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 THE JUDGE DAVID L. BAZELON CENTER FOR MENTAL HEALTH LAW, THE ARC OF THE UNITED STATES, AMERICAN ASSOCIATION OF PEOPLE WITH DISABILITIES, DISABILITY RIGHTS EDUCATION AND DEFENSE FUND, CENTER FOR PUBLIC REPRESENTATION, AND COMPASSION & CHOICES AS *AMICI CURIAE* IN SUPPORT OF RESPONDENT

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INTEREST OF *AMICI CURIAE*[1]

Amici are organizations that advocate on behalf of people with disabilities, including people with mental, intellectual, and developmental disabilities.

The Judge David L. Bazelon Center for Mental Health Law is a national organization that advocates for the civil rights, full inclusion, and equality of adults and children with mental disabilities.

The Arc of the United States is a national community-based organization that works to uphold the access of every individual with intellectual and developmental disabilities to the information, advocacy, and skills needed to support full participation in the community.

American Association of People with Disabilities ("AAPD") works to increase the political and economic power of people with disabilities and to advance their rights. A national cross-disability organization, AAPD advocates for full recognition of the rights of more than 60 million Americans with disabilities.

Compassion & Choices is a national organization that advocates on behalf of terminally ill people by promoting healthcare equity at the end of life, improving the quality of end-of-life care, and expanding access to end-of-life options.

Disability Rights Education and Defense Fund ("DREDF") is a national law and policy center dedicated to protecting and advancing the civil rights

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[1] Pursuant to Supreme Court Rule 37.6, counsel for *amici* represent that they authored this brief in its entirety and that none of the parties or their counsel, nor any other person or entity other than *amici* or their counsel, made a monetary contribution intended to fund the preparation or submission of this brief. Pursuant to Rule 37.3(a), counsel for *amici* also represent that all parties have consented to the filing of this brief.

of people with disabilities. DREDF is recognized for its expertise in the interpretation of federal disability civil-rights laws.

Center for Public Representation is a national legal advocacy organization that has been enforcing the rights of people with disabilities, both in the community and in institutional settings, for almost 50 years. Using both litigation and policy advocacy, the Center ensures that people with disabilities have access to the critical health care services they need to live and participate in their own communities.

Amici have an interest in preserving the right of individuals with disabilities to bring private suits to enforce their entitlements under Spending Clause legislation. Individuals with disabilities, particularly those with mental disabilities, have long been ostracized and excluded from American society. The Rehabilitation Act of 1973, the Americans with Disabilities Act of 1990, and the Medicaid Act have been instrumental in redressing those historic wrongs. Medicaid implements the antidiscrimination protections guaranteed by the Rehabilitation Act and the Americans with Disabilities Act – which are indisputably enforceable by private causes of action – by providing individuals with disabilities the care they need to fully integrate into society. Without a private cause of action to enforce Medicaid's requirements, the most vulnerable beneficiaries will be left without meaningful recourse to ensure access to their Medicaid entitlements.

Accordingly, *amici* submit this brief to urge the Court to affirm the decision of the Seventh Circuit and to reaffirm that 42 U.S.C. § 1983 provides a private cause of action to enforce legislation passed pursuant to Congress's Spending Clause power.

HISTORICAL AND STATUTORY BACKGROUND

Society's historical treatment of people with disabilities – and the struggles they have faced in seeking inclusion and equality – is critical to understanding the importance of federal programs benefiting those individuals.

A. Discriminatory Treatment of People with Disabilities, Especially Those with Mental Disabilities, Has Deep Historical Roots in American Society

People with disabilities have long been excluded from full participation in society. In the late-18th century, care for such individuals "was left to families, jails, poorhouses, and ad hoc community arrangements."[2] John Locke believed that people with mental disabilities should be denied full participation in society. "[L]unatics and id[i]ots . . . and madmen," as Locke called them, were not born into the "full state of equality" because they relied on society "to seek and procure their good for them."[3]

The mid-19th century saw the rise of asylums.[4] First developed by reformers like Dorothea Dix to address the shortcomings in the existing system, those institutions quickly devolved into facilities with

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[2] Jefferson D.E. Smith & Steve P. Calandrillo, *Forward to Fundamental Alteration: Addressing ADA Title II Integration Lawsuits after* Olmstead v. L.C., 24 Harv. J.L. & Pub. Pol'y 695, 706 (2001).

[3] John Locke, *Second Treatise of Government* 31, 34 (C.B. Macpherson ed., Hackett Publ'g Co. 1980) (1690) (emphases omitted).

[4] *See* Samuel W. Hamilton, *The History of American Mental Hospitals*, *in* Am. Psychiatric Ass'n, *One Hundred Years of American Psychiatry* 73, 73-78 (J.K. Hall et al. eds., Colum. Univ. Press 1944).

the primary purpose of isolating patients from society.[5] Because medical professionals believed that people with mental disabilities "were likely to engage in criminal activities and sexually immoral behavior and were therefore a menace to society," "[i]nstitutionalization . . . came to be viewed as an effective solution, providing [them] with the paternalistic protection they needed and, at the same time, safeguarding the community at large."[6] Life in asylums was bleak. "Crowding of patients[] [and] staff shortages" were pervasive problems, and patients suffered from "inadequate diets, widespread [use of] restraint[s], brutality, and poorly trained physicians and staff."[7]

Such treatment mirrored official attitudes that such individuals were "not far removed from the brute, and [were] perhaps cruel with the unconscious cruelty of an animal."[8] And in some States, government officials believed that "seclusion of the recognized, conceded, undeniable idiot or imbecile is the one remedy for a moral, social and physical condition . . . that will, in time, . . . slowly undermine and rot

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[5] *See* U.S. Comm'n on Civil Rights, *Accommodating the Spectrum of Individual Abilities* 19 (Sept. 1983).

[6] Joanne Karger, Note, *"Don't Tread on the ADA":* Olmstead v. L.C. ex rel. Zimring *and the Future of Community Integration for Individuals with Mental Disabilities*, 40 B.C. L. Rev. 1221, 1225 (1999).

