

No. 19-840

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In the Supreme Court of the United States

CALIFORNIA, *et al.*,  
*Petitioners,*

v.

TEXAS, *et al.*,  
*Respondents.*

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

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**BRIEF OF THE AMERICAN ASSOCIATION OF PEOPLE  
WITH DISABILITIES, PARALYZED VETERANS OF  
AMERICA, JUDGE DAVID L. BAZELON CENTER FOR  
MENTAL HEALTH LAW, DISABILITY RIGHTS EDUCATION  
AND DEFENSE FUND, AND 15 OTHER LEADING  
NATIONAL DISABILITY RIGHTS ORGANIZATIONS AS  
*AMICI CURIAE* IN SUPPORT OF PETITIONERS**

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**INTEREST OF *AMICI***

*Amici curiae* are nineteen leading national disability rights organizations: the American Association of People with Disabilities, American Civil Liberties Union, The Arc of the United States, Association of University Centers on Disabilities, Autistic Self Advocacy Network, Autism Society of America, Center for Public Representation, Disability Rights Education and Defense Fund, Disability Rights Legal Center, Judge David L. Bazelon Center for Mental Health Law, Little Lobbyists, Mental Health America, National Association of Councils on Developmental Disabilities, National Association of the Deaf, National Council on Independent Living, National Disability Rights Network, National Down Syndrome Congress, National Federation of the Blind, and Paralyzed Veterans of America.<sup>1</sup>

Together, *amici* are national organizations that are made up of, represent, and advocate for the rights of Americans with disabilities. The Affordable Care Act<sup>2</sup> is of critical importance to *amici*'s membership and constituents because it provides access to needed health care coverage and services that enable people

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<sup>1</sup> No counsel for a party authored this brief in whole or in part, and no such counsel or a party made a monetary contribution intended to fund the preparation or submission of the brief. No person other than *amici curiae*, their leadership, and their counsel made a monetary contribution to the brief's preparation or submission. *Amici* sought and obtained written consent from the parties that had not provided blanket consent to the filing of briefs by *amici curiae*.

<sup>2</sup> The "Affordable Care Act" or "ACA" refers both to the Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010) ("PPACA") and the Health Care and Education and Reconciliation Act of 2010, Pub. L. No. 111-152, 124 Stat. 1029 (2010) ("HCERA").

with disabilities to live healthy and independent lives. Prior to its passage, millions of people with disabilities were unable to access these services. *Amici* submit this brief to assist the Court in understanding Congress's intent that the ACA protect people with disabilities.

Individual statements of interest for each organization are set out in the Appendix.

## SUMMARY OF ARGUMENT

*Amici* support the arguments of petitioners that the individual and state plaintiffs lack standing, and that reducing to zero the tax assessment for failing to obtain minimum coverage does not invalidate that provision. This brief, however, addresses the third issue in the case: whether the minimum-coverage provision is severable from the ACA if the Court deems that provision unconstitutional.

In assessing whether Congress would have wanted to sever the minimum-coverage provision in order to save the remainder of the ACA, it is important to consider the substantial benefits that Congress intentionally extended to people with disabilities in enacting the ACA. The breadth of these benefits, and their critical importance to the lives of millions of people with disabilities, should weigh heavily in favor of finding the minimum-coverage provision severable, thereby preserving the substantial benefits Congress extended. Congress intentionally sought to protect people with disabilities in the ACA, and would not have wanted to scrap all of these benefits simply because the minimum-coverage provision is deemed invalid.

The ACA has been a life-saver for Americans who live with disabilities. It has provided long-denied access to crucial medical insurance and health care to millions of such Americans. It has allowed people with disabilities to obtain health care and supports that can be critically important to their health, independence, and productivity.

In this brief, *amici* bring to the Court's attention the unquestioned and significant, indeed sometimes life-changing, benefits that the ACA has brought to

the many Americans represented by *amici*, and the devastating effect a declaration that the ACA as a whole is unconstitutional would have.

