No. 21-806

In the Supreme Court of the United States

HEALTH AND HOSPITAL CORPORATION OF MARION COUNTY, ET AL.,
Petitioners,

v.

IVANKA TALEVSKI, PERSONAL REPRESENTATIVE OF THE ESTATE OF GORGI TALEVSKI, DECEASED,
Respondent.

On Writ of Certiorari to the United States Court of Appeals for the Seventh Circuit

Brief of Children's Health Care Providers and Advocates as *Amici Curiae* Supporting Respondent

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INTEREST OF AMICI CURIAE[1]

Amici comprise the nation's leading associations of pediatric health care providers, as well as organizations dedicated to thought leadership and advocacy on child health. Our interest in this case stems from our members' singular focus on helping children lead long and healthy lives, including the low-income children served by the Medicaid program. In the face of state policies that impermissibly restrict children's access to Medicaid services, children and families have long relied on 42 U.S.C. § 1983 to defend their federal right to comprehensive coverage and timely provision of medically necessary services. We urge the Court to preserve this crucial mechanism for ensuring that low-income children receive the care they need and to which they are entitled under federal law.[2]

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[1] No counsel for a party authored this brief in whole or in part. No person or entity other than *amici*, their members, or counsel made a monetary contribution for preparation or submission of this brief. The parties have filed blanket consents to the filing of amicus briefs.

[2] With respect to the first question presented in this appeal, *amici* urge the Court to maintain § 1983's role as an enforcement tool in Medicaid and other public programs enacted pursuant to Congress's Spending Clause authority. With respect to the second question presented, *amici* take no position on the enforceability of any specific provisions in the Federal Nursing Home Reform Act of 1987. As the Court considers this issue, however, we urge the Court to bear in mind the potential ripple effects on the enforceability of other important rights defined throughout federal law, including the right for low-income children to access medically necessary services through the Medicaid program.

Children's Hospital Association is the national voice of more than 220 children's hospitals, and advances child health through innovation in the quality, cost, and delivery of care in children's hospitals and health systems. See ChildrensHospitals.org. On average, over half of the children cared for at children's hospitals are covered by Medicaid.

The American Academy of Pediatrics, founded in 1930, is an organization of 67,000 pediatricians, pediatric medical subspecialists, and pediatric surgical specialists committed to the optimal physical, mental, and social health and well-being for all infants, children, adolescents, and young adults. To this end, the Academy has engaged in broad and continuous efforts to prevent harm to children and youth caused by a lack of access to health coverage and care.

Family Voices is a national family-led organization of families and friends of children and youth with special health care needs and disabilities, as well as family organizations that support them. Family Voices advocates for social justice, equity, disability justice, family centered care and inclusion for all children with special health care needs and their families.

First Focus on Children is a national bipartisan children's advocacy organization dedicated to making children and families the priority in federal policy and budget decisions related to healthcare. First Focus on Children leads a comprehensive advocacy strategy to identify and

implement real-world solutions to improve the lives of children and families.

The Georgetown University Center for Children and Families is a nonpartisan policy and research center founded in 2005 with a mission to support access to high-quality, comprehensive and affordable health coverage for all of America's children and families. See CCF.Georgetown.edu.

The National Association of Pediatric Nurse Practitioners (NAPNAP) is an IRC Section 501(c)(6) nonprofit professional membership association, representing more than 8,000 health care practitioners. It is the nation's only professional association for pediatric nurse practitioners and their fellow pediatric-focused advanced practice registered nurses, who are dedicated to delivering high-quality, evidence-based, equitable health care for infants, children, adolescents, and young adults in communities throughout the country.

SUMMARY OF ARGUMENT

America's future depends on the health and well-being of the nation's 73 million children.[3] Almost half of those children—those with the lowest household incomes and, often, the most severe medical needs—receive their health coverage through the Medicaid program,[4] which is jointly funded and administered by the state and federal governments.

In 1967, observing troubling rates of correctable ailments among America's children and young adults, Congress invested in the future by vesting Medicaid-eligible children with the right to receive timely preventive services and all medically necessary services for the diagnosis and treatment of "physical or mental defects . . . and chronic conditions." Social Security Amendments of 1967, Pub. L. No. 90-248 § 302(a), 81 Stat. 821, 929 (1967) (enacting 42 U.S.C. § 1396d(a)(4)(B)). Under this statute, children and youth are entitled to a comprehensive array of specified services referred to as "early and periodic screening, diagnostic, and treatment" (EPSDT). 42 U.S.C. § 1396a(a)(10)(A), (a)(43); *id.* § 1396d(a)(4)(B), (r).

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[3] *See 2020 American Community Survey DP05: 5-Year Estimates, Data Profiles*, U.S. Census Bureau, available at https://data.census.gov/cedsci/table.

[4] *See May 2022 Medicaid and CHIP Enrollment Trends Snapshot*, Centers for Medicare & Medicaid Services (CMS), https://www.medicaid.gov/medicaid/national-medicaid-chip-program-information/downloads/may-2022-medicaid-chip-enrollment-trend-snapshot.pdf.

Despite Congress's clear mandate for comprehensive coverage, over the years some states failed to adequately implement the EPSDT requirement, neglected their obligation to update their coverage standard in accordance with the current standard of care, failed to enlist sufficient providers to ensure timely access to services, or attempted to reduce costs by cutting or capping pediatric Medicaid benefits. For the low-income children who depend on the Medicaid program, these policies and practices jeopardized their health and violated their federal rights.

Time after time, dedicated parents and health care providers have grappled with impermissible restrictions on a child's access to essential services such as organ transplants or therapies to address developmental delays, as well as essential equipment such as age-appropriate wheelchairs or home testing supplies for diabetes management. Time after time, these parents found the Medicaid program's administrative remedies inadequate for redressing violations of federal law that pose immediate threats to their child's well-being. Time after time, they turned to Section 1983 as the most effective vehicle to vindicate the individual rights of program beneficiaries.

