to make additional improvements in Medicaid HCBS.

The Better Care Better Jobs Act (S. 2210 / H.R. 4131) would provide funds—both grants and enhanced FMAP for state Medicaid HCBS—to increase eligibility, improve access, and expand and strengthen the workforce. The Better Care Better Jobs Act would facilitate state planning for improvements and

increase quality and accountability, as well as improve access to services and supports for CSHCN and people with disabilities.

Support for Medicaid and HCBS

Families, professional organizations, and disability rights organizations support Medicaid. It is supported by organizations representing families of CSHCN, such as Family Voices. Professional organizations—representing pediatricians, occupational, physical, and speech-language therapists, social workers, and others—support Medicaid’s role in ensuring that CSHCN and disabilities are able to grow and thrive. Many disability organizations support improvement in Medicaid HCBS, including the Association of University Centers on Disabilities (AUCD), the Arc, and the Consortium of Citizens with Disabilities.

These organizations believe Medicaid is an essential lifeline and allows all eligible children with disabilities to maintain entitlement to a full range of health care and long-term care support and services. Organizations generally believe Medicaid financed services can ensure that children with developmental disabilities are able to thrive and grow into self-sufficient adults.

Medicaid—with its EPSDT benefit, and HCBS financing—is important to CSHCN and disabilities because it covers services they need and enables them to live at home and engage in the community. Federal policy improvements can make Medicaid HCBS access more equitable across states and disability status. It is important that all people with disabilities can benefit from HCBS no matter where they live. Ensuring that children are protected by and benefit from federal Medicaid policy shifts is crucial.

Endnotes

ⁱ Johnson, K. (2021). Medicaid and CHIP Coverage for Women and Children: Politics and Policy. Chapter 20. In Russell S. Kirby and Sarah Verbiest, Editors, *Kotch’s Maternal and Child Health: Programs, Problems and Policy in Public Health*, Fourth Edition. Burlington, MA: Jones and Bartlett Learning.

ⁱⁱ Brooks, T., & Gardner, A. (2020, July). *Snapshot of children with Medicaid by race and ethnicity*. Georgetown University Center for Children and Families. <https://ccf.georgetown.edu/2020/07/27/snapshot-of-children-with-medicare-by-race-and-ethnicity-2018/>

ⁱⁱⁱ Artiga, S., Pham, O., Ranji, U., & Orgera, K. (2020). *Medicaid initiatives to improve maternal and infant health and address racial disparities*. Kaiser Family Foundation. <https://www.kff.org/racial-equity-and-health-policy/issue-brief/medicaid-initiatives-improve-maternal-infant-health-address-racial-disparities/>

^{iv} Centers for Medicare and Medicaid Services. (2014). *EPSDT - A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents*. US Department of Health and Human Services. <https://www.hhs.gov/guidance/document/epsdt-guide-states-coverage-medicare-benefit-children-and-adolescents>

^v Maternal and Child Health. Health Resources and Services Administration. Children and Youth with Special Health Care Needs (CYSHCN). (Website, n.d.). US Department of Health and Human Services. <https://mchb.hrsa.gov/programs-impact/focus-areas/children-youth-special-health-care-needs-cyshcn>

^{vi} Musumeci, M., & Chidambaram, P. (2019). *Medicaid’s role for children with special health care needs: A look at eligibility, services, and spending*. Kaiser Family Foundation. <https://www.kff.org/medicaid/issue-brief/medicaids-role-for-children-with-special-health-care-needs-a-look-at-eligibility-services-and-spending/>

^{vii} Watts, M. O., Musumeci, M., & Chidambaram, P. (2020). *Medicaid home and community based services enrollment and spending*. Kaiser Family Foundation. <https://www.kff.org/medicaid/issue-brief/medicaid-home-and-community-based-services-enrollment-and-spending/>