Even before the current pandemic, the ACA provided crucial additional health care support to people with disabilities. It greatly increased their opportunities to obtain healthcare coverage in the first place through either the federal or state marketplaces or the expansions of Medicaid. It protects against coverage limitations based on preexisting conditions or lifetime limits, which previously limited the healthcare available to people with disabilities. It guarantees coverage of services for mental illnesses and developmental disabilities. It provides access to long-term, home-based health care, which can mean the difference between institutionalization and independence to people with disabilities. And it expressly precludes discrimination in access to healthcare. Indeed, Congress expressly intended the ACA to benefit people with disabilities specifically. By including these provisions, Congress intentionally sought to benefit people with disabilities. It would not have wanted to sacrifice all of these protections merely because the minimum-coverage provision were declared invalid.

The COVID-19 pandemic underscores the impact of the ACA on these issues. Among other things, the pandemic has greatly increased the number of unemployed Americans who may seek coverage through the ACA marketplaces or Medicaid and likely will substantially increase the number of people with disabilities, many of whom will need long-term health care for the lasting effects of the disease. It has also led to concerns about the potential rationing of scarce but potentially lifesaving health care resources (e.g.,

ventilators and ICU beds) based on the existence and severity of a patient's disability—a result the ACA forbids. Now especially, invalidating the ACA as a whole would have a devastating effect on the care and services available to the growing number of people with disabilities in our country.

Congress expressly sought to expand these health benefits for all, but particularly to those most vulnerable to health insurance barriers: people with disabilities. That intention should guide this Court in concluding that, even if the minimum-coverage provision is deemed invalid, it can be severed, saving the remainder of the Act, and avoiding the unthinkable damage to people with disabilities that wholesale invalidation would deliver.

## ARGUMENT

### **I. The ACA Uniquely and Extensively Benefits People With Disabilities, and Congress Would Have Preferred Severability to Avoid Disproportionate Harm to That Same Population.**

In enacting the ACA, one of Congress's express goals was to protect people with disabilities. The act does so in many critically important ways. These benefits, which would survive even in the absence of the minimum-coverage provision, strongly counsel in favor of honoring Congress's intent and severing that provision, if necessary. The extent of the benefits to people with disabilities running through the entire Act supports the conclusion that Congress would not have wanted to cast aside these benefits—and these beneficiaries—merely because the minimum-coverage provision were deemed invalid.

The health care challenges for people with disabilities start with the fact that they face significant barriers to finding and maintaining employment.<sup>3</sup> Whether it is explicit or implicit bias in the hiring process, an adverse employment action based on misguided assumptions, or a failure to provide reasonable accommodations to an employee, disability discrimination in employment remains

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<sup>3</sup> In 2017, the employment rate of non-institutionalized working-age people with disabilities in the United States was 37.3%, compared with 79.4% of people without disabilities. See W. ERICKSON ET AL., CORNELL UNIV. YANG-TAN INST. ON EMP'T & DISABILITY, 2017 DISABILITY STATUS REPORT: UNITED STATES 31 (2019), [http://www.disabilitystatistics.org/StatusReports/2017-PDF/2017-StatusReport\\_US.pdf](http://www.disabilitystatistics.org/StatusReports/2017-PDF/2017-StatusReport_US.pdf) (“2017 DSR”).

pervasive.<sup>4</sup> Moreover, people with disabilities often lack the employment and health care services and supports they need to secure and maintain work.<sup>5</sup>

Because of the many societal barriers to employment, people with disabilities are much less likely to have employer-provided health insurance than people without disabilities.<sup>6</sup> While the majority—65.4% in 2017—of Americans without disabilities obtain health insurance from their employers, this statistic almost perfectly inverts as to people with disabilities.<sup>7</sup> In 2017, only 34.7% of people with disabilities had employer-provided coverage—meaning that 65.3% did not.<sup>8</sup> Accordingly, most people with disabilities must look elsewhere for health insurance, either through plans not sponsored by employers or through Medicaid or Medicare.

Before the ACA's passage, searching for private insurance was often a futile endeavor with limited

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<sup>4</sup> In 2017, the U.S. EEOC reported that 31.9% of all charges filed that year related to workplace disability discrimination. See EQUAL EMP'T OPPORTUNITY COMM'N, CHARGE STATISTICS: FY 1997 THROUGH FY 2017, <https://www.eeoc.gov/eeoc/statistics/enforcement/charges.cfm>.