As the nation's leading health care providers, advocates, and thought leaders concerning the health of America's children, we urge the Court not to disturb this longstanding safeguard for children's rights under the Medicaid program. We know from experience that ready access to "well child" care, preventive services, and timely treatment for health care issues provides essential support for a child's

healthy development into adulthood. And we have seen firsthand how inadequate access to care can diminish a child's odds of surviving a serious illness, successfully managing a chronic condition, or achieving independence despite a congenital disability. Congress sought to prevent those tragic outcomes more than five decades ago by creating a federal right to EPSDT services. Section 1983 offers families the ability to hold states accountable when they fail to honor that right. Section 1983 thus plays a vital role in fulfilling EPSDT's explicit assurance that children will be able to access all medically necessary care, from prevention through treatment.

ARGUMENT

I. The Medicaid Program Provides Low-Income Children with Crucial Coverage and Federal Rights.

Since the Medicaid program was first established, Congress has paid special attention to the needs of children, seeking to promote healthy development from conception to adulthood. As a result of ever-expanding eligibility thresholds, Medicaid now covers more than four out of ten births and almost half of all children in America.[5] Moreover, Congress defined a number of federal

[5] *See Births Financed by Medicaid*, KFF (2020), https://www.kff.org/medicaid/state-indicator/births-financed-by-medicaid/; *May 2022 Medicaid and CHIP Enrollment Trends Snapshot*, *supra*.

rights in the Medicaid Act[6] to shield these groups from state policies that could jeopardize their health and well-being.

A. In Exchange for Receiving Federal Medicaid Funding, States Must Honor Medicaid Beneficiaries' Federal Rights.

Enacted in 1965, Medicaid is a means-tested health care program jointly funded and administered by the federal and state governments. Each state designs and implements a Medicaid "state plan" in accordance with federal parameters, which define baseline requirements as well as areas of state flexibility. *See* 42 U.S.C. § 1396a. Through the Centers for Medicare & Medicaid Services (CMS), the federal government pays for nearly 70 percent of total Medicaid spending, contributing anywhere from 50 to 100 percent of qualifying costs depending on the state, the patient population, and the services at issue. *Id.* §§ 1396b(a), 1396d(b).[7]

To ensure that the Medicaid program fulfills its purpose of enabling access to services and promoting

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[6] As used in this brief, the "Medicaid Act" refers to Title XIX of the Social Security Act, as amended and as codified at 42 U.S.C. §§ 1396 *et seq.*

[7] *See Federal and State Share of Medicaid Spending*, KFF (2021), https://www.kff.org/medicaid/state-indicator/federalstate-share-of-spending/; *Matching Rates*, Medicaid & CHIP Payment & Access Comm'n (MACPAC) (last accessed Sept. 1, 2022), https://www.macpac.gov/subtopic/matching-rates/; *Federal Match Rate Exceptions*, MACPAC (last accessed Sept. 1, 2022), https://www.macpac.gov/federal-match-rate-exceptions/.

health, Congress defined a number of rights that apply to all individuals eligible for or enrolled in the program, including a right to apply for and receive all benefits to which they are entitled under federal law and the state plan "with reasonable promptness," a right against state interference in their choice among willing and qualified providers, and a right to receive notice of, and to file an administrative appeal challenging, an adverse action affecting their Medicaid eligibility or coverage.[8] *Id.* § 1396a(a)(3), (8), (10), (17), (23).

In addition to these rights that are available to all Medicaid applicants and beneficiaries, Congress has established a number of targeted rights and eligibility expansions for children and pregnant women, explicitly codifying Congress's commitment to ensuring timely access to services that promote healthy development, cure treatable ailments, and promote quality of life for children living with disabilities and chronic health conditions. Chief among these provisions is the right for children to receive comprehensive coverage for preventive care, diagnosis, and treatment under the EPSDT provisions of the law, as described further below in Part II.

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[8] These rights are subject to certain exceptions, as defined in statute and CMS regulations. In addition, states may request that CMS waive certain requirements under certain circumstances as part of a statutorily authorized demonstration program. *See* 42 U.S.C. §§ 1315(a), 1396n.

B. Medicaid Is an Essential Source of Health Coverage for Low-Income Children, Children with Special Health Care Needs, and Children of Color.

As originally enacted, the Medicaid program was limited to groups that qualified for cash assistance programs, including extremely low-income families with dependent children, people with disabilities, and older adults. In the ensuing years, however, Congress repeatedly amended the Medicaid Act to expand eligibility, especially for low- and moderate-income children and pregnant women.[9] Today, states must cover children and pregnant women in households up to 133 percent of the federal poverty level—about $37,000 a year for a family of four. Most states have expanded eligibility even further.[10] In addition, although lawfully

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[9] In addition to the Medicaid program, Congress in 1997 enacted the Children's Health Insurance Program (CHIP), which provides additional funding for states to either enhance children's eligibility under the Medicaid program or establish a stand-alone CHIP health coverage program for children with household incomes above their Medicaid eligibility limits. Medicaid, however, remains the much larger program with respect to children's coverage. *See generally* Cindy Mann et al., *Historical Overview of Children's Health Care Coverage*, 13 Future of Children 31 (2003); *Eligibility*, MACPAC (last accessed Sept. 1, 2022), https://www.macpac.gov/medicaid-101/eligibility/.

[10] *See Medicaid and CHIP Income Eligibility Limits for Children as a Percent of the Federal Poverty Level*, Kaiser Family Found. (KFF) (last updated Jan. 1, 2022), https://www.kff.org/health-reform/state-indicator/medicaid-and-chip-income-eligibility-limits-for-children-as-a-

residing immigrants are generally subject to a five-year waiting period before they may access most federally funded public benefits, Congress authorized states to disregard this waiting period for children and pregnant women, which most states have now done.[11]

Congress also established special eligibility pathways, enhanced services, and protections for children living with disabilities and other special health care needs, including by enabling states to better support individuals with disabilities who choose to live at home or in community settings rather than in a long-term care institution.[12]

Federal Medicaid law establishes a detailed set of requirements to ensure comprehensive health coverage and, as needed, long-term care and supports to more than 33 million children, including almost seven out of ten children living in households

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percent-of-the-federal-poverty-level/; *Medicaid and CHIP Income Eligibility Limits for Pregnant Women as a Percent of the Federal Poverty Level,* KFF (last updated Jan. 1, 2022), https://www.kff.org/health-reform/state-indicator/medicaid-and-chip-income-eligibility-limits-for-pregnant-women-as-a-percent-of-the-federal-poverty-level/.

