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Medicaid and Children with Special Health Care Needs

2016-2017 Cohort of New Hampshire-Maine Leadership Education in Neurodevelopmental and Related Disabilities (NH-ME LEND) Program Trainees
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POLICY BRIEF: Medicaid and Children with Special Health Care Needs

Produced by the 2016-2017 Cohort of New Hampshire-Maine Leadership Education in Neurodevelopmental and Related Disabilities (NH-ME LEND) Program Trainees.

Executive Summary

Medicaid funds vital services for children and youth with special health care needs and disabilities (CYSHCN). Proposed changes to the structure of Medicaid would significantly reduce federal funding for this important program. The most concerning are the proposed structural changes including per capita caps and block grants, as well as threats to Early and Periodic Screening, Diagnostic and Treatment (EPSDT) and Medicaid Waiver services. Restructuring would have devastating effects on benefits for low-income children and individuals with disabilities, and their families, putting this very vulnerable population at additional risk.

Current Medicaid Programs

- Medicaid provides comprehensive health care coverage for 30 million low-income children nationwide.
- Children represent 43 percent of the Medicaid enrollees and account for only 19 percent of Medicaid spending.¹
- Children and youth who need the care most, those with special health care needs, make up 20 percent of the 30 million children covered nationwide (6 million).²

For more than 50 years, Medicaid has relied on federal funding to offset states' costs to support CYSHCN and those struggling financially. One-third of children and over half of low-income children are insured through Medicaid or the Children's Health Insurance Program (CHIP). Medicaid provides these children with access to preventive and primary services which results in better long-term health outcomes.³ Medicaid serves just over 93,000 children in NH and over 114,000 children in Maine.⁴

There are two specific Medicaid services which significantly impact children and youth with special health care needs, including those with disabilities. The first is EPSDT – the child health benefit package of Medicaid. EPSDT ensures that children under the age of 21 who are enrolled in Medicaid receive age-appropriate screening, diagnostic, and treatment services that are medically necessary to correct or improve any identified conditions. EPSDT ensures the right care is provided to the right child in the right setting. Covered services under EPSDT include speech-language therapy, occupational and physical therapy, developmental screening and diagnostic assessment, home visiting, mental and behavioral health therapy, dental care, and case management. Research shows that earlier screening and intervention results in better outcomes for CYSHCN and for children with developmental disabilities. In addition to EPSDT, waiver programs that are offered under Medicaid serve individuals with disabilities

¹ Congressional Budget Office (2016). Detail of Spending and Enrollment for Medicaid for CBO's March 2016 Baseline. Retrieved from <https://www.cbo.gov/sites/default/files/recurringdata/51301-2016-03-medicaid.pdf>

² National Center for Health Care Statistics at the Centers for Disease Control and Prevention under the direction and sponsorship of the federal Maternal and Child Health Bureau (2011) National Survey of Children with Special Health Care Needs. SHADAC analysis of the 2015 American Community Survey. Retrieved from <http://www.childhealthdata.org/learn/NS-CSHCN>

³ Medicaid & CHIP: Strengthening Coverage, Improving Health. Retrieved from <http://www.medicaid.gov/medicaid/program-information/downloads/accomplishments-report.pdf>

⁴ National Health Law Program. Retrieved from <http://www.healthlaw.org/issues/child-and-adolescent-health/qa-katie-becket-category-of-eligibility-for-medicaid#.WWziJ9Pysrt>

across the lifespan, including children under 21 and their families. Currently, waivers give states the flexibility to improve their programs and reduce costs by allowing them to waive certain Medicaid requirements and to create their own plans to provide for the needs of their citizens. An example of this is the Katie Beckett waiver. This program, promoted by former President Ronald Reagan, serves children with disabilities regardless of income, and allows children with a high level of medical needs to be cared for in their homes and communities as opposed to in institutions. These two services are crucial and necessary to the health and well-being of children with developmental disabilities.

Proposed Changes

Of particular concern are the following two proposals: the conversion of Medicaid to per capita cap funding in 2020; and the repeal of the increase in Medicaid eligibility to 138% of the Federal Poverty Level (FPL) for children ages 6-19 (effective December 31, 2019), reverting to 100% of the FPL, the minimum federal income eligibility limit for children. These changes at the federal level will have ramifications on the states that could result in the following:

- Movement of people from their communities to more expensive institutional care;
- Reduction in eligibility for Medicaid by making it more difficult to meet financial or other criteria;
- Increases in the cost burden on individuals or family members;
- Elimination or reduction in the availability of critical services such as personal care, prescription drugs, rehabilitative services, or home and community-based waiver programs; and
- Loss of EPSDT services that ensure CYSHCN and children with disabilities receive appropriate services in the appropriate setting when they need them.

Conclusion

A change or cap of Medicaid would greatly impact the lives of 6 million CYSHCN. Many national organizations such as The Arc, the Association of University Centers on Disabilities, Family Voices, the American Association on Intellectual and Developmental Disabilities, the Consortium for Citizens with Disabilities, the Kaiser Family Foundation, and the National Governors Association, are all stakeholders concerned with the future of Medicaid. For the first time, in a long time, these organizations are in agreement that capping Medicaid will have detrimental effects on children with disabilities, CYSHCN, and their families. They advocate for the maintenance of an individual's entitlement to a full range of Medicaid health care, long-term supports, and services for all eligible individuals with disabilities. Cuts in community-based Medicaid services may force households with working parents and caregivers to give up their jobs in order to become full-time unpaid care providers. This could create additional financial hardship for a vulnerable population already at risk.

A letter to Congress signed by 60 national professional groups, voiced the concerns of service providers that a block grant or per capita cap approach will shift costs of these services to families, states, and providers, reducing coverage.⁵ States may be forced to limit coverage or eligibility, or shift immense costs to hospitals and medical providers reducing the quality of patient and family care, potentially causing long-term negative effects for children.⁶ Additionally, schools rely on Medicaid funds to fulfill obligations under the Individuals with Disabilities Education Act (IDEA) to provide a Free and Appropriate Public Education (FAPE).

Proposed changes to Medicaid could lead to fewer children receiving vital health care and services. Furthermore, it could result in radical disparities between services to children with disabilities throughout the United States. Research shows that earlier screening and intervention results in better outcomes for CYSHCN and for children with developmental disabilities.⁷ Block grants or caps in Medicaid funding will expose already vulnerable children and their families to greater risk and financial hardship by reducing the availability of critical community-based services and essential health care.

⁵ Consortium for Citizens with Disabilities. Available at http://www.c-c-d.org/fichiers/Letter-on-AHCA_3-16-17.pdf

⁶ Kaiser Family Foundation. Retrieved from <http://kff.org/>

⁷ Centers for Disease Control and Prevention. Retrieved from <https://www.cdc.gov/ncbddd/childdevelopment/screening.html>