

Case No. 21-2495

**UNITED STATES COURT OF APPEALS
FOR THE SEVENTH CIRCUIT**

T.S., by and through his parents and guardians, T.M.S. and M.S., individually and derivatively on behalf of the Heart of CarDon, LLC Employee Benefit Plan,
Plaintiff-Appellee,

v.

HEART OF CARDON, LLC and HEART OF CARDON, LLC EMPLOYEE
BENEFIT PLAN,
Defendants-Appellants.

On Appeal from the United States District Court for the Southern District of
Indiana, Case No. 20-CV-01699 (Pratt, C.J.)

**BRIEF OF NONPROFIT CIVIL RIGHTS, ADVOCACY, AND PUBLIC
INTEREST ORGANIZATIONS AS *AMICI CURIAE* IN SUPPORT OF
PLAINTIFF-APPELLEE T.S.**

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IDENTITY AND INTEREST OF *AMICI CURIAE*

The *amici curiae* submitting this brief are Equip for Equality (“EFE”), The Center for Health Law and Policy Innovation of Harvard Law School (“CHLPI”), The National Health Law Program (“NHeLP”), and The National Autism Law Center (“NALC”).

EFE is a non-profit organization that has been designated by the Governor of Illinois to implement the federally mandated Protection and Advocacy System. EFE’s mission is to advance the human and civil rights of children and adults with disabilities in Illinois. In pursuit of its goals of tackling common problems affecting people with disabilities, EFE undertakes a sophisticated combination of strategies that include public policy and legislative reform, class action litigation, and watchdog reports on troubled institutions.

NHeLP is a public interest law firm working to advance access to quality health care and protect the legal rights of lower-income people and people with disabilities. NHeLP engages in education, policy analysis, administrative advocacy, and litigation at the state and federal levels. Throughout its more than 50-year history, NHeLP has fought to address discrimination in health care based on disability, gender, race, national origin, age, and other protected classes.

CHLPI advocates for legal, regulatory, and policy reform to improve the health of underserved populations, with a focus on the needs of low-income people

living with chronic illnesses and disabilities. CHLPI's health law and policy work focuses on systems-level change to assure and expand access to health care, reduce health disparities, and contribute to a more equitable individual and public health environment.

NALC is a nonprofit advocacy organization dedicated to enforcing and expanding the legal rights of individuals on the autism spectrum and serving as a resource for such individuals and their families, as well as the service providers and attorneys who support them.

While each *amicus* has particular interests, they share a mission of promoting broad access to affordable, dependable, and quality health care, regardless of race, age, sex, or disability. Additionally, *amici* each have an extensive history of combating discrimination against historically marginalized communities. As such, *amici* are uniquely situated to provide insight on how the Patient Protection and Affordable Care Act (the "ACA") changed the landscape of healthcare discrimination, including the introduction of Section 1557 as an enforcement mechanism of the ACA's protections. *Amici* also can provide perspective on the harms that would and could arise should the judgment of the district court be reversed. *Amici*'s arguments thus further demonstrate, beyond the parties' briefing, why the ACA and § 504 of the Rehabilitation Act grant T.S. and other similarly situated persons a right to sue to combat pervasive and debilitating

discriminatory practices in the exclusion of benefits by organizations receiving federal funding.

No party's counsel authored this brief in whole or in part, and no party, party's counsel, or other person contributed money intended to fund the preparation or submission of this brief.

All parties have consented to the filing of this brief.

I. INTRODUCTION

Prior to the enactment of the Patient Protection and Affordable Care Act (the “ACA”), health insurance plans like Appellants could discriminate against individuals with disabilities with few limitations. And they routinely did, employing a variety of practices to deny or limit health care coverage. As a result, people with disabilities commonly faced exclusions from enrollment or terminations of health coverage, annual or lifetime benefits limits, and higher health care costs on the basis of disability. Even if a person with a disability could find health coverage, it would often exclude coverage for pre-existing conditions or otherwise deny essential benefits based on health status or disability. Individuals harmed by these discriminatory practices challenged them in court, with only limited success, leaving many discriminatory practices embedded in health insurance. This landscape was dramatically changed by the ACA.

The ACA’s most fundamental goal was to ensure access to quality, affordable health care for all Americans, and especially to individuals who previously struggled to access care under the status quo. T.S. personifies the purpose that Congress sought to achieve through health care reform. The ACA thus specifically outlaws discriminatory insurance practices—this is not a secondary effect of the ACA; it lies at the core of the statute. Section 1557 of the ACA comprises a principal component of the law’s purpose. It creates a new

prohibition on discrimination in most health programs, including many private insurance plans. Section 1557 prohibits discrimination by health care entities receiving federal financial assistance based on race, color, national origin, sex, age, and disability, and it creates a private enforcement mechanism for individuals to enforce their right to be free from discrimination in federal court. Section 1557 mutually reinforces the ACA's other market reforms aimed at ending discrimination in health care access and benefits design.