<sup>5</sup> See, e.g., Silvia Yee et al., *Compounded Disparities: Health Equity at the Intersection of Disability, Race, and Ethnicity*, NAT'L ACADS. SCI., ENGINEERING & MED. (2017), available at <https://dredf.org/wp-content/uploads/2018/01/Compounded-Disparities-Intersection-of-Disabilities-Race-and-Ethnicity.pdf> (documenting the disparities in access to health care, quality of care, and health outcomes among people with disabilities).

<sup>6</sup> 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 Nondisabled Working-Age Adults*, 54 J. OF HEALTH CARE ORG., PROVISION, & FIN. 1, 1 (2017).

<sup>7</sup> 2017 DSR, *supra* note 3, at 55.

<sup>8</sup> *Id.*



coverage options. Private insurance was not a realistic option for many people with disabilities because of pre-existing condition exclusions, annual or lifetime limits on benefits, and high premium costs.<sup>9</sup> Even if private coverage was available, people with disabilities still might require services that those private health insurance plans refused to cover, such as durable medical equipment, mental health and substance use disorder services, or rehabilitation and habilitation services.<sup>10</sup>

Unable to obtain adequate private insurance, many people with disabilities turned to Medicaid<sup>11</sup> and/or Medicare<sup>12</sup> as their only options.<sup>13</sup> Indeed, in 2009—before passage of the ACA—58.2% of people with disabilities received insurance from Medicare or Medicaid, compared to just 7.6% of people without disabilities.<sup>14</sup> But many people with disabilities could not qualify for Medicare or Medicaid. For example,

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<sup>9</sup> Kennedy et al., *supra* note 6, at 1.

<sup>10</sup> Jody S. Hyde & Gina A. Livermore, *Gaps in Timely Access to Care Among Workers by Disability Status: Will the Patient Protection and Affordable Care Act Reforms Change the Landscape?*, 26 J. OF DISABILITY POL'Y STUD. 221, 221 (2016); Kennedy et al., *supra* note 6, at 1.

<sup>11</sup> Medicaid is the primary public health insurance program for people with low incomes and is a program administered and financed jointly by states and the federal government. 42 U.S.C. § 1396 et seq.; 42 C.F.R. § 430 et seq.

<sup>12</sup> Medicare provides benefits for individuals aged 65 or older and individuals who are entitled to Social Security Disability Insurance (“SSDI”) benefits for at least 25 months. 42 U.S.C. §§ 423, 426(b), 1395c, 1395i-2a; 42 C.F.R. § 406.12.

<sup>13</sup> See W. ERICKSON ET AL., CORNELL UNIV. YANG-TAN INST. ON EMP'T & DISABILITY, 2009 DISABILITY STATUS REPORT: UNITED STATES 55, 56 (2011), [http://www.disabilitystatistics.org/StatusReports/2009-PDF/2009-StatusReport\\_US.pdf](http://www.disabilitystatistics.org/StatusReports/2009-PDF/2009-StatusReport_US.pdf) (“2009 DSR”).

<sup>14</sup> 2017 DSR, *supra* note 3, at 55-56.

individuals without a “qualifying permanent disability” (e.g., a blind or Deaf individual) and those who earned income in excess of a defined poverty line were excluded from coverage. Still others faced long waiting periods—a newly disabled individual had to wait two years from the date of disability before Medicare benefits could begin, or up to a year for Medicaid, depending on the individual’s state of residence.<sup>15</sup> These individuals were left stranded, without the coverage they needed to maintain their health and live full and independent lives.