[7] Gerald M. Grob, *From Asylum to Community: Mental Health Policy in Modern America* 9, 75 (Princeton Univ. Press 1991) ("Grob, *From Asylum to Community*"); *see generally* Karen M. Tani, *The* Pennhurst *Doctrines and the Lost Disability History of the "New Federalism,"* 110 Calif. L. Rev. 1157 (2022).

[8] *Mental Defectives in Virginia: A Special Report of the State Bd. of Charities and Corrections to the General Assembly of Nineteen Sixteen* 18-19 (1915).

the very foundations of the society and the state." *Martin v. Taft*, 222 F. Supp. 2d 940, 965 (S.D. Ohio 2002) (quoting "an early superintendent of the Institution for Feeble-Minded Youth in Columbus, Ohio"); *see also Buck v. Bell*, 274 U.S. 200, 207 (1927) (Holmes, J.) ("Three generations of imbeciles are enough.").

Between 1890 and 1940, "the proportion of long-term chronic patients increased dramatically" with "more than half of all patients ha[ving] been institutionalized for five years or more" by 1923.[9] But after World War II, societal sentiment toward people with disabilities began to change.

B. Congress Enacted the Rehabilitation Act and the Americans with Disabilities Act To Combat a Long History of Pervasive Discrimination and Institutionalization

In 1973, Congress recognized the importance of deinstitutionalization and the integration of people with disabilities into society when it enacted the Rehabilitation Act ("RA"). *See* Pub. L. No. 93-112, 87 Stat. 355 (codified as amended at 29 U.S.C. § 701 *et seq.*). Congress's express goal was, in part, "to empower individuals with disabilities to maximize employment, economic self-sufficiency, independence, and inclusion and integration into society." 29 U.S.C. § 701(b)(1).

Section 504 of the RA, commonly considered "the civil rights bill of the disabled," *ADAPT v. Skinner*, 881 F.2d 1184, 1187 (3d Cir. 1989) (en banc), was "the first federal statute to deal with discrimination against individuals with disabilities."[10] The relevant

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[9] Grob, *From Asylum to Community* at 6.

[10] Karger, 40 B.C. L. Rev. at 1233.

portion of the RA reads: "No otherwise qualified individual with a disability . . . shall, solely by reason of his or her disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance." 29 U.S.C. § 794(a). Implementing regulations from the Department of Justice ("DOJ") state that entities receiving federal funding must "administer programs and activities in the most integrated setting appropriate to the needs of qualified handicapped persons." 28 C.F.R. § 41.51(d).

In 1975, Congress enacted the Developmental Disabilities Assistance and Bill of Rights Act ("DDA"), 42 U.S.C. § 6000 *et seq.*, *repealed by* Developmental Disabilities Assistance and Bill of Rights Act of 2000, Pub. L. No. 106-402, § 401(a), 114 Stat. 1677, 1737. The DDA established a cooperative federalism scheme whereby the federal government provided financial assistance to participating States "to aid them in creating programs to care for and treat the developmentally disabled." *Pennhurst State Sch. & Hosp. v. Halderman*, 451 U.S. 1, 11 (1981).

Despite Congress's attempts to integrate people with disabilities into society, institutionalization remained prevalent in the United States, largely because of the absence of any meaningful enforcement authority.[11] Courts had held that the DDA, the RA, and the Equal Protection Clause did not require treatment in the least restrictive environment. *See id.* at 18 (DDA did not provide right to treatment in least restrictive environment); *City of Cleburne v. Cleburne Living Ctr.*, 473 U.S. 432, 442-46 (1985)

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[11] *See* Smith & Calandrillo, 24 Harv. J.L. & Pub. Pol'y at 707.

(people with disabilities not a suspect class subject to heightened protection); *P.C. v. McGlaughlin*, 913 F.2d 1033, 1041-42 (2d Cir. 1990) (the RA did not provide right to treatment in least restrictive environment).

Congress acted to strengthen protections against institutionalization and to accelerate the integration of people with disabilities when it enacted the Americans with Disabilities Act ("ADA") in 1990. *See* 42 U.S.C. § 12101. One purpose of the statute was "to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities." *Id.* § 12101(b)(1). In the ADA's opening provisions, Congress recognized that, "historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem." *Id.* § 12101(a)(2). Congress further recognized that "discrimination against individuals with disabilities persists in such critical areas as . . . institutionalization," thus explicitly calling out institutionalization as a form of discrimination. *Id.* § 12101(a)(3).[12]

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[12] Congress also instructed the DOJ to issue regulations implementing the ADA's antidiscrimination provisions. *See* 42 U.S.C. § 12134(a); *see also* Jasmine E. Harris, *The Aesthetics of Disability*, 119 Colum. L. Rev. 895, 916-24 (2019). The Attorney General accordingly adopted implementing regulations, including regulations that mirrored the coordinating regulations under the RA. *See* 28 C.F.R. § 35.130(d).

C. While Congress Was Strengthening Protections Against Disability Discrimination, It Amended Medicaid Law To Give Persons with Disabilities the Tools To Achieve Full Inclusion in Their Communities

Although Congress had gradually provided protections against discrimination on the basis of disability, it had done little to ensure that people with disabilities received care adequate to keep them out of institutionalized settings. Congress amended the Medicaid statute to fill that gap.

"Before 1981, Medicaid provided assistance for long-term care only if the individual resided in an institution."[13] In parallel to its passage of legislation prohibiting unnecessary institutionalization, Congress amended the Medicaid statute in 1981 to provide funding for state-run home- and community-based care through a waiver program. *See* Medicare and Medicaid Amendments of 1981, Pub. L. No. 97-35, tit. XXI, § 2176, 95 Stat. 357, 783, 812-13 (codified as amended at 42 U.S.C. § 1396n(c)). By 2003, Medicaid became the single most significant source of support for healthcare services (including community-based services) for people with mental, intellectual, or developmental disabilities.[14]

Congress's enactment of the Patient Protection and Affordable Care Act ("ACA") in 2010 was another sea-change in the Medicaid program because of provisions intended to improve access to and afford-

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[13] Karger, 40 B.C. L. Rev. at 1229.