Appellants argue that the nondiscrimination protections of the ACA and Section 1557 do not apply to T.S. and other similarly situated persons. They assert that those protections only reach their patients—characterized as the sole intended beneficiaries of the federal funds Appellants receive—and not those enrolled in Appellants' employee benefits plan. Appellants' position, however, runs headlong into the primary purpose of the ACA: to eliminate the type of discriminatory practices countenanced before its enactment, to expand the availability and scope of health insurance, and to assist individuals in securing and enrolling in health insurance coverage. Moreover, adopting that position would result in exactly the type of conditions-based exclusion and accompanying negative effects that Congress set out to eliminate with the ACA. In concluding that T.S. fell within the zone of interests of Section 1557, the district court correctly recognized this broad

remedial purpose of the ACA. Accordingly, this Court should affirm the judgment of the district court that T.S. has statutory standing to file suit under Section 1557.

II. ARGUMENT

A. In Enacting the ACA and Section 1557, Congress Intended to Curb or Eliminate Discrimination Against Persons with Disabilities in Health Care Access and Coverage

The ACA reset the landscape of healthcare in the United States. Prior to the enactment of the ACA, individuals with disabilities, including autism, faced pervasive, legally countenanced discrimination in health insurance access and coverage. Congress specifically enacted the ACA to halt that discrimination and thus expand access to adequate and affordable health care and health coverage. To that end, the ACA contains sweeping protections outlawing many of the practices insurers used to discriminate against historically marginalized classes of individuals, including those with disabling conditions. Reading the statutory language in light of pre-ACA history, the district court therefore correctly concluded that Congress intended the ACA's broad nondiscrimination protections to include within their reach enrollees with disabilities whose covered health plans exclude them from all coverage for their disability.

1. The ACA Addressed Entrenched Discrimination in Insurance Practices Against People with Disabilities

Congress passed the ACA against the backdrop of decades of discrimination in the health insurance industry. Before the ACA, the business model of health

insurance incentivized insurers and health plans to avoid covering individuals who would have high health care needs or who would otherwise be costly to the plans. Insurers could employ an array of mechanisms to deny enrollment, limit benefits, and impose high costs on the insured. Plans could exclude treatment for specific conditions from coverage, design their benefits to discourage people with high needs from enrolling, or deny medically necessary care once a person had enrolled. Insurers could also increase premium rates based on various factors, including whether an individual had pre-existing conditions. As a result of these practices, individuals with disabilities faced frequent exclusions from enrollment or terminations of health insurance coverage, annual and lifetime benefits limits, and a lack of quality, affordable coverage. *See generally*, Valarie K. Blake, *An Opening for Civil Rights in Health Insurance After the Affordable Care Act*, 36 B.C. J.L. & Soc. Just. 235 (2016) (describing pre-ACA health insurance discrimination and how the ACA addressed those issues); Sara Rosenbaum et al., *Crossing the Rubicon: The Impact of the Affordable Care Act on the Content of Insurance Coverage for Persons with Disabilities*, 25 Notre Dame J.L. Ethics & Pub. Pol’y 527 (2014) (describing ACA nondiscrimination provisions and focusing on function of “essential health benefits” in state-regulated individual and small group health insurance markets).

People with autism, in particular, endured profound and pervasive discrimination in access to health care treatment. Insurers often designated autism as a diagnostic exclusion, thus explicitly excluding services rendered for treatment of autism from insurance coverage. *See* Douglas L. Leslie & Andrés Martin, *Health Care Expenditures Associated with Autism Spectrum Disorders*, 161 *Archives Pediatric & Adolescent Med.* 350, 354 (2007). For example, a 2002 study of pre-ACA diagnostic exclusions in private behavioral health care plans examined 128 commercial, employment-based behavioral health plans covering a total of 615,691 individuals. *See* Pamela B. Peele et al., *Exclusions and Limitations in Children’s Behavioral Health Care Coverage*, 53 *Psychiatric Servs.* 591, 591 (2002). The researchers conducting the study found that autism was a diagnostic exclusion for over 80% of these individuals. *Id.* at 592.

When insurance policies did cover autism, the content of those policies frequently provided inadequate coverage. For example, many health plans excluded from coverage a common treatment for autism known as Applied Behavior Analysis (“ABA”). *See* Lorri S. Unumb, *Legislating Autism Insurance Coverage: The Conservative Autism Mandate*, 2 *Belmont L. Rev.* 59, 74 (2015) (“As recently as the turn of the millennium it was widely accepted that health insurance did not cover applied behavior analysis” (internal quotation marks and citation omitted)); *Doe v. United Behavioral Health*, 523 F. Supp. 3d 1119, 1128

(N.D. Ca. 2021) (discussing ABA as “a core treatment” and “the primary treatment modality” for autism). Even in the small but growing number of states¹ where grassroots advocacy efforts had secured some state-mandated coverage for autism, significant limitations on coverage such as dollar and age caps on benefits remained. See Lorri Shealy Unumb & Daniel R. Unumb, *Autism and the Law: Cases, Statutes, and Materials* 59–105 (2011) (compiling state autism insurance mandates, 2001–2009). Moreover, these state legislative mandates could not reach self-funded plans, which continue to comprise the most prevalent source of health care coverage in the United States², because federal, not state, law governs those plans. See Marissa Mazza, Comment, *Are You Covered? The Need for Improvement in Insurance Coverage for Autism Spectrum Disorder*, 44 J. Marshall L. Rev. 291, 292–93 (2010).