[11] *See* 42 U.S.C. § 1396b(v)(4)(A); *Medicaid and CHIP Coverage of Lawfully Residing Children & Pregnant Women*, CMS (last updated July 9, 2021), https://www.medicaid.gov/medicaid/enrollment-strategies/medicaid-and-chip-coverage-lawfully-residing-children-pregnant-women.

[12] *See generally Medicaid and Persons with Disabilities* at 33–36, in March 2012 Report to Congress, MACPAC (Mar. 2012), https://www.macpac.gov/wp-content/uploads/2012/03/Medicaid-and-Persons-with-Disabilities.pdf.

below 200 percent of the poverty level.[13] More than 6 million of these children—nearly one out of every five—have special health care needs that require a heightened level of attention and care,[14] including children who cannot hear without a hearing aid, children with developmental delays who are unable to speak until they receive speech therapy, and children with serious health conditions who require a ventilator to breathe.

Medicaid-enrolled children are also disproportionately Black and Brown, reflecting America's persistent racial disparities in wealth and income. Whereas approximately 30 percent of White children receive their health coverage through Medicaid, the program covers *more than half* of children who are Black, Hispanic, American Indian, or Alaska Native.[15] Medicaid is thus a key driver of health equity for America's youngest generation. That promise can be achieved, however, only if Medicaid-enrolled children can enforce their federal right to access all medically necessary screening, diagnostic, and treatment services.

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[13] *May 2022 Medicaid and CHIP Enrollment Trends Snapshot, supra*; *Health Insurance Coverage of Low Income Children 0-18 (Under 200% FPL)*, KFF (2020), https://www.kff.org/other/state-indicator/health-insurance-coverage-of-low-income-children-0-18-under-200-fpl-cps/.

[14] *See* Reem M. Ghandour et al., *Children and Youth with Special Health Care Needs: A Profile*, 147 Pediatrics Suppl. 7 at S7 (Table 3) (2022).

[15] *Health Coverage by Race and Ethnicity, 2010-2019,* KFF at Figure 2 (July 16, 2021), https://www.kff.org/racial-equity-and-health-policy/issue-brief/health-coverage-by-race-and-ethnicity/.

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From the Medicaid program's inception through to the present day, Congress has consistently and explicitly created beneficiary rights and state responsibilities with respect to the children who apply for, enroll in, and receive services through the Medicaid program. Although states have a choice about whether to adopt certain optional enhancements to eligibility, children enrolled under that enhanced standard receive all the same federal rights as other Medicaid enrollees—including the right to receive all EPSDT services, as described in the following part.

II. With EPSDT, Congress Created a Federal Right for Low-Income Children to Receive Comprehensive Health Care Services.

For children, a lack of timely and adequate access to health care can impede healthy development, with lifelong consequences. It is imperative that children receive timely preventive care, well-child visits, and developmentally appropriate screenings to identify challenges early. When health care needs are identified, it is equally important that children have access to appropriate treatment, including acute care for conditions like infections or physical trauma, pediatric specialty care for serious conditions like cancer or heart defects, and services to support the activities of daily living for children with intellectual and developmental disabilities.

Access to care is especially important for the low-income children served by the Medicaid program. As compared to the general population, these children are more likely to have special health care needs such as chronic health conditions, developmental delays, and learning disorders. *EPSDT—A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents*, CMS 36 (2014) [hereinafter "*CMS EPSDT Guide*"], https://www.hhs.gov/guidance/sites/default/files/hhs-guidance-documents/epsdt_coverage_guide_72.pdf.

Recognizing this need, Congress created the EPSDT coverage standard, providing Medicaid-enrolled children and youth with a federal right to receive all medically necessary screening, diagnostic, and treatment services, including physical health, mental health, vision, hearing, and dental services. Moreover, these services must be available at no cost to the child's family: Although states have the ability to require nominal cost sharing for certain Medicaid services from certain covered populations, Congress prohibited states from imposing any cost-sharing requirements on services for children. *Id.* §§ 1396o(a)(2), 1396o-1(b)(3).

The evidence shows unequivocally that access to these services helps children live longer, healthier lives, as discussed below in Part IV.

A. Congress Enacted EPSDT to Ensure Healthy Development for America's Children.

Congress enacted the EPSDT requirement to address troubling rates of treatable medical ailments among America's children and young adults.

Notably, a 1964 federal report estimated that one in six young men had medical conditions that made them unfit for military service. Troublingly, a large majority of this group—three out of four—had disqualifying conditions that could have been cured or significantly ameliorated with timely medical treatment. President's Task Force on Manpower Conservation, One-Third of a Nation: A Report on Young Men Found Unqualified for Military Service 11, 25 (Jan. 1, 1964).

Two years later, a federal report on child and maternal health recommended steps to improve children's access to health care services, especially in underserved areas. The report emphasized the potential impact on "health problems which are highly prevalent, which are highly adverse, and which can be mitigated or even avoided given proper health care," including infant mortality, "chronic handicapping conditions," and oral health. *Program Analysis: Maternal and Child Health Care Programs*, Off. of the Assistant Sec'y for Program Coordination, U.S. Dept. of Health, Educ. & Welfare at II.1–3 (1966).

President Johnson emphasized these imperatives in a 1967 speech to Congress on America's children and youth, commenting that "our

whole society pays a toll for the unhealthy and crippled children who go without medical care: a total of incalculable human suffering, unemployment, rising rates of disabling disease, and expenditures for special education and institutions for the handicapped." Lyndon B. Johnson, *Special Message to the Congress Recommending a 12-Point Program for America's Children and Youth* (Feb. 8, 1967).