[14] *See* Chris Koyanagi, *Learning From History: Deinstitutionalization of People with Mental Illness As Precursor to Long-Term Care Reform*, Kaiser Comm'n on Medicaid and the Uninsured at 9 & n.22 (Aug. 2007).

ability of Medicaid healthcare for adults, especially those with disabilities. The ACA, among other things, creates state and federal health insurance marketplaces with guaranteed issue plans (meaning that enrollees cannot be rejected because of health status or other factors that might otherwise disqualify them from coverage) that contain enumerated essential benefits.[15]

In its current form, Medicaid provides important benefits for people with disabilities besides the home- and community-based care supplied under the waiver program. Medicaid supplies "long-term services and supports," which provide assistance with daily activities like meal preparation, eating, bathing, dressing, housekeeping, and transportation.[16] Further, Medicaid guarantees beneficiaries home health services, and some States also provide personal care services under their Medicaid programs.[17] The largest share of benefit spending on both mandatory

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[15] *See* Jae Kennedy et al., *Disparities in Insurance Coverage, Health Services Use, and Access Following Implementation of the Affordable Care Act: A Comparison of Disabled and Non-disabled Working-Age Adults*, 54 INQUIRY 1 (2017).

[16] *See* Erica L. Reaves & MaryBeth Musumeci, *Medicaid and Long-Term Services and Supports: A Primer*, Kaiser Family Found. (Dec. 2015).

[17] Medicaid also provides services like end-of-life (hospice) care and palliative care, both of which are important benefits for people with disabilities. *See* Medicaid.gov, *Hospice Benefits*, https://www.medicaid.gov/medicaid/benefits/hospice-benefits/index.html; *see also* Emily Adam et al., *The Palliative Care Needs of Adults with Intellectual Disabilities and Their Access to Palliative Care Services: A Systematic Review*, 34 Palliative Care 1006 (2020) (discussing palliative care needs of adults with intellectual disabilities).

and optional services under state Medicaid plans is for people with disabilities.[18]

SUMMARY OF ARGUMENT

Medicaid is a crucial part of Congress's antidiscrimination protections for people with disabilities. Medicaid provides important health benefits, including alternatives to institutional care, that private insurers rarely offer. People with disabilities – including those whose incomes are above the standard limits for Medicaid eligibility, who pay a premium to use Medicaid – depend on those services to live and work in their communities. By affording people with disabilities greater opportunities to achieve full inclusion in their communities, Medicaid effectuates the antidiscrimination provisions of the RA and the ADA.

Last Term, this Court reiterated that it is "beyond dispute" that the antidiscrimination provisions contained in the RA and the ADA are enforceable in private lawsuits. *See Cummings v. Premier Rehab Keller, P.L.L.C.*, 142 S. Ct. 1562, 1569-70 (2022). Various Medicaid requirements – including the "entitlement," "reasonable promptness," and "free-choice-of-provider" guarantees – implement the antidiscrimination provisions by ensuring that people with disabilities have access to healthcare in the most integrated setting appropriate to their needs. Those Medicaid requirements thus effectuate the RA's and the ADA's guarantee against unjustified institutionalization of people with disabilities.

The linkage between the RA's and the ADA's antidiscrimination mandate and Medicaid provisions

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[18] *See* Medicaid and CHIP Payment and Access Comm'n, *Mandatory and Optional Enrollees and Services in Medicaid* 13 (June 2017).

implementing that mandate is evidence that Congress intended both aspects of its disability-rights scheme to be privately enforceable. That conclusion is bolstered by the fact that Congress, when enacting the ACA, broadened Medicaid's "entitlement" provisions by expanding the definition of "medical assistance." Congress did so in direct response to judicial decisions narrowly construing that term in § 1983 suits brought by people with disabilities.

Petitioners' request that this Court abandon its longstanding holding that Spending Clause legislation can give rise to a private right of action under § 1983 would undermine Congress's scheme for enforcing disability rights. People with disabilities, including children, regularly bring private lawsuits to enforce each of their independent, mutually reinforcing entitlements under the RA, the ADA, and Medicaid. Those lawsuits have vindicated important rights, providing access to life-saving therapies and everyday living support services close to one's family and community. Absent a private right of action to enforce their Medicaid guarantees, enforcement of Medicaid would be left to the federal government, which may have few enforcement options other than reduction of States' Medicaid funding. That may exacerbate rather than remedy States' failure to comply with Medicaid's requirements.

ARGUMENT

I. Both Private Suits To Enforce Medicaid Entitlements and Private Suits To Remedy Disability Discrimination Under the RA and the ADA Are Needed To Remedy Disability Discrimination

Medicaid enables people with disabilities to obtain healthcare in community settings rather than in institutions. In this way, Medicaid furthers Congress's mandate in the RA and the ADA against unjustified institutionalization, a form of disability discrimination. This Court has recently confirmed that the anti-discrimination provisions of the RA and the ADA are enforceable by private causes of action; it follows that Medicaid requirements that implement those provisions and confer rights on individual beneficiaries are privately enforceable as well.

A. Medicaid Guarantees People with Disabilities, Including Mental Disabilities, Alternatives to Unnecessary Institutional Care

More than one-third of adult Medicaid enrollees under the age of 65 are people with disabilities.[19] Medicaid is also the primary source of healthcare for people with intellectual or developmental disabilities.[20] More than 90% of those people receive Medicaid services through the Medicaid Home- and Community-Based Services ("HCBS") waiver program.[21] Under that program, States may use federal dollars to pay for in-home attendant care, habilitation services, specialized therapies, and other benefits designed to promote the well-being of people with disabilities. *See* 42 U.S.C. § 1396n(c)(4)(b) (listing forms of "medical assistance" that may be provided under HCBS waiver). Some States provide home- or community-based behavioral health services through

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[19] *See* Ctr. on Budget & Pol'y Priorities, *Medicaid Works for People with Disabilities* 1 (Aug. 29, 2017) ("CBPP, *Medicaid Works*").

[20] *See* Sarah Barth et al., *Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences* 7 (Oct. 2020) ("Barth, *Evolution*").