This discrimination resulted in poor health outcomes, personal financial strains, and tremendous costs to society at large. For example, children with

¹ At the time the ACA passed, fifteen states had some mandated insurance coverage of ABA and other autism treatments. *State Regulated Health Benefit Plans*, Autism Speaks (last updated March 2020), <https://www.autismspeaks.org/state-regulated-health-benefit-plans>.

² See Katherine Keisler-Starkey & Lisa N. Bunch, U.S. Census Bureau, *Health Insurance Coverage in the United States: 2020* at 3 (2021), <https://www.census.gov/content/dam/Census/library/publications/2021/demo/p60-274.pdf> (reporting that employment-based insurance is most common type of health care coverage, covering 54.4% of population); see also Jenny Yang, *U.S. Workers Covered by Self-Funded Health Insurance Plans 1999–2021*, Statista (2021), <https://www.statista.com/statistics/985324/self-funded-health-insurance-covered-workers/> (reporting that for employment-based health coverage, the percentage of employees with self-funded plans has increased ranged from 44% in 1999 to 64% in 2021).

autism had much higher rates of chronic medical conditions, including: “eczema, allergies, asthma, ear and respiratory infections, gastrointestinal problems, severe headaches, migraines, and seizures.” *Treating Autism & Autism Treatment Tr., Medical Comorbidities in Autism Spectrum Disorders: A primer for Health Care Professionals and Policy Makers* 3 (2013), <http://nationalautismassociation.org/pdf/MedicalComorbiditiesinASD2013.pdf>. Their families took on the burden of greater out-of-pocket costs, diminished work hours, more lost income, and more negative health plan experiences. *See* Jessica Dickler, *The Financial Toll of Autism*, CNN Money (Apr. 2, 2012), <https://money.cnn.com/2012/04/02/pf/autism/index.htm>. Society at large also suffered, bearing the long-term costs associated with autism, including “special education, vocational training, group housing or institutionalization, community supports, escalated medical costs and more.” *See* Lorri S. Unumb, *Legislating Autism Coverage*, *supra* at 81.

Challenges to the discriminatory practices used by insurers under existing antidiscrimination laws in the pre-ACA era generally proved unsuccessful. For example, before the ACA insurers commonly capped the amount of services available for a particular condition (e.g., limits on numbers of visits) or lifetime benefits (e.g., a \$25,000 annual or lifetime limit on coverage for benefits related to a specific condition). Individuals harmed by these limits challenged them under Section 504 of the Rehabilitation Act on grounds that they discriminated against

individuals with disabilities. Courts, however, repeatedly rejected these challenges, focusing on access to an insurance policy rather than the coverage content within the policy and holding that regulation of insurance fell within the purview of state insurance commissions. *See e.g., Modderno v. King*, 82 F.3d 1059, 1062 (D.C. Cir. 1996) (permitting \$75,000 lifetime cap on mental health benefits even absent comparable limit on physical health benefits).

Individuals with disabilities similarly could not resort to the Americans with Disabilities Act (“ADA”) to combat discrimination, largely because of the ADA’s “safe harbor” provision. *See* 42 U.S.C. § 12201(c). This provision states that the ADA “shall not be construed to prohibit or restrict” insurers and others from establishing or administering benefit plans “based on underwriting risks, classifying risks, or administering such risks that are based on or not inconsistent with State law.” *Id.* Although the statute instructs that the safe harbor provision “shall not be used as subterfuge to evade the purposes of [the ADA],” *id.*, many cases relying on the ADA to challenge discriminatory health insurance decisions did not even reach the subterfuge question because they rejected claims based on the access and content distinction at the outset, *see, e.g., Doe v. Mut. of Omaha Ins. Co.*, 179 F.3d 557, 564–65 (7th Cir. 1999) (concluding that policies with lifetime limits did not discriminate based on disability under federal law and that regulating insurance was purview of state insurance commissioner); *McNeil v. Time Ins. Co.*,

205 F.3d 179, 188–89 (5th Cir. 2000) (concluding that \$10,000 limit during first two years of coverage for AIDS-related care was not disability discrimination in violation of the ADA); *see also* Samuel R. Bagenstos, *The Future of Disability Law*, 114 Yale L.J. 1, 40–41 (2004) (noting that “cases have consistently rejected challenges to disability-related caps or exclusions . . . on access/content grounds” instead of the safe harbor provision).

Courts rejected further challenges to limits and exclusions in health insurance by purporting to follow the Supreme Court’s decision in *Alexander v. Choate*, 469 U.S. 287 (1985). After *Choate*, plaintiffs challenging disability discrimination in health insurance using Section 504 or the ADA would generally prevail if they could show that they were denied access to the benefit—such as being denied enrollment. Even though *Choate* did not preclude claims based on content of a benefit, challenges to the content or adequacy of benefits often failed. *See, e.g., Rome v. MTA/N.Y. City Transit*, No. 97-CV-2945, 1997 WL 1048908, at *4 (E.D.N.Y. Nov. 18, 1997) (applying *Choate*’s interpretation of Section 504 to conclude that plaintiffs lacked standing to bring ADA claim based on coverage of speech therapy for other conditions but not autism); *see also* Bagenstos, *supra*, at 41 nn.168–70 (listing cases that, citing *Choate*, refused to analyze whether coverage excluding benefits based on diagnosis or treatment was discriminatory).