Congress established the first EPSDT requirements later that same year. Social Security Amendments of 1967, Pub. L. No. 90-248 § 302. This initial version defined the goal of covering screening, diagnosis, and treatment for children and youth, but left it to CMS's predecessor agency to fill in the details through rulemaking. In subsequent years, observing that many eligible children were not receiving—or even aware of their right to receive—all services described in federal regulations, Congress bolstered the EPSDT requirements by, for example, imposing a temporary financial penalty on states that failed to cover all EPSDT services, followed by an amendment that affirmatively required states to inform Medicaid-eligible children about their right to receive EPSDT services and how to access them. *See* Jane Perkins & Sarah Somers, *Medicaid's Gold Standard Coverage for Children and Youth: Past, Present, and Future*, 30 Annals Health L. & Life Sci. 153, 159–62 (2021).

In 1989, noting that the "EPSDT benefit is not currently defined in statute," Congress enacted detailed provisions that enumerated specific services that must be covered, and also crystalized states' obligation to cover any other medically

necessary services that qualify for federal Medicaid funding, as described further below. H.R. Rep. 101-247, 398, 1989 U.S.C.C.A.N. 1906, 2124 (Sept. 20, 1989); Omnibus Budget Reconciliation Act of 1989, Pub. L. No. 101-239 § 6403, 103 Stat. 2106, 2262 (1989) (enacting 42 U.S.C. § 1396d(r)). These changes were motivated by Congress's recognition that "the EPSDT benefit is, in effect, the nation's largest preventive health program for children" and that "as Medicaid coverage of poor children expands, . . . the EPSDT benefit will become even more important to the health status of children in this country." H.R. Rep. 101-247, 398.

B. Federal Law Guarantees Medicaid-Enrolled Children Access to Regular and Periodic Health Screenings, Diagnostic Services, and Medically Necessary Treatment.

With respect to adults age 21 and over, the Medicaid Act defines a number of mandatory benefits that all states must cover (such as hospital and physician services), along with a list of optional benefits that states may choose to include in their state plan (such as non-emergency vision and dental services, physical therapy services, and in-home services including private-duty nursing and personal care services). 42 U.S.C. §§ 1396a(a)(10), 1396d(a).[16]

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[16] *See also Mandatory & Optional Medicaid Benefits*, CMS (last visited Sept. 7, 2022), https://www.medicaid.gov/medicaid/benefits/mandatory-optional-medicaid-benefits/index.html.

By contrast, children and youth under age 21 have a federally established right to receive *any* medically necessary service that is recognized as a "Medicaid" service under federal law, regardless of whether the state covers that service for older enrollees. Moreover, Congress designed the EPSDT standard to update automatically over time, ensuring that care for Medicaid-enrolled children meets the current pediatric standard of care.

The EPSDT requirement consists of three distinct elements, as set forth below. Although "the states must live up to their obligations to provide all EPSDT services," as described above, federal law "afford[s] them discretion as to how to do so." *Katie A. v. Los Angeles County*, 481 F.3d 1150, 1159 (9th Cir. 2007). A state may, for example, require prior authorization for services or "place[] tentative limits on services pending an individualized determination by the state," as long as "additional services [are] provided if determined to be medically necessary for an individual child." *CMS EPSDT Guide* at 23–24.

1. Scheduled Screenings and Preventive Services

States must establish a schedule of recommended visits for pediatric medical, vision, hearing, and dental care, including screening services and routine preventive care such as vaccinations and dental cleanings.[17] These

[17] By statute, the medical screenings and preventive services must include: (1) a comprehensive health and developmental history; (2) an unclothed physical exam; (3) age-appropriate vaccinations in accordance with federal

"periodicity" schedules must "meet reasonable standards of medical and dental practice, as determined by the State after consultation with recognized medical and dental organizations involved in child health care." 42 U.S.C. § 1396d(r)(1)–(4).

By requiring states to meet current standards of practice and consult with recognized authorities, Congress ensured that the EPSDT coverage standard would not lag behind the standard of care for children with private insurance. Consistent with that obligation, CMS has advised states to "review their EPSDT periodicity schedules regularly to keep them up to date." *CMS EPSDT Guide* at 4; *see also* State Medicaid Manual, CMS § 5310 (last updated 1995) ("Effective EPSDT program design and implementation require[] continuing involvement of health professional organizations.").

Most states have adopted the *Bright Futures* recommendations that were developed by *amicus* the American Academy of Pediatrics, which are updated on an annual basis to reflect the best available evidence on preventive health services for

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guidelines; (4) laboratory tests (including lead blood level assessment, as appropriate); and (5) health education. 42 U.S.C. § 1396d(r)(1)(B). States must also provide diagnosis of and treatment for vision or hearing defects, including the provision of eyeglasses or hearing aids, as well as dental care for the "relief of pain and infections, restoration of teeth, and maintenance of dental health." *Id.* § 1396d(r)(2)–(4).

children and youth.[18] The remaining states have developed a state-specific periodicity schedule, typically relying in large part on *Bright Futures*.

2. Medically Necessary Diagnostic and Treatment Services

In addition to the recommended schedule of preventive health visits, states must cover ad hoc screening and diagnostic services "as medically necessary" to identify medical, vision, dental, or hearing conditions. 42 U.S.C. § 1396d(r)(1)–(4). Children are further entitled to any "other necessary health care, diagnostic services, treatment, and other measures . . . to correct or ameliorate" any health conditions "discovered by the screening services." *Id.* § 1396d(r)(5).