[21] *See id.*

an HCBS waiver.[22] Moreover, a separate Medicaid provision gives States flexibility to offer home- and community-based care without a waiver to individuals who do not qualify for institutional care.[23] Access to community care allows individuals to "maintain[] emotional ties to both family and friends, thereby improving their quality of life."[24]

Private insurers typically do not cover the services available under the HCBS program and other Medicaid programs for persons with disabilities.[25] And when they do cover such services, the policies are generally too expensive for most people.[26] To address the gap in private insurance for people with disabilities, Congress authorized the Medicaid "buy-in" program.[27] That program allows workers with disabilities whose incomes are above the standard limits for

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[22] *See* Medicaid and CHIP Payment and Access Comm'n, *Behavioral Health Services Covered Under HCBS Waivers and 1915(i) SPAs*, https://www.macpac.gov/subtopic/behavioral-health-services-covered-under-hcbs-waivers-and-spas/ (last visited Sept. 21, 2022).

[23] *See* Barth, *Evolution* at 59 (explaining that the section "1915(i) Medicaid state plan option" allows States to cover home- and community-based services for people who do not qualify for institutional care "without the need to seek a federal waiver").

[24] Margaret K. Feltz, *Playing the Lottery: HCBS Lawsuits and Other Medicaid Litigation on Behalf of the Developmentally Disabled*, 12 Health Matrix 181, 184 (2002).

[25] *See* Molly O'Malley Watts et al., Kaiser Family Found., *Medicaid Home and Community-Based Services Enrollment and Spending* 11 (Feb. 2020) ("Watts, *Medicaid Home and Community-Based Services*").

[26] *See* CBPP, *Medicaid Works* at 1.

[27] *See* HHS Admin. for Cmty. Living & DOL Off. of Disability & Emp. Pol'y, *Medicaid "Buy-in" Q&A* (last updated July 2019).

Medicaid eligibility to pay a premium to access Medicaid services.[28] The buy-in program thus "benefits the business community" by promoting the participation of persons with disabilities in the workforce.[29]

As Congress designed it, Medicaid therefore not only promotes the well-being of persons with disabilities but also saves taxpayers money. Medicaid-funded employment programs and short-term housing-assistance programs work in tandem with the buy-in program to help people with disabilities find and hold jobs in their communities.[30] Further, because in-home and community care is far less costly than institutional care, Congress's preference for community placement reduces federal Medicaid spending.[31] To illustrate, in a recent § 1983 suit challenging a state agency's failure to provide in-home nursing for children with severe intellectual or developmental disabilities under Medicaid, the Seventh Circuit emphasized the "oddity" that the agency was paying *four times* the cost of home nursing for institutional

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[28] *See id.* at 1.

[29] *Id.* at 2.

[30] *See* CBPP, *Medicaid Works* at 1-2 ("[Under their Medicaid programs,] [s]ome states provide supportive employment programs that offer services such as skills assessment, job search, job development and placement, and job training to help people with disabilities join the workforce and remain employed."); Craig Evan Pollack & Teresa Souza, *Medicaid Demonstration Expands Access To Short-Term Housing Assistance*, Health Affairs (June 9, 2022) (describing Medicaid's short-term housing-assistance programs that help people with disabilities transition from institutions to home- and community-based care).

[31] *See* Barth, *Evolution* at 7; Watts, *Medicaid Home and Community-Based Services* at 2; 42 U.S.C. § 1396n(c)(2)(D) (capping expenditures on home- and community-based services at price of institutional care, on per-capita basis).

care. *See O.B. v. Norwood*, 838 F.3d 837, 843 (7th Cir. 2016).

B. Medicaid's Alternatives to Institutional Care Effectuate the RA's and the ADA's Antidiscrimination Provisions, Which Are Indisputably Enforceable Through Private Causes of Action

In *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 (1999), this Court held that the unjustified institutionalization of people with disabilities is illegal discrimination in violation of the ADA. *Id.* at 597-603, 607. The Court explained that this rule reflects two congressional judgments about the harms of institutionalization. "First, institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life." *Id.* at 600. "Second, confinement 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." *Id.* at 601.

Olmstead imposes an obligation on States to integrate disabled persons into their communities. *See id.* at 607. This Court has repeatedly held that it is "beyond dispute" that individuals have a private right of action to enforce that obligation in suits under Section 202 of the ADA and Section 504 of the RA. *Cummings v. Premier Rehab Keller, P.L.L.C.*, 142 S. Ct. 1562, 1569-70 (2022); *Barnes v. Gorman*, 536 U.S. 181, 185 (2002). That is because, after this Court first found an implied right of action to enforce those provisions, Congress expressly acknowledged that right in amendments to Title VI of the Civil

Rights Act of 1964, which supply the enforcement authority for the RA and the ADA. *See Barnes*, 536 U.S. at 184-85. Petitioners also acknowledge (at 25) that Congress "expressly provided for" a private right of action to enforce the antidiscrimination provisions of the RA and the ADA.

Medicaid, meanwhile, provides States with substantial federal funding to meet their community integration obligations under the RA and the ADA.[32] *See Olmstead*, 527 U.S. at 601 (explaining that since 1981 the Medicaid statute has reflected a preference for treatment in the community in light of the funding the HCBS program provides "for state-run home and community-based care"). In exchange, States must comply with federal requirements designed to ensure that the funds they receive are put toward financing important benefits and services, including non-institutional care, for persons with disabilities. The HCBS program provides States a ready way to finance compliance with *Olmstead*'s integration mandate.[33] Indeed, nearly every State has at least one Medicaid HCBS waiver for people with mental, intellectual, or developmental disabilities or behavioral health conditions.[34]

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[32] *See* Watts, *Medicaid Home and Community-Based Services* at 11.

[33] *See id.*

[34] *See* Barth, *Evolution* at 14; Sheryl A. Larson et al., *In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends 2017*, at 231 (Univ. of Minn.: Inst. on Cmty. Integration, Research & Training Ctr. on Community Living, 2020) ("Larson, *Status and Trends*"). In response to COVID-19, Congress increased the federal medical-assistance percentage for certain Medicaid expenditures for home- and community-based

Medicaid's various programs thus implement Congress's antidiscrimination mandate, including its prohibition on unjustified institutionalization. That is, the RA and the ADA provide an up-front guarantee that people with disabilities receive healthcare in the most integrated setting appropriate and within a reasonable time after qualifying for those benefits. *See Olmstead*, 527 U.S. at 591-601; *id.* at 605-06 (plurality); 28 C.F.R. § 35.130(d). Medicaid, in turn, is an integral means of effectuating that right, as it helps States provide people with disabilities healthcare that meets those criteria.