In sum, before the ACA, insurers could discriminate against people with disabilities in the administration and design of health care benefit plans without many federal legal consequences. *See Blake, An Opening for Civil Rights, supra*, at 240–42.

2. Congress Intended the ACA and Section 1557 to Outlaw Conditions-Based Exclusions and Other Previously Lawful Insurance Practices Used to Discriminate Against Persons with Disabilities

Congress crafted the ACA to expand access to health coverage and prohibit many of the longstanding discriminatory practices health insurers used to minimize costs and risks. As the Supreme Court has articulated, Congress enacted the ACA “to increase the number of Americans covered by health insurance and decrease the cost of health care.” *Nat’l Fed’n of Indep. Bus. v. Sebelius*, 567 U.S. 519, 538–39 (2012). Consistent with this broad mandate, the ACA ushered in significant protections for individuals in several different areas, including enrollment, cost-sharing, premium rates, and benefit design and provision. Indeed, many of the ACA’s provisions explicitly targeted a range of discriminatory practices in their titles. *See, e.g.*, 42 U.S.C. §§ 300gg-3 (“Prohibition of Preexisting Condition Exclusions or Other Discrimination Based on Health Status”); 300gg(a) (“Prohibiting Discriminatory Premium Rates”); 300gg-4 (“Prohibiting Discrimination Against Individual Participants and Beneficiaries Based on Health Status”); 18116 (“Nondiscrimination”).

The ACA includes among its protections provisions to combat discrimination in plan content, benefit design, and scope of coverage. The Act mandates coverage of certain preventive services and requires that covered insurance plans provide comprehensive health insurance coverage that includes ten general essential health benefits (“EHBs”). *Id.* § 300gg-6. The Secretary of Health and Human Services defines these ten EHBs. *Id.* § 18022(a)–(b). According to the statute, “the Secretary shall . . . not make coverage decisions, determine reimbursement rates, establish incentive programs, or design benefits in ways that discriminate against individuals because of their age, disability or expected length of life.” *Id.* § 18022(b)(4)(B). The EHB design must also account for the health needs of a diverse population, including those with disabilities. *Id.* § 18022(b)(4)(C)–(D). Insurers are not in compliance with EHB requirements if their coverage discriminates. *Id.* § 18022(b)(4). The EHB framework thus reinforces the design of the ACA to ensure that people have access not only to an affordable health plan but also to a broad array of necessary services within those plans.

In determining the categories of EHBs that would serve as the backbone for assuring adequate health benefit coverage, Congress recognized the needs of and difficulties confronting individuals with disabilities like autism. Senator Robert Menendez, for example, testified at length in support of an amendment adding the

term “including behavioral health treatment” to the EHB of “mental health and substance use disorder services.” Senator Menendez explained:

Behavioral health treatments help to reinforce wanted behaviors and reduce unwanted behaviors, and the treatments are critical for individuals affected by autism, Down Syndrome, and a variety of other disorders.

They can help a child to communicate and care for themselves; they can help that child from – stop him from hitting himself and those around him; they can enable a child to attend regular education classes, rather than special education classes; they can enable a child to live at home, rather than an institution.

All of these alternatives save money in the long run, and this is an effort to decrease long-term health care costs.

Executive Committee Meeting to Consider Health Care Reform: Hearing on Proposed Amendments to S. 1796 Before the S. Subcomm. on Fin., 111th Cong. 354 (2009) (statement of Sen. Robert Menendez). While seeking to provide comprehensive health coverage through the ACA, Congress thus specifically revised the EHB language to encompass behavioral health treatments to treat conditions such as autism.

To complement and reinforce the ACA’s broader initiative to eliminate discrimination and increase meaningful health care coverage, Congress included an enforcement mechanism in Section 1557. Section 1557 imported civil rights protections to the health insurance context to create a health-care-specific civil right and prohibit discrimination in health care coverage. *See* 42 U.S.C.

§ 18116(a); *see also Schmitt v. Kaiser Found. Health Plan Wash.*, 965 F.3d 945,

949, 955 (9th Cir. 2020) (noting that Section 1557 imposes “an affirmative obligation not to discriminate in the provision of health care” and recognizing claim for discriminatory benefit design).

The language of Section 1557 makes plain its “unmatched” reach as the ACA’s key tool to combat discrimination across the health insurance landscape. *See Griffin v. Gen. Elec. Co.*, No. 15–CV–4439, 2017 WL 3449607, at *5 (N.D. Ga. 2017). The statute specifically prohibits discrimination based on race, color, national origin, sex, age, and disability and creates a private right of action for individuals to complain of such discrimination. § 18116(a). Reflecting its broad scope, Section 1557’s private enforcement mechanism reaches “any health program or activity, any part of which is receiving Federal financial assistance.” *Id.*; *see also* 45 C.F.R. § 92.3(a)(1), (b) (“[H]ealth program or activity” encompasses “all of the operations of entities principally engaged in the business of providing healthcare that receive Federal financial assistance . . .”).³

³ Appellants do not dispute CarDon’s status as a qualifying health program or activity, nor do they dispute CarDon’s receipt of federal financial assistance. Rather, they assert that CarDon’s receipt of federal financial assistance in one of its activities ought not to extend Section 1557’s prohibitions to another of its functions, i.e., its provision of employee health insurance. That argument recalls the defendant in *Grove City Coll. v. Bell*, 465 U.S. 555 (1984) (limiting reach of Title IX’s provisions to specific parts of programs and activities receiving federal financial assistance). As the district court noted below, Congress explicitly overruled *Grove City* in the Civil Rights Restoration Act of 1987 (“CRRA”), Pub. L. No. 100-259, 102 Stat. 28 (1988). Congress then signaled its intent to enact an expansive reach of federal financial assistance when it adopted Section 1557’s “any part of which” language from the CRRA, which amended the same four preexisting statutes.