The ACA brought significant and measurable improvements in access to health insurance and the quality of health insurance plans to people with disabilities. Since the ACA’s passage, the uninsured rate for people with disabilities has fallen significantly. In 2009, 17.4% of disabled individuals were not insured. By 2017, that rate had fallen to 9.8%.<sup>16</sup> The rate of those with disabilities who received health insurance from their employer stayed roughly constant during that time frame, namely,

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<sup>15</sup> Individuals with disabilities who receive SSDI are eligible for Medicare, but benefits do not begin until 25 months from the individual’s date of disability. In addition, states are generally required to provide Medicaid coverage to people with disabilities who receive Supplemental Security Income (“SSI”) benefits, but establishing eligibility for SSI based on a qualifying disability through the Social Security Administration (“SSA”) can take up to a year. 42 U.S.C. § 1396a(a)(10)(A)(i)(II)(aa); 42 C.F.R. § 435.120 (2019); *see* SOC. SEC. ADMIN., SOCIAL SECURITY ADMINISTRATION (SSA) ANNUAL DATA FOR INITIAL DISABILITY CASES INVOLVING THE PROCESSING CENTERS AVERAGE PROCESSING TIME (2018), <https://www.ssa.gov/open/data/program-service-centers.html>.

<sup>16</sup> Compare 2009 DSR, *supra* note 13, at 55, with 2017 DSR, *supra* note 3, at 56.

36.5% in 2009 and 34.7% in 2017.<sup>17</sup> Thus, the largest gains for people with disabilities came from the ACA’s Medicaid expansion, with 42.9% receiving Medicaid coverage in 2017, up from 34.9% in 2009.<sup>18</sup> Altogether, at least **2.5 million** more Americans with disabilities gained access to health care due to the ACA.

These effects were fully intended by Congress. Several provisions of the ACA specifically and expressly address deficiencies in previously available services for people with disabilities, relieving them and their families from often overwhelming out-of-pocket costs.<sup>19</sup> The legislative history is in accord. As one Senator observed, “[The ACA] is good to remind

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<sup>17</sup> *Id.*

<sup>18</sup> *Id.*

<sup>19</sup> *See, e.g.*, PPACA § 2705(a)(8) (forbidding discrimination in coverage and benefits based on disability); PPACA § 1302(b)(4)(C)-(D) (“essential health benefits” must “take into account the health care needs of . . . persons with disabilities” and must “ensure that health benefits . . . not be subject to denial to individuals based on . . . the individuals’ present or predicted disability”); PPACA § 2401(k)(3)(B) (requiring state plans to provide home and community based services “without regard to the individual’s age, type or nature of disability, severity of disability, or the form of home and community-based attendant services and supports that the individual requires in order to lead an independent life”); PPACA § 2405 (appropriating funding “to expand State aging and disability resource centers”); PPACA § 2406 (stating that under *Olmstead v. L.C.*, 527 U.S. 581 (1999), people with disabilities have the “right to choose to receive their longterm services and supports in the community, rather than in an institutional setting”; and that “Congress should address long-term services and supports in a comprehensive way that guarantees elderly and disabled individuals the care they need” “in the community in addition to in institutions”); PPACA § 4001(d)(2) (establishing national Council to, among other things, “reduc[e] the incidence of preventable . . . disability”).

us that we are, once again, an American family; that no one should be discriminated against simply because they are sick or have an illness or *because fate has dealt them a blow by becoming disabled*. That is what this bill is about more than anything else.”<sup>20</sup> As another legislator explained, “this landmark legislation will end abusive health insurance practices that prevent people from purchasing and maintaining their coverage when they are sick; *it will ban yearly and lifetime insurance caps, so individuals with chronic, disabling conditions don’t lose coverage and end up in bankruptcy.*”<sup>21</sup>

Now more than ever, it is vitally important to preserve the gains the ACA created and to continue to provide people with disabilities—and indeed all Americans—access to expanded health care coverage through non-employer based insurance or Medicaid. Early estimates show that COVID-19 and the economic devastation it has brought may result in up to 35 million people losing their jobs, and their employer-based insurance, thereby becoming newly reliant on the expanded insurance and (in some states) Medicaid options provided by the ACA.<sup>22</sup> Given the systemic discrimination that already makes obtaining and maintaining employment difficult for people with disabilities, the ACA’s programs and services are more important than ever. Because

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<sup>20</sup> 156 Cong. Rec. S1831 (2010) (emphasis added).

<sup>21</sup> 156 Cong. Rec. H2432 (2010) (emphasis added).