Several provisions of Medicaid support the rights of persons with disabilities to receive healthcare consistent with Congress's integration mandate. First, the "entitlement" mandate of § 1396a(a)(10)(A) entitles all Medicaid-eligible individuals to receive minimum levels of "medical assistance." For those with mental, intellectual, or developmental disabilities, such assistance includes services in locations "other than in an institution for mental diseases." *Id.* § 1396d(a)(15). Further, children under the age of 21 are entitled to "early and periodic screening, diagnostic, and treatment services [('EPSDT')]" and "corrective treatment" (including mental-health treatment) for ailments disclosed by such screening. *Id.* §§ 1396d(a)(4)(B), 1396a(a)(43)(C). States partic-

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services. All States took advantage of that funding to expand access to non-institutional care. *See* Medicaid.gov, *Strengthening and Investing in Home and Community Based Services for Medicaid Beneficiaries: American Rescue Plan Act of 2021 Section 9817*, https://www.medicaid.gov/medicaid/home-community-based-services/guidance/strengthening-and-investing-home-and-community-based-services-for-medicaid-beneficiaries-american-rescue-plan-act-of-2021-section-9817/index.html (last visited Sept. 21, 2022).

ipating in the HCBS waiver program need also provide “payment for part or all of the cost of home or community-based services.” *Id.* § 1396n(c)(1).

Second, the “reasonable promptness” mandate requires that “medical assistance . . . be furnished with reasonable promptness to all eligible individuals.” *Id.* § 1396a(a)(8). Third, the “free-choice-of-provider” provision gives Medicaid recipients the right to choose their service provider, so long as the provider is “qualified to perform” those services. *Id.* § 1396a(a)(23). An analogous free-choice-of-provider provision requires States participating in the HCBS program to ensure that individuals with mental, intellectual, or developmental disabilities who are eligible for institutional care “are informed of the feasible alternatives, if available under the [State’s home- and community-based services] waiver, at the choice of such individuals, to the provision of inpatient hospital services, nursing facility services, or services in an intermediate care facility.” *Id.* § 1396n(c)(2)(C); *see also id.* § 1396n(d)(2)(C) (similar provision that applies to the elderly).

C. People with Disabilities Rely on Private Suits To Enforce Their Mutually Reinforcing Entitlements Under the RA, the ADA, and Medicaid

1. The United States correctly argues that overruling this Court’s long line of cases upholding private suits under Spending Clause legislation would “frustrate the reliance interests of private parties who depend on Section 1983 to provide protection for important rights secured to them by the Social Security Act.” U.S. Br. 21. *Amici* share that concern. People with disabilities rely on private lawsuits to enforce Medicaid requirements that guarantee them prompt access to healthcare in the most integrated setting appropriate. Such lawsuits can be divided into two overlapping categories: (1) lawsuits challenging delays in the receipt of Medicaid benefits; and (2) lawsuits seeking access to Medicaid benefits.

First, people with disabilities file private suits to require state agencies to provide them with healthcare for which they were deemed eligible, but have not yet received, because of agency delay. Taking the HCBS program as an example, studies show that many people with intellectual or developmental disabilities wait years – sometimes decades – to receive home- and community-based care after being approved for such care.[35] One 2017 national study found that States placed more than 182,000 people with intellectual or developmental disabilities on "waitlists" for home- and community-based care.[36] Meanwhile, those individuals are forced to live in institutions to receive the treatment they need or to forgo that treatment entirely.[37]

"Delay" lawsuits commonly invoke Medicaid's "reasonable promptness" provision. *See* 42 U.S.C. § 1396a(a)(8). The Eleventh Circuit's decision in *Doe ex rel. Doe, Sr. v. Chiles*, 136 F.3d 709 (11th Cir. 1998), recognized the right of people with disabilities to invoke the "reasonable promptness" provision in suits under § 1983 to challenge their placement on slow-moving waiting lists. The *Doe* plaintiffs were "developmentally disabled" individuals whom a state agency placed on years-long waiting lists. *Id.* at 711. Those individuals therefore were not "receiving

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[35] *See* Barth, *Evolution* at 17 (collecting studies).

[36] *Id.* (citing Larson, *Status and Trends* at 58).

[37] *See id.*

the therapies, training and other active treatment" that they were guaranteed under Medicaid. *Id.* In affirming the district court's entry of an injunction directing the state agency to provide the Medicaid services at issue within 90 days, the Eleventh Circuit emphasized that the "reasonable promptness" provision unambiguously confers an individual right to reasonably prompt medical assistance, which federal regulations define with further specificity. *Id.* at 713-19.

Many other "delay" lawsuits have followed. For example, in *Sabree v. Richman*, 367 F.3d 180 (3d Cir. 2004), the Third Circuit likewise permitted a group of plaintiffs with intellectual or developmental disabilities to sue under the "reasonable promptness" provision and § 1983 to speed up their transition from institutions after they had "languished on waiting lists for years." *Id.* at 182-93. Several courts have also allowed people with disabilities to bring § 1983 suits challenging the promptness of medical assistance provided through an HCBS waiver. *See Susan J. v. Riley*, 254 F.R.D. 439, 454-55 (M.D. Ala. 2008) (collecting cases finding private right of action when HCBS waiver services are at issue).

Children's lawsuits under the "reasonable promptness" and EPSDT provisions have also been successful in accelerating access to critical healthcare. In one recent case, a state agency determined that the plaintiffs – infants and toddlers with severe intellectual or developmental disabilities – qualified for 16 hours per day of private nursing services under the EPSDT program. *See A.H.R. v. Washington State Health Care Auth.*, 469 F. Supp. 3d 1018, 1029 (W.D. Wash. 2016) (citing 42 U.S.C. § 1396d(a)). But the agency did not provide those services – even though they were concededly "more cost effective" than extended hospital stays or other forms of institutionalization – because the wages the agency offered were too low to hire and retain nurses. *Id.* at 1029-32. The result was that the children were needlessly institutionalized away from their communities or their families were forced to care for their children themselves at great personal sacrifice. *See id.* (explaining that one infant was forced to remain in a group institution, and the mother of another child regularly went "more than 24 hours without sleep" to make up for the lack of nursing care). The district court, citing the "reasonable promptness" provision and the EPSDT mandate, granted the plaintiffs' request for an injunction requiring the agency to provide the requisite 16 hours per day of private nursing. *Id.* at 1039-43.