Moreover, although Section 1557 references the “ground[s]” and “enforcement mechanisms” of other major civil rights statutes, *see* § 18116(a), it established a new standalone enforcement mechanism that prohibits discriminatory practices once permitted prior the ACA. Given that the ACA significantly changed the obligations of covered entities against the backdrop of these longstanding discriminatory practices under existing law, pre-ACA precedent addressing the constituent statutes does not provide the dispositive answer regarding the scope of Section 1557’s protections and remedies. That the ACA refers to Title VI, Title IX, the Age Discrimination Act, and Section 504 of the Rehabilitation Act to identify the distinct grounds on which discrimination is prohibited—i.e., race, sex, age, and disability—does not mean that Congress intended to import all of the caselaw under those statutes. “Reading Section 1557 otherwise would lead to an illogical result, as different enforcement mechanisms and standards would apply to a Section 1557 plaintiff depending on whether the plaintiff’s claim is based on her race, sex, age, or disability.” *Rumble v. Fairview Health Servs.*, No. 14-CV-2037, 2015 U.S. Dist. LEXIS 31591, at *30–31 (D. Minn. Mar 16, 2015). Additionally, “if different standards were applied based on the protected class status of the Section 1557 plaintiff, then courts would have no guidance about what standard to apply for a Section 1557 plaintiff bringing an intersectional discrimination claim.” *Id.* at *31–32.

Similarly, the statute’s incorporation of other laws’ enforcement mechanisms does not necessarily incorporate their substance. *See Consol. Rail Corp. v. Darrone*, 465 U.S. 624, 632–34 (1984) (holding that Section 504’s incorporation of “remedies, procedures, and rights” set forth in Title VI of the Civil Rights Act of 1964 did not mean that Section 504 incorporated Title VI’s substantive limitations on actionable discrimination). Instead, Section 1557 should be read in light of Congress’s intent to shift the landscape of health insurance and broadly prohibit discrimination in health care.

Statements made by members of Congress around the time of the ACA’s passage into law demonstrate this intent. As Senator Patrick Leahy stated at the time the legislation was signed into law, the ACA’s “explicit[] prohibit[ion]” of “discrimination on the basis of race, color, national origin, sex, disability or age in any health program or activity receiving Federal funds” was “necessary to remedy the shameful history of invidious discrimination and the stark disparities in outcomes in our health care system” and “ensure that all Americans are able to reap the benefits of health insurance reform equally without discrimination.”

156 Cong. Rec. S1842 (2010) (statement of Sen. Patrick Leahy); *see also* Valarie K. Blake, *Civil Rights as Treatment for Health Insurance Discrimination*, 2016 Wis. L. Rev. Forward 37, 42 (2016) (“Section 1557 is driven by the Civil Rights Act of 1964, the mission of which was that ‘[s]imple justice requires that

public funds, to which all taxpayers . . . contribute, not be spent in any fashion which encourages, entrenches, subsidizes or results in . . . [protected class] discrimination.” (alteration in original) (quoting *Overview of Title VI of the Civil Rights Act of 1964*, U.S. Dep’t of Justice, <https://www.justice.gov/crt/fcs/TitleVI>)). As the President signed the ACA into law, Senator Tom Harkin similarly reflected on the intended sweeping “victory” over discrimination:

As a Nobel Prize-winning economist recently put it, the new health reform law is a “victory for America’s soul.” At long last, we are realizing Senator Ted Kennedy’s great dream of extending access to quality, affordable health insurance to every American. We are ending the last shameful bastion of legal discrimination and exclusion in our country.

156 Cong. Rec. S1983 (2009) (statement of Sen. Tom Harkin).

Viewed in whole, the broad remedial purpose and structure of the ACA and Section 1557 to eliminate discrimination in health care access and coverage undermines Appellants’ position. *See* H. Rep. No. 102–40(I), at 88, U.S. Code Cong. & Admin. News at 626 (observing that “remedial statutes, such as civil rights law[s], are to be broadly construed”). Nowhere in the statutory language or legislative history of the ACA did Congress indicate an intent to exclude the employees of covered entities receiving federal funds from the ambit of the anti-discrimination protections of Section 1557. Furthermore, an exclusion of this type would contradict the ACA provisions prohibiting health care providers from discriminating in benefits coverage, which applies to employees, not patients. The

significance of that contradiction looms particularly large when applied to the health care industry, the nation's largest employer. *See* Earlene K.P. Dowell, *Census Bureau's 2018 County Business Patterns Provides Data on Over 1,200 Industries*, U.S. Census Bureau (Oct. 14, 2020), <https://www.census.gov/library/stories/2020/10/health-care-still-largest-united-states-employer.html>.