Crucially, if certain services are medically necessary for an individual child, the state must enable access "regardless of whether these services are [otherwise] provided under the State Plan and regardless of any restrictions that states may impose on coverage for adult services, as long as those services *could* be covered under the State Plan"—that is, as long as the services fall within the scope

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[18] *Early and Periodic Screening, Diagnostic, and Treatment*, Early Childhood Learning & Knowledge Ctr., Admin. for Children & Families, HHS (last updated May 6, 2022), https://eclkc.ohs.acf.hhs.gov/physical-health/article/early-periodic-screening-diagnostic-treatment-epsdt (identifying states that have adopted *Bright Futures*); *see also* Bright Futures & Am. Ass'n of Pediatrics, *Recommendations for Preventive Pediatric Health Care* (last updated July 2022), https://downloads.aap.org/AAP/PDF/periodicity_schedule.pdf.

of any mandatory or optional Medicaid benefit that is approvable under federal law.[19] *CMS EPSDT Guide* at 10 (explaining the import of 42 U.S.C. § 1396d(r)(5)); State Medicaid Manual, CMS § 5110 (last updated 1990). As described by the Fifth Circuit, Congress intended that the scope of coverage "under the EPSDT program be determined by reference to federal law, not state preferences." *S.D. v. Hood*, 391 F.3d 581, 592 (5th Cir. 2004).

As with the periodicity schedules, moreover, this right to "medically necessary" treatment is defined far more concretely than the corresponding statutory standards for adults, and necessarily accommodates an evolving standard of care.[20]

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[19] The EPSDT standard is limited to services that may be covered under the state plan, and so does not require states to add coverage for services that are permissible only pursuant to a CMS-approved waiver or demonstration program. But if a state enhances *eligibility* for children through a waiver or demonstration program, those newly eligible children are entitled to full EPSDT coverage, in addition to coverage of any special services under the waiver or demonstration (unless otherwise authorized by CMS). *See CMS EPSDT Guide* at 26–27.

[20] *See CMS EPSDT Guide* at 16 ("If a requested service or treatment is not listed by name in Medicaid's list of services, it should nonetheless be provided if the service or item is determined to be medically necessary and coverable" under the Medicaid program.); Perkins & Somers, *Medicaid's Gold Standard*, *supra*, at 147 (explaining that, for purposes of EPSDT, "children's health needs [must be] determined based on individualized assessments that reflect the current state of health care, not outdate[d] and/or across-the-board coverage guidelines").

3. Outreach and Education

To ensure that children and their families are aware and make use of their EPSDT entitlement, Congress required states to proactively educate all eligible individuals about their EPSDT rights. 42 U.S.C. § 1396a(a)(43)(A). CMS's implementing regulations specifically direct states to provide, using "clear and nontechnical language," educational materials discussing the benefits of preventive health care, the services available at no cost under EPSDT, and how to access those services, including the ability to request transportation and scheduling assistance. 42 C.F.R. § 441.56(a).

C. Comprehensive EPSDT Coverage Is Particularly Important for Children with Medically Complex Needs.

All children deserve the chance to thrive, including children with special health care needs. The EPSDT guarantees are integral to the well-being and even survival of these children.

The federal government estimates that almost 14 million children have, or have a heightened risk of, chronic health conditions that require care "of a type or amount beyond that required by children generally." *Children and Youth with Special Health Care Needs: NSCH Data Brief*, Maternal & Child Health Bureau, U.S. Dep't Health & Human Servs. (HHS) 1 (June 2022), https://mchb.hrsa.gov/sites/default/files/mchb/programs-impact/nsch-data-brief-children-youth-special-health-care-needs.pdf. The most commonly reported chronic conditions among this group include autism and other

developmental and intellectual disabilities, asthma, allergies, and mental health and behavioral conditions. Reem M. Ghandour et al., *Children and Youth with Special Health Care Needs: A Profile*, 147 Pediatrics Suppl. 7 at S3 (Fig. 3) (2022).

More than half of these children rely on prescription drugs to manage their chronic conditions, and approximately one in four have moderate to severe limitations on their daily activities. *Children and Youth with Special Health Care Needs: NSCH Data Brief*, *supra*, at 2. As compared to other children, children with special health care needs are more likely to be Black and more likely to live in poverty. *Id.* at 1–2.

Given these demographics—together with targeted Medicaid eligibility pathways for children with disabilities—it is no surprise that children with special health care needs disproportionately rely on Medicaid for their care. *See* Ghandour et al., *supra*, at S5. For these children, the EPSDT benefit guarantees a wide range of critical services, as set forth below. Recognizing the Medicaid Act's requirement for states to cover all medically necessary services to "correct *or ameliorate*" a child's condition, CMS has emphasized that EPSDT includes both curative services as well as "services that maintain or improve" a permanent or chronic condition—a form of coverage that is "particularly important for children with disabilities, because such services can prevent conditions from worsening, reduce pain, and avert the development of more costly illnesses and conditions." *CMS EPSDT Guide* at 10 (discussing 42 U.S.C. § 1396d(r)(5)).

In addition to guaranteeing cost-free access to prescription drugs, specialist visits, and other services, EPSDT ensures coverage of services that may be less familiar to the general population but that provide crucial support for children with functional limitations and their families. Consider the following supports and services, all of which would likely be unaffordable—and therefore unavailable—for low-income children were it not for Medicaid coverage:

- Medical equipment such as wheelchairs, bed rails, pressure-reducing mattresses, incontinence supplies, and hearing aids;
- In-home private-duty nursing and personal care services, which help to alleviate intensive and complex caregiving responsibilities that would otherwise fall solely on family members;
- Targeted case management services, which connect children with complex needs and their families with needed health and social services; and
- Physical and speech therapy, applied behavioral analysis therapy for autism, and other rehabilitative services.

Because many of these services are classified as optional benefits under the Medicaid Act, states have discretion as to whether these services will be covered for adults age 21 and over. *See* 42 U.S.C. §§ 1396a(a)(10), 1396d(a). Congress did not afford similar discretion with respect to children and

youth, however, who enjoy a federal right to comprehensive coverage.

* * *

The Medicaid Act establishes a legally enforceable promise of access to comprehensive health care services for low-income children in America. Making that promise a reality depends on states' faithful implementation of the EPSDT requirements, however. As set forth in the following section, Section 1983 has been an essential tool for children and families to hold states accountable for coverage restrictions that violate children's federal rights.