Cases like *A.H.R.* enforce Medicaid guarantees that protect against "the unnecessary isolation of a child in an expensive residential facility." *Rosie D. v. Romney*, 410 F. Supp. 2d 18, 23-24 (D. Mass. 2006); *see id.* at 24 (after a bench trial, affirming judgment for a class of children with "serious emotional disturbances" in a § 1983 suit alleging violations of the "reasonable promptness" and EPSDT provisions). Prompt enforcement of those guarantees is crucial, as children face a special risk of long-term harm from periods of isolation. *See id.* (underscoring that institutionalization of children who qualified for home- or community-based care leads to "failure at school, inability to relate positively to others, isolating depression, and assaultive or anti-social behavior"); *see also S.R. ex rel. Rosenbauer v. Pennsylvania Dep't of Hum. Servs.*, 309 F. Supp. 3d 250, 255-62 (M.D. Pa. 2018) (denying state agency's motion to dismiss § 1983 suit brought by children and teens alleging violations of the "reasonable promptness" and EPSDT mandate, where plaintiffs allegedly waited for months or years in juvenile detention facilities, psychiatric hospitals, and other "inappropriate settings" because of the lack of adequate discharge options).

Second, in other § 1983 lawsuits, people with disabilities have alleged that state agencies deemed them ineligible for, or denied them access to, services for which they were qualified. For example, in *Waskul v. Washtenaw County Community Mental Health*, 979 F.3d 426 (6th Cir. 2020), five individuals with severe intellectual or developmental disabilities challenged a change in the method by which a state agency calculated the budget for community living support services funded through the State's Medicaid program, alleging that those services were underfunded and underprovided as a result. *Id.* at 435-36. The plaintiffs grounded their challenge in several Medicaid provisions, including the overarching "entitlement" mandate, *see* 42 U.S.C. § 1396a(a)(10)(A), the more specific entitlement mandate that governs HCBS waiver programs, *see id.* §§ 1396n(c)(1), 1396d(a)(23), and the free-choice-of-provider provision applicable under an HCBS waiver, *see id.* § 1396n(c)(2)(C). *See Waskul*, 979 F.3d at 445-57. The Sixth Circuit reversed the district court's decision dismissing the plaintiffs' claims, holding that the plaintiffs plausibly alleged that inadequate payments effectively denied them the right to medical assistance and a "meaningful right to choose" among healthcare alternatives. *Id.*; *see id.* at 456 ("[T]he current budget methodology means that if they opt for home-based services, [plaintiffs] are effectively homebound, unable to get out into the community and unable to receive necessary care, services, and support.") (internal quotation marks omitted).

Similarly, in *Ball v. Rodgers*, 492 F.3d 1094 (9th Cir. 2007), the Ninth Circuit held that a class of elderly, physically disabled, and developmentally disabled HCBS-eligible Medicaid beneficiaries could sue to challenge a state agency's failure to provide enough attendant care workers under the free-choice-of-provider provisions for HCBS waivers, 42 U.S.C. §§ 1396n(c)(2)(C), 1396n(d)(2)(C). *See* 492 F.3d at 1097-98 (holding that those provisions were enforceable under § 1983 and remanding to district court for further fact-finding and entry of injunction). Specifically, the plaintiffs alleged that Arizona's meager wages for attendant care workers created a shortage of such workers. According to evidence before the district court, several plaintiffs were "trapped in bed unable to change position or care for personal hygiene, abandoned for hours in a bathroom, [and] left without food or water . . . due to the lack or absence of health care providers." *Id.* at 1101 (ellipsis in original).

Cases brought by children with disabilities seeking access to medical assistance have also resulted in meaningful relief. *See*, *e.g.*, *Collins v. Hamilton*, 349 F.3d 371, 372 (7th Cir. 2003) (affirming district court's entry of permanent injunction requiring state agency to provide long-term psychiatric treatment to children with mental illnesses under EPSDT mandate); *A.M.T. v. Gargano*, 781 F. Supp. 2d 798, 802-08 (S.D. Ind. 2011) (entering permanent injunction requiring state agency to provide medically necessary "maintenance" therapies to children with disabilities pursuant to Medicaid's entitlement and EPSDT mandates, and rejecting as "absurd" the agency's argument that it was required to provide such therapies only when there was a showing that the child had "regressed," rather than to prevent regression in the first place); *Ekloff v. Rodgers*, 443 F. Supp. 2d 1173, 1175-82 (D. Ariz. 2006) (entering permanent injunction requiring state agency to provide incontinence briefs to disabled children who could not control their bowel movements, and reasoning that EPSDT provisions mandated "the provision of incontinent briefs for preventive purposes rather than merely after there are skin breakdowns with open sores").

2. When people with disabilities bring private suits to enforce Medicaid requirements, they effectively enforce the antidiscrimination provisions of the RA and the ADA. That is because denial of access or delayed access to Medicaid services forces people with disabilities to depend on restrictive institutional environments to receive the care they need. Medicaid, in other words, is an important instrument by which Congress's integration mandate is implemented.

People with disabilities alleging violations of Medicaid often claim violations of Section 202 of the ADA and Section 504 of the RA as well, illustrating the interplay between the statutory regimes. For example, in *Waskul*, the plaintiffs alleged that underfunding of community living support services effectively compelled them to choose institutional care, in violation of those provisions of the RA and the ADA. 979 F.3d at 458-64. Relying on *Olmstead*, the Sixth Circuit reasoned that "individuals with disabilities are subjected to discrimination when they are forced to choose between forgoing necessary medical services while remaining in the community or receiving necessary medical services while institutionalized – not just when they are actually institutionalized." *Id.* at 460.