According to the Bureau of Labor Statistics, 16.8 million people work in the health care field in a variety of services and facilities. *See Total Healthcare Employment*, Kaiser Fam. Found. (May 2020), <https://www.kff.org/other/state-indicator/total-health-care-employment> (compiling data from U.S. Bureau of Labor Statistics Occupational Employment and Wage Statistics (“OEWS”) program). If Congress had intended to withhold the ACA's protections against “invidious” and “shameful” discrimination in health care from this population, it would have clearly specified such an extraordinary result; “Congress does not hide elephants in mouseholes.” *Cyan, Inc. v. Beaver Cnty. Emps. Ret. Fund*, 138 S. Ct. 1061, 1071 (2018) (internal quotation marks and citation omitted).

B. Appellants' Restrictive Reading of the Remedial Scope of Section 1557 Would Result in the Very Harms Congress Designed the ACA and Section 1557 to Prevent

Appellants suggest that Congress did not intend to prevent health care entities receiving federal financial assistance from discriminating against enrollees in their benefit plans by completely excluding coverage for disabling conditions.

Yet, as discussed above, Congress intended to outlaw precisely this conduct against this class of historically marginalized persons to prevent numerous harms. In passing the ACA, Congress sought to remedy a long history of discrimination in health care coverage, including by prohibiting condition-based exclusions that had deprived persons with disabilities of access to care. This discrimination, which persists today, perpetuates poor individual health outcomes, increases long term health care costs, and imposes financial burdens on individuals with disabilities and their families. Additionally, discrimination in health care subjects society in general to increased long-term costs and lost productivity due to the failure to provide adequate care to significant segments of the population. By narrowing Section 1557's application as Appellants suggest, the carve out sought here would limit the ability of the ACA to eliminate these harms, undermining the Act's primary purpose.

Secretary of Health and Human Services Kathleen Sebelius specifically assured the autism community that the ACA's passage had rendered this discrimination and its attendant consequences a thing of the past: "Perhaps the biggest step we've taken to support those affected by autism and their families happened over a year ago, with the signing of the Affordable Care Act. . . . Insurers will [] no longer be allowed to deny children coverage for a pre-existing condition such as [autism spectrum disorder] or to set arbitrary lifetime or annual limits on

benefits.” Kathleen Sebelius, *Meeting the Needs of People with Autism*, The White House (Apr. 25, 2011), <https://obamawhitehouse.archives.gov/blog/2011/04/25/meeting-needs-people-autism>.

Allowing Appellants and similarly situated federally funded healthcare providers subject to Section 1557 to discriminate in the health care coverage they provide their employees would result in the very harms the ACA sought to prevent. Individuals with any disability, whether physical or mental, suffer these consequences when plans discriminate against them. The predicament faced by those with autism, like T.S., provides an illustrative example of the severity of these consequences.

1. Allowing Appellants’ to Categorically Exclude Coverage for Autism Would Undermine the Intent of the ACA by Imposing Severe Health, Financial, and Social Costs

Autism is the nation’s fastest growing developmental disorder and is now more common than childhood cancer, juvenile diabetes, and pediatric AIDS combined. The Interagency Autism Coordinating Comm., U.S. Dep’t of Health & Hum. Servs., *2011 Strategic Plan for Autism Spectrum Disorder Research 1* (2011), https://iacc.hhs.gov/publications/strategic-plan/2011/strategic_plan_2011.pdf. In 2020, the CDC reported that 1 in 54 children in the United States is diagnosed with autism. *Autism Statistics and Facts*, Autism Speaks, <https://www.autismspeaks.org/autism-statistics-asd> (last visited Nov. 23,

2021). The effects of autism also do not end with childhood; over the next decade, an estimated 707,000 to 1,116,000 teens with autism (70,700 to 111,600 each year) will enter adulthood. *Id.*

Denying or delaying health care to individuals with autism has devastating long-term effects. As a spectrum disorder, autism may present a wide range of impairments requiring treatment, but it is diagnosed based on clinically significant impairments in social interaction, communication and behavior. *See* Am. Psychiatric Ass'n, *Diagnostic and Statistical Manual of Mental Disorders* 50 (5th ed. 2013) [hereinafter *DSM-5*]. Some individuals are non-verbal while others develop typical capabilities in terms of speech and language but struggle with significant social and behavioral impairments. Some individuals may have challenges in communication, social interaction, sensory sensitivities, and behaviors, including meltdowns, obsessive repetitive behaviors, aggression, elopement or self-harm.⁴

Additionally, autism is often accompanied by various co-morbid conditions. These include gastrointestinal disorders, sleep disturbance, seizures, tics, oral motor deficits, anxiety disorders, depression, and attention deficit hyperactivity

⁴ *See DSM-5, supra*, at 50–55 & n.10 (diagnostic criteria for autism spectrum disorder); *Autism Statistics and Facts, supra*; Elizabeth O’Nions et al., *How Do Parents Manage Irritability, Challenging Behaviour, Non-Compliance and Anxiety in Children with Autism Spectrum Disorders? A Meta-Synthesis*, 48 *J Autism & Developmental Disorders* 1272, 1272 (2018).