<sup>22</sup> Health Management Associates, *Covid-19 Impact on Medicaid, Market, and the Uninsured, by State*, Apr. 3, 2020 (estimating that the number of people with employer-sponsored health insurance could decline by 12 to 35 million), *available at* <https://www.healthmanagement.com/wp-content/uploads/HMA-Estimates-of-COVID-Impact-on-Coverage-public-version-for-April-3-830-CT.pdf>.

Congress would not have wanted to jettison these critical protections, the Court should find that the minimum-coverage provision is severable should it conclude that it is invalid.

## **II. The ACA's Expansion of Health Care Access and Coverage for People With Disabilities Has Greatly Benefitted Society as a Whole.**

The ACA's specific, positive impacts on people with disabilities extend beyond that population alone. Research has consistently demonstrated that the ACA's improved access to health care for people with disabilities has benefited the broader population in many ways.

First, the ACA's expansion of Medicaid eligibility has enabled more people with disabilities to access the workforce. Many people with disabilities depend on health care services and supports—items and services as simple as a wheelchair, pain management treatment, mental health supports, or an accurate glucose monitor—to perform basic tasks, go to work, or even get out of bed. Several studies examined the impact that increased access to health care—and specifically the expansion of Medicaid—has had on employment rates. Most studies show a significant positive link between Medicaid expansion and employment rates; none show a negative correlation.<sup>23</sup> Because of the ACA, people with disabilities are less likely to face the dilemma of keeping their health

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<sup>23</sup> Larisa Antonisse et al., *The Effects of Medicaid Expansion under the ACA: Updated Findings from a Literature Review*, KAISER FAMILY FOUND. 7-8 (Mar. 2018), <http://files.kff.org/attachment/Issue-Brief-The-Effects-of-Medicaid-Expansion-Under-the-ACA-Updated-Findings-from-a-Literature-Review>.

insurance or working to their fullest potential and losing good health coverage because of income thresholds or other barriers to coverage.<sup>24</sup> In the now 37 states (including the District of Columbia) that have expanded Medicaid coverage, people with disabilities are more likely to be employed and fewer people are likely to report not working because of a disability, in comparison to states that have not expanded Medicaid.<sup>25</sup>

Second, research shows that expanded access to health care may reduce hospital emergency room usage. A study examining California emergency room usage found that “[emergency] patients actually had a lower likelihood of being frequent users after [the ACA’s] implementation,” after controlling for other variables in the population.<sup>26</sup> The study’s authors explained:

While our findings do not provide evidence that the ACA caused these changes, they suggest that expanded Medicaid coverage might have allowed patients to access needed medical services outside of the [emergency room]. This might have been especially true among people with chronic conditions who used the [emergency room] frequently pre ACA but who became connected to a primary care provider as

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<sup>24</sup> Jean P. Hall et al., *Medicaid Expansion as an Employment Incentive Program for People With Disabilities*, 108 AM. J. PUB. HEALTH 1235, 1235 (2018).

<sup>25</sup> *Id.*

<sup>26</sup> Shannon McConville et al., *Frequent Emergency Department Users: A Statewide Comparison Before And After Affordable Care Act Implementation*, 37 HEALTH AFFAIRS 881, 886 (2018).

a result of the ACA Medicaid expansion via Medicaid managed care plans.<sup>27</sup>

The ACA's increase in options for Medicaid coverage of disabled individuals and the provision of long-term services and supports ("LTSS") under Medicaid also have important ramifications for the broader population. Specifically, these options have reduced reliance on informal, unpaid caregivers, such as family members who provide care to a disabled parent, child or other family member. In 2013, unpaid informal caregivers (primarily family members) provided up to three-quarters of uncompensated LTSS care, amounting to an estimated \$470 billion in unpaid care.<sup>28</sup> Additionally, family members and other informal caregivers are frequently called on to provide more complex and demanding medical or nursing care for which they may lack training, including medication management, wound care, and incontinence care.<sup>29</sup> Providing LTSS coverage through Medicaid to individuals with disabilities relieves economic and practical the burdens on caregivers, allowing some to be paid for their caregiving work and others to return to other work while their family members receive proper and necessary care.