III. Section 1983 Is an Essential Tool for Protecting Children's Federal Right to Receive Medically Necessary Services.

Despite robust federal requirements to promote and protect children's health, state compliance with EPSDT is often deficient, creating health risks for children as well as anxiety and administrative obstacles for parents, providers, and health care advocates. History offers numerous examples of state policies or practices restricting children's access to needed health care services, whether arising out of neglect, a misunderstanding of federal law, or an attempt to reduce program costs.

Section 1983 provides a critical remedy, offering as it does a route to redress the "deprivation of any rights" under federal law, including the Social Security Act's parameters for Medicaid and public programs. 42 U.S.C. § 1983; *see Wilder v. Virginia Hosp. Ass'n*, 496 U.S. 498 (1990); *Maine v. Thiboutot,*

448 U.S. 1 (1980). Congress has, moreover, expressly ratified Section 1983's place in the Medicaid enforcement regime, which otherwise lacks any opportunity for beneficiaries to vindicate their federal rights in many circumstances.

A. Children Have Long Relied on Section 1983 to Secure Access to Needed Health Care Services.

Over the past five decades, low-income children have relied on Section 1983 in dozens of lawsuits that successfully secured access to needed medical services. The courts have had no trouble concluding that the federal EPSDT provisions create an individually enforceable right to comprehensive coverage for Medicaid-enrolled children, consistent with this Court's directives in *Blessing v. Freestone,* 520 U.S. 329 (1997), and *Gonzaga University v. Doe,* 536 U.S. 273 (2002).[21] As one district court noted in 2016, "every circuit court to have decided the question has concluded that Medicaid beneficiaries can enforce the EPSDT provisions." *O.B. v. Norwood*, 170 F. Supp. 3d 1186, 1191 (N.D. Ill.),

[21] The *Blessing* Court set forth three factors to guide courts in identifying statutory rights that may be enforced under Section 1983: (1) "Congress must have intended that the provision in question benefit the plaintiff"; (2) the asserted right must not be "so vague and amorphous that its enforcement would strain judicial competence"; and (3) the relevant statutory provision "must be couched in mandatory, rather than precatory, terms." 520 U.S. at 340–41. In *Gonzaga*, the Court emphasized the need to consider whether "Congress intended to confer *individual rights* upon a class of beneficiaries." 536 U.S. at 285 (emphasis added).

aff'd, 838 F.3d 837 (7th Cir. 2016); *see also, e.g.*, *Westside Mothers v. Olszewski*, 454 F.3d 532, 543 (6th Cir. 2006); *S.D.*, 391 F.3d at 603–05.[22]

When a child seeks judicial recourse based on denied Medicaid services, the legal analysis is often quite straightforward: "states have an obligation to cover every type of health care or service necessary for EPSDT corrective or ameliorative purposes" if the service is both "medically necessary" to correct or ameliorate the child's health condition and "allowable" under federal Medicaid law, meaning that it falls within one of the mandatory or optional Medicaid benefits enumerated at 42 U.S.C. § 1396d(a). *Katie A.*, 481 F.3d at 1158 (citing 42 U.S.C. § 1396a(a)(43)(C)).

Armed with this simple statutory logic, children have used Section 1983 to secure timely access to a wide range of essential health care services they would otherwise have been denied, including the following:

- **Life-saving organ transplants**. *Pittman v. Sec'y, Fla. Dep't of Health & Rehab. Servs.*, 998 F.2d 887 (11th Cir. 1993) (liver transplant); *Pereira v. Kozlowski*, 996 F.2d 723 (4th Cir. 1993) (heart transplant).

[22] District courts have, in addition, continued to apply pre-*Gonzaga* appellate decisions that found EPSDT rights enforceable under Section 1983, concluding that these longstanding circuit precedents are consistent with the updated standards articulated in *Blessing* and *Gonzaga*. *See, e.g.*, *Salazar v. D.C.*, 729 F. Supp. 2d 257, 268–71 (D.D.C. 2010); *Hunter v. Medows*, No. CIVA 108CV-2930, 2009 WL 5062451, at *2 (N.D. Ga. Dec. 16, 2009).

- **Blood lead-level screenings**. *Thompson v. Raiford*, No. 3:92-CV-1539-R, 1993 WL 497232 (N.D. Tex. Sept. 24, 1993) (approving a settlement agreement in which the state agreed to update its lead screening program based on guidelines from the Centers for Disease Control & Prevention).
- **Glucose testing supplies** for children with diabetes. *Biewald v. State*, 451 A.2d 98, 100 (Me. 1982) (observing that "successful treatment of insulin dependent, diabetic children is impossible without" glucose testing materials "to determine proper insulin dosage").
- **Incontinence supplies**. *S.D.*, 391 F.3d at 585 (noting that, without prescription moisture-wicking underwear, a teenager with spina bifida was at risk of developing "chronic irritation and infection from urine wetness," as well as becoming "home bound, isolated, and unable to attend school or engage in other age-appropriate activities"); *see also, e.g.*, *Smith v. Benson*, 703 F. Supp. 2d 1262 (S.D. Fla. 2010); *Ekloff v. Rodgers*, 443 F. Supp. 2d 1173 (D. Ariz. 2006).
- **Early intervention services** for very young children with special health care needs. *Pediatric Specialty Care v. Ark. Dept. of Human Servs.*, 293 F.3d 472, 479 (8th Cir. 2002) (affirming a finding of medical necessity based on evidence that such services "provide numerous benefits to children, including increased IQ levels, reduction in

developmental disabilities, and a decreased chance of being placed in special education classes").