disorder. *See Medical Comorbidities in Autism Spectrum Disorders, supra*, at 3–13. Attempts to treat such co-morbid conditions without also treating autism generally prove less effective. *See Kiyoharu Takara et al., How and Why is Autism Spectrum Disorder Misdiagnosed in Adult Patients?—From Diagnostic Problem to Management for Adjustment*, 11 *Mental Health in Fam. Med.* 73, 82 (2015). That is because “autistic traits can often make their psychiatric comorbidity resistant to standard treatments. In other words, psychiatric comorbidity tends to be prolonged or easily relapses when autistic traits are not dealt with.” *Id.*

Left untreated, the debilitating effects of autism may thus compound, becoming substantial and lifelong. A child with autism denied medically necessary treatment is unlikely to progress and faces a lifetime of impaired functioning, unemployment, social isolation, poor health, and restricted living options.⁵ That an individual should face this predicament is especially tragic given

⁵ *See Lynn Kern Koegel et al., The Importance of Early Identification and Intervention for Children with or at Risk for Autism Spectrum Disorders*, 16 *Int’l J. of Speech-Language Pathology* 50, 51–52 (2014) (discussing importance of early intervention for improved long term health outcomes, employment prospects, and communication skills and prospect for functioning without special support; “without early intervention this is unlikely”); Leann Smith DaWalt et al., *Mortality in Individuals with Autism Spectrum Disorder: Predictors Over a 20-Year Period*, 23 *Autism* 1732 (2019) (finding higher premature mortality rates among individuals with autism with poor scores on measures of social ability or daily-living skills). In one recent study of middle-aged adults with autism, who did not have access to intensive treatment in their childhood years, 12 % had full-time unsupported employment, 75% had no experience with dating, 9% lived independently, 47% lived with their parents, and 36% lived in a group home or institutional setting. Megan Farley et al., *Mid-Life Social Outcomes for a Population-Based Sample of Adults with ASD*, 11 *Autism Res.* 142 (2017).

that effective behavioral treatments for autism exist and can substantially improve the prognosis and lifelong functioning of those with early access to these medically necessary treatments. Many who receive treatment can be independent and successful in all aspects of their lives: school, employment, recreation, sports, independent living and civic involvement. Scott M. Myers & Chris Plauché Johnson, *Management of Children with Autism Spectrum Disorders*, 120 *Pediatrics* 1162, 1164 (2007). Individuals who receive early intensive behavioral treatment can make substantial, sustained gains in IQ, language, academic performance, and adaptive behavior as well as some measures of social behavior, and those individuals have had significantly better outcomes than those in control groups. *Id.* Adopting Appellants' position, however, would deny individuals with autism access to this needed and potentially life-altering care.

Congress also intended the ACA to prevent the significant financial strain that comes with denials of healthcare coverage. As set forth in the report of the House Budget Committee:

“Guaranteeing access to health care and protecting against medical debt largely depends on implementing comprehensive insurance reforms. . . .

Discrimination based on health, gender and other factors has severe economic consequences for those . . . unable to find affordable health coverage and for those who have coverage, but are under-insured. . . . [T]hese practices have resulted in about 57 million Americans having debt because of medical bills, and over 42 million of

that number has some sort of medical coverage. Medical debt is now the leading cause of personal bankruptcy.

H.R. Rep. No. 111-443, pt. 2, at 990–91 (2010).

Families caring for an individual with autism report more financial hardships and work reductions than families caring for individuals with other special needs.⁶

See Data Res. Ctr. for Child & Adolescent Health, *National Profile of Children with Special Health Care Needs and Autism Spectrum Disorders: Key Findings*

from the 2009/10 NS-CSHCN & 2007 NSCH 2 (2013), [https://www.childhealth](https://www.childhealthdata.org/docs/drc/asd-data-brief_4.2.12.pdf)

[data.org/docs/drc/asd-data-brief_4.2.12.pdf](https://www.childhealthdata.org/docs/drc/asd-data-brief_4.2.12.pdf). On average, medical expenditures

incurred for individuals with autism are four to six times greater than for

individuals without autism. Tom T. Shimabukuro et al., *Medical Expenditures for*

Children with an Autism Spectrum Disorder in a Privately Insured Population,

38 *J. Autism & Developmental Disorders* 546, 552 (2008). As a result, their

families must pay more out of pocket and give up more income by spending more

time away from work. See Susan H. Busch & Colleen L. Barry, *Does Private*

⁶ On a pre-ACA 2009/2010 national survey of children with special health care needs, 43% of the families with autism reported that the condition caused financial problems for the family, while only 19.6% of the surveyed families of children with other special health care needs reported that the condition caused financial problems for the family. Likewise, 29.9% of families of children with autism reported spending eleven or more hours per week providing or coordinating the child's health care, while 10.9% of surveyed families of children with special health care needs other than autism spent that amount of time. Furthermore, 57.1% of families of children with autism reported that the autism caused a family member to cut back or stop working, while 21.6% of families of children with special health care needs other than autism reported such reduction or stoppage. Data Res. Ctr., *supra*, at 2.

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124 Pediatrics S399, S399 (2009); Guillermo Montes & Jill S. Halterman, *Association of Childhood Autism Spectrum Disorders and Loss of Family Income*, 121 Pediatrics e821, e821 (2008); Dickler, *supra*.