Finally, Medicaid expansion has the potential to reduce the needless incarceration of people with

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<sup>27</sup> *Id.* at 887.

<sup>28</sup> Susan C. Reinhard et al., AARP PUB. POLICY INST., VALUING THE INVALUABLE: 2015 UPDATE 1 (2015), <https://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-new.pdf>.

<sup>29</sup> Kali S. Thomas & Robert Applebaum, *Long-term Services and Supports (LTSS): A Growing Challenge for an Aging America*, 25 PUB. POL'Y & AGING REP. 56, 59 (2015).

disabilities. As a result of the expansion, many people with disabilities now have access to community-based services that reduce the likelihood that they will have police encounters and find themselves incarcerated.<sup>30</sup> The expansion has also made it possible for many people with disabilities to receive needed services when they re-enter society following incarceration. “Upon release from prison and jail, individuals are often uninsured, making it difficult to access stable sources of care in the community to address these needs. Expanding health insurance to these individuals [through the ACA] will likely facilitate their ability to access needed care and manage their ongoing conditions.”<sup>31</sup> In fact, states that have expanded Medicaid have enrolled a significant percentage of newly incarcerated individuals, helping to connect those individuals to the services and care they need upon their release.<sup>32</sup>

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<sup>30</sup> Sarah Liebowitz et al., AM. CIVIL LIBERTIES UNION OF S. CAL. & BAZELON CTR. FOR MENTAL HEALTH LAW, *A Way Forward: Diverting People with Mental Illness from Inhumane and Expensive Jails into Community-Based Treatment that Works* (2014).

<sup>31</sup> Alexandra Gates, *Health Coverage and Care for the Adult Criminal Justice-Involved Population*, KAISER COMM’N ON MEDICAID & THE UNINSURED 5-6 (Sept. 2014), <https://www.kff.org/uninsured/issue-brief/health-coverage-and-care-for-the-adult-criminal-justice-involved-population/>.

<sup>32</sup> Vikki Wachino and Samantha Artiga, *How Connecting Justice-Involved Individuals to Medicaid Can Help Address the Opioid Epidemic*, KAISER FAMILY FOUND. 4-5 (JUNE 2019), <http://files.kff.org/attachment/Issue-Brief-How-Connecting-Justice-Involved-Individuals-to-Medicaid-can-Help-Address-the-Opioid-Epidemic>.



### **III. Several Generally Applicable Provisions in the ACA Are Critical to Providing People With Disabilities Access to Health Care.**

The ACA contains a number of provisions that apply equally to all Americans, regardless of disability status or income, but have been especially valuable—indeed critical—to ensure that people with disabilities have access to adequate and affordable health care. None are dependent on the continued existence of the minimum-coverage provision.

The current COVID-19 pandemic underscores the crucial nature of these protections and their importance to people with disabilities. As the nightly news reminds us on a daily basis, people with chronic conditions such as diabetes or weakened immune systems and people in long-term care facilities or other institutions are far more likely to be infected with the virus and far more likely to suffer its most severe effects.<sup>33</sup> In addition, early indications are that the disease itself and its effects will increase the

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<sup>33</sup> Priya Chidambaram, *State Reporting of Cases and Deaths Due to COVID-19 in Long-Term Care Facilities*, KAISER FAMILY FOUND. (Apr. 23, 2020), <https://www.kff.org/medicaid/issue-brief/state-reporting-of-cases-and-deaths-due-to-covid-19-in-long-term-care-facilities/> (finding that in 29 reporting states, deaths due to long-term care facilities represent about 27-50% of COVID-19 related deaths in those states).

incidence and severity of physical<sup>34</sup> and cognitive disabilities as well as increased mental illness.<sup>35</sup>

### A. Protections for Pre-Existing Conditions

One of the ACA's central benefits is the protection it provides to people with pre-existing conditions.<sup>36</sup> This requirement protects such individuals from being denied coverage altogether or from being charged exorbitant premiums.<sup>37</sup>

The non-partisan Kaiser Family Foundation estimates that nationwide, roughly 27% of adults

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<sup>34</sup> Henk J. Stam, et al., *Covid-19 and Post Intensive Care Syndrome: A Call for Action*, 52 J. Rehabil. Med. (Apr. 14, 2020), <https://www.medicaljournals.se/jrm/content/abstract/10.2340/16501977-2677> (noting that at least 25% of ICU patients experience a loss of independence, and incidence of poor mobility, frequent falls, and disability).