Waskul is one of many cases recognizing the link between Medicaid requirements such as the "entitlement," "reasonable promptness," and "free-choice-of-provider" provisions and the integration mandate. *See*, *e.g.*, *Cramer v. Chiles*, 33 F. Supp. 2d 1342, 1353 (S.D. Fla. 1999) ("Underfunding of the Home and Community-Based Waiver program compels institutionalization, thus negating a meaningful choice."); *Murphy ex rel. Murphy v. Minnesota Dep't of Hum. Servs.*, 260 F. Supp. 3d 1084, 1116 (D. Minn. 2017) ("Like their reasonable promptness claim [under Medicaid law], Plaintiffs' integration mandate claims [under the RA and the ADA] rest in large part on Defendants' failure to ensure that Plaintiffs are fairly offered and provided individualized housing services."); *S.R.*, 309 F. Supp. 3d at 262-66 (holding that youth with mental-health disabilities alleging violations of the ESPDT and "reasonable promptness" provisions of Medicaid had concomitant right to challenge their resultant isolation and segregation under the RA and the ADA).

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Medicaid gives persons with disabilities the tools to live and work in their communities, helping to reverse the systemic institutionalization Congress sought to address in the RA and the ADA. This interdependence between Medicaid and the anti-discrimination statutes supports the conclusion that Congress intended *both* aspects of its scheme for enforcing disability rights to be enforceable through private causes of action.

II. Accepting Petitioners' Premise That Spending Clause Legislation Is Not Privately Enforceable Under § 1983 Would Upend Congress's Scheme for Enforcing Disability Rights

Congress's understanding, based on this Court's holdings, that individuals can bring suits under § 1983 to enforce unambiguously conferred rights made it "unnecessary for Congress to create additional private rights of action every time it established new rights in Spending Clause legislation." U.S. Br. 21. Congress's scheme for enforcing disability-rights legislation illustrates the point. Petitioners nevertheless argue that Congress did *not* intend for a critical means of implementing its overarching command of antidiscrimination to be privately enforceable. That perverse interpretation would significantly undermine Congress's enforcement scheme.

A. Congress Has Legislated Protections for People with Disabilities with This Court's Holdings in Mind

Congress has repeatedly indicated its support for a private right to sue to enforce Medicaid requirements that advance the guarantees of the RA and the ADA. Congress has expressed a strong preference for home- and community-based care over institutional care. It first expressed this preference in 1981, with the adoption of the HCBS waiver program. More recently, Congress's enactment of the ACA in 2010 further promotes non-institutional care through pilot programs and financial incentives.[38] Congress's

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[38] *See* Sarah Barth et al., *State Trends and Innovations in Medicaid Long-Term Services and Supports* 1-4 (Dec. 2012) (describing the opportunities the ACA created for States to "expand availability of HCBS for Medicaid beneficiaries,"

progressive strengthening of Medicaid entitlements that effectuate the antidiscrimination provisions – which are unquestionably privately enforceable – evidences its intent to provide a private cause of action to enforce *each* of those independent guarantees against disability discrimination.

Congress made this clear when it amended Medicaid's definition of "medical assistance" following divergent judicial decisions interpreting that term in § 1983 lawsuits. On one side of the split, the First and Eleventh Circuits interpreted "medical assistance" to encompass the provision of medical services. *See Bryson v. Shumway*, 308 F.3d 79, 88-89 (1st Cir. 2002) (holding that the failure to fill HCBS waiver slots may "indicate that New Hampshire is not being reasonably prompt in its provision of medical assistance"); *Doe*, 136 F.3d at 713-19. On the other side, the Seventh Circuit held that "medical assistance" refers to financial assistance, not the provision of medical services, such that Illinois did not violate the Medicaid statute by failing to provide intermediate care facilities for individuals with mental disabilities. *See Bruggeman v. Blagojevich*, 324 F.3d 906, 910 (7th Cir. 2003). The Sixth and Tenth

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including through grant money that assists States with improving individuals' access to eligibility information and "enhanced federal matching dollars" for infrastructure projects that help transition individuals from institutional settings like nursing homes to community care).

The Department of Health and Human Services ("HHS") recently announced its intention to incorporate the integration mandate into Section 1557 of the ACA. *See* Notice of Proposed Rulemaking, Nondiscrimination in Health Programs and Activities, 87 Fed. Reg. 47,824, 47,872 (Aug. 4, 2022) ("The Department's existing Section 504 regulation includes an integration provision at 45 CFR 84.4(b)(2), which would be incorporated into Section 1557 at proposed § 92.101(b)(1).").

Circuits followed suit, rejecting beneficiaries' claims that they were entitled to more than just financial assistance. *See Westside Mothers v. Olszewski*, 454 F.3d 532, 540 (6th Cir. 2006); *Mandy R. ex rel. Mr. & Mrs. R. v. Owens*, 464 F.3d 1139, 1143 (10th Cir. 2006). That view of medical assistance as a mere payment scheme would have dramatically curtailed the right of people with disabilities to receive care in the most integrated setting. That is because, if a State were merely required to pay for home- and community-based services without ensuring any such services are actually provided, the entitlement would become illusory.[39]

In the ACA, Congress rejected the decisions narrowly interpreting "medical assistance." Congress made clear that "[t]he term 'medical assistance' means payment of part or all of the cost of the following care and services *or the care and services themselves, or both*." 42 U.S.C. § 1396d(a) (emphasis added); *see also Norwood*, 838 F.3d at 843 (Congress "clarif[ied] that where the Medicaid Act refers to the provision of services, a participating State is required to provide (or ensure the provision of) services, not merely to pay for them"). Congress's confirmation of a Medicaid entitlement to services, and not just a payment for services – to address a judicial narrowing of that entitlement in suits under § 1983 – renders petitioners' argument that Congress did not intend to provide for private suits to enforce the entitlement especially implausible.

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[39] *See* Nicole Huberfeld, *Bizarre Love Triangle: The Spending Clause, Section 1983, and Medicaid Entitlements*, 42 U.C. Davis L. Rev. 413, 457 (2008).

B. There Is No Substitute for Private Enforcement of Medicaid

In the absence of a private right of action under § 1983, people with disabilities will have to seek redress through Medicaid's limited administrative scheme or rely on federal enforcement. Neither option provides an adequate means for Medicaid beneficiaries to vindicate their rights.