Furthermore, although highly effective, prescribed programs for behavioral treatment exceed the reach of most families to bear out of pocket, ranging in cost between \$30,000 and \$100,000 per year. See Unumb, *Legislating Autism Coverage, supra*, at 79; Ariana Cernius, Note, “No Imbecile at All”: How California Won the Autism Insurance Reform Battle, and Why its Model Should Be Replicated in Other States, 10 Harv. L. & Pol’y Rev. 565, 573 (2016).

Nevertheless, families may strive to pay out-of-pocket for needed treatment for a family member with autism, leading to significant financial stress and, in many cases, bankruptcy. See Jonathan Weiss et al., *Defining Crisis in Families of Individuals with Autism Spectrum Disorders*, 18 Autism 985, 990–91 (2014); Susan D. James, *Autism Bankrupts Families, Emotionally and Financially*, ABC News (April 1, 2013), <https://abcnews.go.com/Health/autism-families-fight-insurance-coverage-diagnosis-treatment/story?id=18856645>. Alternatively, this financial stress can have an equally negative effect, as children with autism are more likely than other special needs children to delay or forego care entirely.

Michael D. Kogan et al., *A National Profile of the Health Care Experiences and*

Family Impact of Autism Spectrum Disorder Among Children in the United States, 2005–2006, 122 *Pediatrics* e1149, e1149 (2008). Allowing Appellants to exclude T.S. and similarly situated individuals from necessary health coverage would greatly exacerbate these already crushing financial costs of accessing adequate health care, in direct contradiction to the intent of the ACA.

Additionally, withholding treatment for autism imposes significant costs on society, another negative impact that Congress intended to combat through the ACA. Denying an individual with autism access to medically necessary treatment to ameliorate his or her disabilities costs society an average of \$3.2 to \$3.6 million over that individual's lifetime. See Michael L. Ganz, *The Lifetime Distribution of the Incremental Societal Costs of Autism*, 161 *Archives Pediatric & Adolescent Med.* 343, 343 (2007); Janet Cakir et al., *The Lifetime Social Cost of Autism: 1990–2029*, 72 *Resch. Autism Spectrum Disorders* 101502 (2020). The direct care costs associated with autism alone exceed an estimated \$1 million over an individual's lifetime. See John W. Jacobson et al., *Cost-Benefit Estimates for Early Intensive Behavioral Intervention for Young Children with Autism—General Model and Single State Case*, 13 *Behavioral Interventions* 201, 201 (1998) (projecting that provision of early intensive treatment could result in actual direct cost savings of up to \$1,082,000 per individual for state of Pennsylvania). Other societal costs include special education, vocational training, group housing or

institutionalization, community supports, and escalated medical costs. Unumb, *Legislating Autism Coverage, supra*, at 81.

Finally, allowing a Section 1557-covered entity to discriminate against enrollees in its employee benefits plan undermines public confidence in the commitment of the federal government to provide care for persons with disabilities. Even with the ACA, individuals with disabilities continue to struggle and require strong enforcement actions in the face of continued discrimination.⁷ If deprived of Section 1557 to challenge these practices, people with disabilities will again suffer the substantial harms they experienced prior to the passage of the ACA—the very harms Congress sought to eradicate with the Act. The interpretation Appellants seek here would permit the outright exclusion of health coverage for women, minorities, older persons, persons with disabilities and other chronic health conditions, and others in the self-funded health plans of thousands

⁷ People with disabilities already experience significant disparities in health outcomes and access to health care. See Silvia Yee et al., Nat'l Acads. Sci., Eng'g, & Med., *Compounded Disparities: Health Equity at the Intersection of Disability, Race, and Ethnicity* 31–32, 43–44 (2017), <https://dredf.org/wp-content/uploads/2018/01/Compounded-Disparities-Intersection-of-Disabilities-Race-and-Ethnicity.pdf> (summarizing and analyzing abundance of research). For example, obesity rates are 58% higher among adults with disabilities, and those individuals are three times more likely to be diagnosed with diabetes and nearly four times more likely to have early-onset cardiovascular disease. *Id.* at 32. Moreover, they are nearly three times more likely to have not accessed needed health care because of cost and twice as likely to have unmet mental health needs. *Id.* at 31. Even with the passage of the ACA, enforcement remains critical to address large gaps in health care access. See H. Stephen Kaye, *Disability-Related Disparities in Access to Health Care Before (2008–2010) and After (2015–2017) the Affordable Care Act*, 109 Am. J. Pub. Health, 1015, 1019–21 (2019). Yee et al., *supra*, at 31–32, 39–44.

CERTIFICATION OF COMPLIANCE

This brief complies with the 7,000 word limit of Seventh Circuit Rule 29 for amicus briefs because it contains 6,786 words.

This brief complies with the typeface requirements of Federal Rule of Appellate Procedure 32(a)(5) and the type style requirements of Federal Rule of Appellate Procedure 32(a)(6) because this brief has been prepared in a proportionally spaced typeface using Microsoft Word in 14-point Times New Roman font.

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CERTIFICATION OF SERVICE

I hereby certify that I electronically filed the foregoing *amici curiae* brief with the Clerk of the Court for the United States Court of Appeals for the Seventh Circuit by using the appellate CM/ECF system on November 24, 2021.

I certify that all participants in the case are registered CM/ECF users and that service will be accomplished by the CM/ECF system.

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