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2020-2021 Cohort of New Hampshire-Maine Leadership Education in Neurodevelopmental and Related Disabilities Program Trainees

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

Produced by the 2020-2021 Cohort of New Hampshire-Maine Leadership Education in Neurodevelopmental and Related Disabilities (NH-ME LEND) Program Trainees.

Medicaid plays a critical role in protecting the health and well-being of US children, covering half of infants and toddlers as well as two-thirds of children with special health care needs and disabilities. Since its inception in 1965, Medicaid has provided health coverage for low-income children. For some time, while many children with special health care needs and disabilities were covered under the income eligibility criteria, a large share were not. A major shift occurred in 1982 during the Reagan administration with the creation of the Katie Beckett program, which allowed Medicaid eligibility for medical services in the home (rather than in an institutional setting) for children with significant disabilities based only on their own income. Since then, home and community-based services (HCBS), have increasingly provided a vital safety net for children with special health care needs and disabilities and their families.¹

No matter their eligibility pathway, all children from birth to 21 enrolled in Medicaid are entitled to its Early and Periodic Screening, Diagnostic and Treatment (EPSDT) child health benefit. EPSDT offers comprehensive coverage for prevention, early intervention, and a wide range of treatments that are important for healthy development.² For children with special health care needs and disabilities, this may include an array of medically necessary home and community based services such as behavioral health support, respite care, case management, personal care services, and durable medical equipment.³

Research shows that children with greater access to Medicaid have improved long-term health-related outcomes and life trajectories.^{4,5} Unfortunately, the current Medicaid HCBS system does not adequately serve all individuals with special health care needs and disabilities and is dependent on an under-resourced workforce to serve them. Applying for HCBS waivers is complex and difficult for families,⁶ which can be an initial barrier to coverage.⁷ Disability definitions for waiver eligibility are often siloed and inconsistent, which causes some individuals to fall into coverage gaps. Some HCBS waivers are subject to enrollment caps, resulting in lengthy waiting lists.⁸ Finally, HCBS are delivered by a workforce that has long been plagued by low wages and high turnover rates, which limits the availability of providers and ultimately reduces service quality.⁹

Policy to Support Improvements in HCBS under Medicaid

The [Home and Community Based Services Access Act \(HAA\)](#), as proposed on March 16, 2021 by Representative Dingell and Senators Hassan, Casey, and Brown, is designed to address problems with current Medicaid Home and Community Based Services, particularly waivers. It would provide federal funding to help states to fulfill the promise of the legislation. The HAA would also:

- **Consolidate HCBS into one comprehensive state program**, streamlining and simplifying the application process for families.
- **Base Medicaid HCBS eligibility on individualized assessment of functional need**, not on siloed, inconsistent, and sometimes confusing disability definitions. The HAA would ensure that people with all kinds of disabilities and functional limitations would receive the HCBS they need.
- **Eliminate waiting lists.** The HAA would replace waivers with a state program that covers HCBS for all eligible Medicaid beneficiaries with functional need, without capped enrollment.

- **Specify a more consistent set of benefits.** Defining a baseline set of benefits at the federal level will ensure equitable and appropriate services for all who are eligible. While children can rely on EPSDT benefit standards, currently this is not true for adults with disabilities or for seniors.
- **Support and increase the capacity of essential frontline HCBS workers.** HAA also aims to support the workforce. Providing workers with fair pay, benefits, and training will reduce turnover and help families gain access to needed HCBS services, as well as improve the quality of those services.⁶

These improvements to Medicaid HCBS would allow more children with special health care needs and disabilities to receive timely, high-quality services in their homes and communities. This will lead to lower costs, greater independence, enhanced health and safety, and improved outcomes.⁶ Furthermore, with their children receiving the HCBS they need, many family caregivers may then choose to re-enter the workforce,¹⁰ a benefit both to families and the communities in which they live.

Conclusion

While the Home and Community Based Services Access Act is [currently considered a discussion bill](#), it is quickly building support among families, providers, advocates, and self-advocates in the disability community. To date, numerous state and national organizations have announced their support, including: the Association of University Centers on Disabilities (AUCD); the Autistic Self Advocacy Network (ASAN); the HCBS Advocacy Coalition; The Arc; and the Center for Public Representation.

The HAA will make it possible for more children to live at home, with their families and in their communities, and to experience full and productive lives. Providing equitable access to comprehensive, high-quality health care to children with special health care needs and disabilities should be a national priority.

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