<sup>35</sup> *Id.*; see also Sandro Galea, et al., *Then Mental Health Consequences of COVID-19 and Physical Distancing: The Need for Prevention and Early Intervention*. JAMA Intern Med. (April 10, 2020), <https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/2764404> (“In the context of the COVID-19 pandemic, it appears likely that there will be substantial increases in anxiety and depression, substance use, loneliness, and domestic violence . . .”); Nirmita Panchal, et al., *The Implications of COVID-19 for Mental Health and Substance Abuse*, KAISER FAMILY FOUND. (Apr. 21, 2020), <https://www.kff.org/health-reform/issue-brief/the-implications-of-covid-19-for-mental-health-and-substance-use/> (summarizing early tracking polls of mental health effects related to the pandemic).

<sup>36</sup> See 42 U.S.C. § 300gg-3.

<sup>37</sup> Louise Norris, *Health Insurance and High-Risk Pools: ACA's coverage of pre-existing conditions made high-risk pools obsolete. Will they be resurrected as an Obamacare replacement?*, HEALTHINSURANCE.ORG (Dec. 10, 2018), <https://www.healthinsurance.org/obamacare/risk-pools>.

under the age of 65—**totaling 53.8 million Americans**—have a pre-existing condition that without the ACA could result in the loss of coverage.<sup>38</sup> Research conducted before the ACA’s passage by the non-partisan Commonwealth Fund found that 53% of individuals with health problems who tried to buy coverage in the individual market found it very difficult or impossible to find a health plan with the coverage they needed, compared to 31% of those without a pre-existing condition.<sup>39</sup> In addition, 46% were denied coverage, charged more, or had benefits excluded from their plan because of a pre-existing condition.<sup>40</sup>

Because many people have disabilities for their entire lives, they were particularly at risk for losing insurance coverage on this basis. They also have a disproportionate need for health insurance, given the high health care costs associated with certain types of disabilities. Prior to the ACA, insurers routinely denied coverage to people with disabilities such as vision loss, autism, and mental health-related conditions. In fact, according to a 2012 Government Accountability Office study, mental health disorders were the second most commonly reported condition

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<sup>38</sup> Gary Claxton et al., *Pre-Existing Condition Prevalence for Individuals and Families*, KAISER FAMILY FOUND. (Oct. 4, 2019), <https://www.kff.org/health-reform/issue-brief/pre-existing-condition-prevalence-for-individuals-and-families/>.

<sup>39</sup> Sara R. Collins et al., *Help on the Horizon: How the Recession Has Left Millions of Workers Without Health Insurance, and How Health Reform Will Bring Relief*, THE COMMONWEALTH FUND 4 (Mar. 2011), [https://www.commonwealthfund.org/sites/default/files/documents/media\\_files\\_publications\\_fund\\_report\\_2011\\_mar\\_1486\\_collins\\_help\\_on\\_the\\_horizon\\_2010\\_biennial\\_survey\\_report\\_final\\_v2.pdf](https://www.commonwealthfund.org/sites/default/files/documents/media_files_publications_fund_report_2011_mar_1486_collins_help_on_the_horizon_2010_biennial_survey_report_final_v2.pdf).

<sup>40</sup> *Id.*

that could result in a denial of coverage, affecting 19 million people nationwide.<sup>41</sup>

## B. Guaranteed Issue

Prior to the ACA, insurers could effectively deny coverage to someone because of their disability. The ACA's guaranteed-issue provision prohibits that. In general, this provision requires insurers to issue a health plan to any applicant, regardless of their health status or disability. Previously, only six states required insurers to do so.<sup>42</sup>

The ACA expands that protection to the entire country and requires each issuer that offers coverage in the individual or group market to accept *every* employer and individual in the state that applies for it during the operative enrollment periods.<sup>43</sup>

Though many people with disabilities use public health insurance programs, access to the private markets is another important avenue for obtaining coverage.<sup>44</sup> Prohibiting issuers from refusing to issue policies to people with disabilities helps expand private insurance as a viable source of coverage for them and may serve to reduce reliance on (and thus save costs for) public programs.