- **Therapy for autism**, such as applied behavioral analysis (ABA). *Parents' League for Effective Autism Servs. v. Jones-Kelley*, 339 F. App'x 542, 552 (6th Cir. 2009) (finding that the loss of ABA services would cause "the plaintiff children [to] suffer irreparable injury in the form of severe regression of symptoms"); *see also, e.g.*, *K.G. v. Dudek*, 981 F. Supp. 2d 1275 (S.D. Fla. 2013); *Chisholm v. Hood*, 133 F. Supp. 2d 894 (E.D. La. 2001).
- ***Preventive dental services***. *Mitchell v. Johnston*, 701 F.2d 337, 348 (5th Cir. 1983) (observing that the state's coverage restrictions would require dentists to "[forgo] treatment of a detected dental problem until it culminated in a more serious, perhaps irreversible dental problem," an outcome inconsistent with the EPSDT requirement for a "program of *preventive* dental health" (emphasis added)).
- ***Physical, occupational, and speech therapy***. *C.R. v. Noggle*, 559 F. Supp. 3d 1323 (N.D. Ga. 2021) (directing the state to cover therapies that prevent a child's condition from regressing, even if the child does not show continued improvement); *A.M.T. v. Gargano*, 781 F. Supp. 2d 798 (S.D. Ind. 2011) (same).

- ***Private-duty nursing services***.[23] *M.H. v. Berry*, No. 1:15-CV-1427, 2021 WL 1192938, at *6–7 (N.D. Ga. Mar. 29, 2021) (enjoining a policy under which the number of skilled nursing hours authorized for a given child were automatically phased down over time, which "arbitrarily shifted more of the burden of a child's care to the caregiver without any consideration of caregiver's capacity to provide the care," including "activities which require the knowledge and skill of a licensed nurse"); *see also*, *e.g.*, *O.B.*, 838 F.3d 837; *I.N. v. Kent*, No. C 18-03099, 2019 WL 1516785, at *3 (N.D. Cal. Apr. 7, 2019).

Each of these cases highlights the devastating consequences when a child is denied access to needed services. These cases also underscore the vital role of the courts in preventing or redressing such harms by enforcing the Medicaid Act's directives. In the early years following EPSDT's enactment, one court grimly observed that, without robust adherence to federal coverage and notification requirements, by the time a "child is brought for treatment it may too often be on a stretcher." *Stanton v. Bond*, 504 F.2d 1246, 1251 (7th Cir. 1974).

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[23] CMS regulations define "private duty nursing services" as "nursing services for beneficiaries who require more individual and continuous care than is available from a visiting nurse or routinely provided by the nursing staff of the hospital or skilled nursing facility." 42 C.F.R. § 440.80.

B. Section 1983 Represents an Essential Pillar in the Medicaid Act's Enforcement Regime.

When a state fails to honor a child's federal right to comprehensive Medicaid coverage, Section 1983 may provide the only avenue for effective relief. Although the Medicaid Act defines certain administrative remedies at the state and federal levels, as set forth below, these processes may be unfit for a crucial class of claims: challenging a state action that, although ostensibly compliant with state law, impermissibly deprives a child of specific services to which he or she is entitled under federal law. Section 1983 provides that opportunity—a role that Congress has recognized and expressly endorsed.

1. State Administrative Appeals Focus on State Policies.

The Medicaid Act requires states to establish a process for beneficiaries to appeal adverse decisions regarding their eligibility or coverage for specific services. 42 U.S.C. §§ 1396a(a)(3), 1396u-2(b)(4); *see also* 42 C.F.R. §§ 431.200–50, 438.400–24. However, this process was designed to collect evidence and correct misapplications of state policies, not to adjudicate claims that the state policies themselves have been designed or applied in a manner that violates federal law. Indeed, states may forgo a hearing entirely if the "sole issue is a . . . State law requiring an automatic change adversely affecting some or all beneficiaries." 42 C.F.R. § 431.220(b).

Moreover, the EPSDT requirement's breadth means that children with special health care needs may be requesting highly specialized services that are neither discussed in state Medicaid manuals nor listed in the state's fee schedule of covered billing codes. Absent any state policy expressly authorizing coverage, the child may find their coverage request denied and their administrative remedies unavailing.

Thus, as long as the state is acting in accordance with its own policies, as interpreted by the state's Medicaid officials and administrative adjudicators, the administrative appeal process may offer no relief for a child who has been deprived of needed services in violation of federal law.

2. Federal Administrative Oversight Focuses on Egregious and Systemic Violations.

In carrying out its oversight responsibilities, CMS does have responsibilities to ensure state compliance with federal law. However, its visibility into state operations and its enforcement tools both suffer from a lack of granularity. In this regard, the scope of the EPSDT guarantees—together with the overall size of the Medicaid program, and the fact that it is operated by 56 different state and territorial jurisdictions—creates challenges for federal oversight and enforcement gaps for children.

As a preliminary matter, CMS provides prospective oversight by reviewing Medicaid state plans and proposed amendments and withholding approval for any requested changes that would

violate federal law. *See* 42 U.S.C. § 1396c; 42 C.F.R. §§ 430.10–25. States need only offer a high-level certification of compliance with the EPSDT standard, however. *See* 42 C.F.R. § 441.55. The "State Plan need not specifically list every treatment service conceivably available under the EPSDT mandate." *Pediatric Specialty Care*, 293 F.3d at 480. Nor are states required to spell out their service definitions and utilization management protocols for each and every covered benefit. Thus, on the face of the state plan, it may be impossible for CMS to determine whether the state's policies comply with federal EPSDT obligations.

In addition to verifying compliance on paper, CMS has the authority to take enforcement action against a state that fails to *operate* its state plan in substantial compliance with federal law. *See* 42 U.S.C. § 1396c; 42 C.F.R. §§ 430.60–104. CMS's sole remedy, however, is to withhold federal funds, a drastic step that threatens to further harm the very program beneficiaries whose interests CMS seeks to protect. CMS thus reserves this blunt tool only for the most egregious and systemic violations.

If a state policy affects a relatively small number of very sick children who require specialized services, the policy is unlikely to come to CMS's attention at all, much less prompt the lengthy audit and hearing procedures necessary to establish and penalize substantial noncompliance by the state. CMS receives regular reports from the states, including certain metrics related to utilization of pediatric screening and preventive services, but these reports are insufficiently granular to assess the many ways that a state may fall short,

particularly for children who require specialized services. *See* Perkins & Somers, *Medicaid's Gold Standard*, *supra*, at 168–74; *A New Medicaid Access Monitoring System* at 2*,* in June 2022 Report to Congress on Medicaid and CHIP, Medicaid & CHIP Payment & Access Comm'n, https://www.macpac.gov/wp-content/uploads/2022/06/Chapter-1-A-New-Medicaid-Access-Monitoring-System.pdf (concluding that CMS's "current approach to monitoring access does not measure key domains of access or provide comparable or actionable data, which are needed to assess whether the program is meeting" federal requirements).