Medicaid's administrative scheme is limited to a narrow subset of issues, such as simple claims denials, *see* 42 U.S.C. § 1396a(a)(3), and notifications for denial of eligibility, *see* 42 C.F.R. §§ 431.200-431.245.[40] Several provisions of Medicaid that people with disabilities rely on to receive care in the most integrated setting do not provide any means for administrative redress; for this reason, courts have held that Medicaid lacks a comprehensive administrative scheme. *See*, *e.g.*, *Planned Parenthood S. Atl. v. Baker*, 941 F.3d 687, 699 (4th Cir. 2019) (Wilkinson, J.) ("[T]he Medicaid Act's enforcement scheme is not sufficiently 'comprehensive' because, inter alia, it does not provide a private remedy—either judicial or administrative—for patients seeking to vindicate their rights under the free-choice-of-provider provision."), *cert. denied*, 141 S. Ct. 550 (2020); *Ball*, 492 F.3d at 1117 (holding that HCBS waiver provision does not contain a remedy other than a federal funds cutoff).

Given the lack of a detailed administrative scheme, the "typical" remedy for state noncompliance with Spending Clause legislation is to cut off federal funds to the State. *Pennhurst*, 451 U.S. at 28. But withholding funds is a "blunt and seldom-used club" that

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[40] *See id.* at 417 n.14.

the federal government has been reluctant to wield.[41] In Medicaid's nearly six decades, the Centers for Medicare & Medicaid Services ("CMS") and its predecessors have rarely, if ever, sought to cut off federal funds to a State.[42] A funding cutoff is particularly unpalatable in the context of a safety-net program such as Medicaid, which is dependent on a steady supply of federal dollars to fund life-saving care. As the Fourth Circuit has explained, "to view a wholesale cutoff of funding to the states as vindicating the interests of individual Medicaid beneficiaries . . . would be illogical." *Baker*, 941 F.3d at 698; *see also Pennhurst*, 451 U.S. at 52 (White, J., dissenting in part) ("a funds cutoff is a drastic remedy with injurious consequences"). The federal government has itself acknowledged that cutting off federal funds would cripple the Medicaid program and the people who rely on it. *See* Br. of Former HHS Officials as *Amici Curiae* in Support of Respondents at 23-24, *Douglas v. Independent Living Ctr. of S. California, Inc.*, 565 U.S. 606 (2012) (Nos. 09-958 et al. (Aug. 5, 2011)) ("Former HHS Officials *Douglas* Br."), 2011 WL 3706105 ("If [CMS] were to withhold [federal financial participation] pursuant to a compliance action, recipients may well be deprived of medical assistance because the State may no longer be able to provide certain services.") (quoting Br. for the United States as *Amicus Curiae* at 13 n.11, *Exeter Mem'l Hosp. Ass'n v. Belshe*, 943 F. Supp. 1239 (E.D. Cal. 1996) (No. CIV-S-96-693, Dkt. No. 26 (Sept. 6, 1996))).

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[41] Sasha Samberg-Champion, *How to Read* Gonzaga*: Laying the Seeds of a Coherent Section 1983 Jurisprudence*, 103 Colum. L. Rev. 1838, 1839 (2003).

[42] *See* Jane Perkins, *Medicaid: Past Successes and Future Challenges*, 12 Health Matrix 7, 32 (2002).

In part because of the drastic nature of the cutoff remedy, CMS has been hesitant to enforce state compliance with Medicaid requirements.[43] Further, "the unique state budgetary problems involved with Medicaid make HHS enforcement of the Medicaid Act essentially a nullity."[44] When CMS does act, it tends to be forgiving, even in the face of significant noncompliance.[45] CMS instead prefers to focus on encouraging state compliance rather than strict enforcement of the program's requirements, adopting the posture of "a coach giving support in the form of cash and expertise" rather than "a referee calling fouls."[46]

Even if CMS more vigorously enforced Medicaid's requirements, the federal government would still be ill-equipped to pursue such enforcement effectively. *See* Former HHS Officials *Douglas* Br. 3 (calling exclusive federal enforcement of Medicaid "logistically, practically, legally, and politically unfeasible"). Federal agencies lack the resources to ensure strict state compliance with Medicaid. *See id.* at 21-22 (noting that CMS's enforcement budget constitutes less than four-hundredths of 1% of total Medicaid program costs). This is partially due to the government's historical reliance on private rights of action under § 1983.[47] Because Medicaid beneficiaries can

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[43] *See* Huberfeld, 42 U.C. Davis L. Rev. at 461.

[44] Brian J. Dunne, *Enforcement of the Medicaid Act under 42 USC § 1983 after* Gonzaga University v Doe: *The "Dispassionate Lens" Examined*, 74 U. Chi. L. Rev. 991, 994-95 (2007).

[45] *See* Samberg-Champion, 103 Colum. L. Rev. at 1858.

[46] Dunne, 74 U. Chi. L. Rev. at 994.

[47] *See* Abigail R. Moncrieff, *The Supreme Court's Assault on Litigation: Why (and How) It Might Be Good for Health Law*, 90 B.U. L. Rev. 2323, 2340-41 (2010).

bring suits challenging state compliance with the Medicaid Act's requirements, CMS and HHS never had to develop the infrastructure necessary to serve a strong enforcement role.[48] *See id.* at 19 (stating that HHS "rel[ies] on the availability of private enforcement to supplement—if not supplant—its own responsibilities"). Due to this reliance on § 1983 lawsuits, "CMS tends to rubber-stamp state plans and to pass the buck to state agencies when providers and beneficiaries complain."[49]

Stripping private rights of action from beneficiaries would virtually end the already scarce enforcement of Medicaid.[50] Medicaid's administrative scheme covers only a small fraction of claims that people with disabilities bring under § 1983, and the federal government has shown that it is not willing or able to seek strict state compliance with the Medicaid Act's requirements. Enforcement of Medicaid law is therefore unlikely without § 1983 lawsuits, and "it was this systematic nonenforcement that led to the explosion of litigation by frustrated beneficiaries in the first place."[51] Non-enforcement of Medicaid would be an especially devastating outcome for people with disabilities, who depend on that program for services that are virtually inaccessible on the private market.

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[48] *See id.*

[49] *Id.*

[50] *See* Perkins, 12 Health Matrix at 32 ("For the entitlement to have meaning, the individually insured person needs a legally enforceable right to the benefits provided by federal law.").

[51] Samberg-Champion, 103 Colum. L. Rev. at 1858-59.

CONCLUSION

The judgment of the court of appeals should be affirmed.

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