Given CMS's inability to monitor access to all needed services for all children, states could quietly cut coverage with impunity. Unlike CMS, however, children, families, and providers notice right away when needed services are denied. Section 1983 thus acts as both a deterrent and a cure for state actions that violate children's federal coverage rights.

3. Congress Has Ratified Section 1983's Role in Enforcing Individual Rights in Public Benefit Programs.

As set forth above, neither the state administrative appeal process nor CMS's federal oversight offers a meaningful remedy for children who have been denied access to the services they need. "This administrative scheme cannot be considered sufficiently comprehensive to demonstrate a congressional intent to withdraw the private remedy of § 1983." *Wilder*, 496 U.S. at 522. To the contrary, Section 1983 supports Congress's vision for EPSDT by empowering children and

families to seek targeted relief for violations of their federal rights.

Moreover, the Social Security Act's statutory history shows that Congress understands and endorses this application of Section 1983, as demonstrated by its partial legislative repeal of *Suter v. Artist M.*, 503 U.S. 347 (1992). The *Suter* Court held that beneficiaries in joint federal-state programs generally cannot use Section 1983 to enforce rights that are defined as federal requirements on state plans for public assistance. *Id*. at 363. In response, Congress enacted the following proviso: "In an action brought to enforce" a provision of the Social Security Act, the provision may not be "deemed unenforceable" merely because of its inclusion in a statutory section that specifies the "required contents of a State plan." 42 U.S.C. §§ 1320a-2, 1320a-10. Congress has thus expressly ratified Section 1983's use as a private enforcement mechanism for beneficiaries in public programs like Medicaid that are jointly administered by the federal and state governments.

IV. Medicaid's Comprehensive Coverage for Children Yields Lifelong Benefits.

Congress enacted the EPSDT requirements with the goal of promoting the healthy development of children in lower-income families. The program has generated tremendous benefits for individual children and the nation as a whole: A robust evidence base shows that children who gain access to Medicaid coverage live longer, healthier lives, in addition to achieving higher levels of education and income. These outcomes are due in part to the

tireless advocacy of families, children's rights organizations, and children's health providers, including Section 1983 lawsuits that held states accountable for providing all federally required benefits.

Because states incrementally expanded Medicaid eligibility for children over time, researchers have been able to identify the impacts of Medicaid coverage for newly eligible children who, until that point, typically were uninsured. Researchers have comprehensively documented the many benefits of Medicaid coverage during childhood, both for children and for society as a whole. For example, Medicaid coverage during childhood is associated with:

- A lower risk of dying during childhood, including a 20 percent drop in mortality rates among children of color who gained access to Medicaid in the program's early decades;[24]
- Improved health and well-being later in life, including decreased rates of hospitalization, disability, and premature mortality;[25]

[24] Andrew Goodman-Bacon, *Public Insurance and Mortality: Evidence from Medicaid Implementation*, 126 J. Pol. Econ. 216 (2018); Laura R. Wherry & Bruce D. Meyer, *Saving Teens: Using a Policy Discontinuity to Estimate the Effects of Medicaid Eligibility*, 51 J. Hum. Resources 556 (2016).

[25] Andrew Goodman-Bacon, *The Long-Run Effects of Childhood Insurance Coverage: Medicaid Implementation, Adult Health, and Labor Market Outcomes*, 111 Am. Econ. Rev. 2550 (2021); David W. Brown et al., *Long-Term Impacts of Childhood Medicaid Expansions on Outcomes in*

- Higher educational attainment, including elevated graduation rates for both high school and college;[26] and
- Higher wages in adulthood, as well as lower rates of participation in means-tested public benefit programs.[27]

These outcomes demonstrate the vital importance of honoring low-income children's federal right to receive comprehensive Medicaid services.

CONCLUSION

For more than 50 years, the Medicaid program has provided access to essential services for low-income children. That access exists thanks to the federal rights and responsibilities that Congress has defined and built upon to ensure that children have timely access to the health care services they need to survive and thrive. As pediatric health care providers and child health advocates, we have observed the many types of barriers established by

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Adulthood, 87 Rev. Econ. Stud. 792 (2019); Laura R. Wherry et al., *Childhood Medicaid Coverage and Later-Life Health Care Utilization*, 100 Rev. Econ. & Stat. 287 (2018); Janet Currie et al., *Has Public Health Insurance for Older Children Reduced Disparities in Access to Care and Health Outcomes?* 27 J. Health Econ. 1567 (2008).

[26] Sarah R. Cohodes et al., *The Effect of Child Health Insurance Access on Schooling: Evidence from Public Insurance Expansions,* 51 J. Hum. Resources 727 (2016).

[27] Bacon, *The Long-Run Effects of Childhood Insurance Coverage*, *supra*; Brown, *Long-Term Impacts of Childhood Medicaid Expansions on Outcomes in Adulthood*, *supra*.

state Medicaid programs—intentionally or not—that jeopardize children's health by denying access to needed services. Because Congress intended for coverage of EPSDT benefits to be an enforceable right, aggrieved children and families have relied on Section 1983 to secure access to essential services.

Were it not for Section 1983, the EPSDT guarantees would be little more than empty promises. A glance at the litany of cases brought by families and their health providers demonstrates the need for access to the courts when states infringe children's rights. Losing this longstanding enforcement tool would leave children and families without recourse when states deprive them of access to needed services. Weakening Section 1983 in this way would be inconsistent both with Congress's legislative intent as to the enforceability of the EPSDT benefit guarantee and with Congress's goal of comprehensive health coverage for the nation's youngest generation.

Respectfully submitted,

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