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<sup>41</sup> U.S. GOV'T ACCOUNTABILITY OFFICE, GAO-12-439, PRIVATE HEALTH INSURANCE: ESTIMATES OF INDIVIDUALS WITH PRE-EXISTING CONDITIONS RANGE FROM 36 MILLION TO 122 MILLION 10 (2012), <https://www.gao.gov/assets/590/589618.pdf>.

<sup>42</sup> KAISER FAMILY FOUND., *Health Insurance Market Reforms: Guaranteed Issue* 3 (2012), <https://www.kff.org/wp-content/uploads/2013/01/8327.pdf>.

<sup>43</sup> 42 U.S.C. § 300gg-1; 45 C.F.R. § 147.104.

<sup>44</sup> Nancy A. Miller et al., *The Relation Between Health Insurance and Health Care Disparities Among Adults with Disabilities*, 104 AM. J. OF PUB. HEALTH e85 (2014).

### C. Dependent Coverage for Adult Children

The ACA also requires many health plans to make dependent child coverage available under a parent's plan for children up to the age of 26.<sup>45</sup> This provision has improved access to health care for all young adults, including young adults with disabilities.

The ACA's expanded dependent coverage has reduced the overall uninsured rate by approximately 20%.<sup>46</sup> Studies have shown that "young adults with health problems and foreseeable health care needs" have seen greater increases in health coverage as a result of the ACA's expanded dependent coverage.<sup>47</sup> Similarly, "the uninsurance rate among young adults who may have mental health care needs and seek treatment declined by [12.4%] because of the provision."<sup>48</sup>

The disproportionate benefits for youths with disabilities are consistent with research showing that young adults with disabilities on average have lower rates of coverage, are more likely to lack regular health care providers, have more unmet health care needs, receive fewer routine checkups, and have decreased access to health care than older adults.<sup>49</sup>

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<sup>45</sup> 42 U.S.C. § 300gg-14.

<sup>46</sup> See NAT'L COUNCIL ON DISABILITY, THE IMPACT OF THE AFFORDABLE CARE ACT ON PEOPLE WITH DISABILITIES: A 2015 STATUS REPORT 18 (2016), [https://ncd.gov/sites/default/files/NCD\\_ACA\\_Report02\\_508.pdf](https://ncd.gov/sites/default/files/NCD_ACA_Report02_508.pdf) (citing studies).

<sup>47</sup> *Id.* at 20-21.

<sup>48</sup> *Id.* at 21.

<sup>49</sup> Catherine A. Okoro et al., *Prevalence of Disabilities and Health Care Access by Disability Status and Type Among Adults—United States, 2016*, 67 MORBIDITY & MORTALITY WKLY. REP.

Without the ACA, these disparities would surely grow even wider, resulting in a reversal of these positive developments for younger people with disabilities.

#### D. Essential Health Benefits

The ACA also mandates a minimum level of benefits that health plans in the individual and small-group markets must provide. The ACA requires all individual and small-group plans, and all plans sold in the state exchanges, to cover “essential health benefits.”<sup>50</sup> The ACA defines “essential health benefits” to include, *inter alia*, hospitalization, outpatient medical care, mental health and substance abuse treatment, rehabilitative and habilitative services and devices, and prescription drugs.<sup>51</sup> The ACA grants the Secretary of the Department of Health and Human Services (“HHS”) authority to further define the benefits included in each benefit category, and directs the Secretary to ensure that the scope of “essential health benefits” is equal to the scope of benefits provided by a “typical employer plan.”<sup>52</sup> Notably, HHS must define “essential health benefits” in a manner that does not discriminate on the basis of disability or health status or otherwise discourage people with significant health needs from enrolling in their plans.<sup>53</sup>

Of particular importance is the inclusion of rehabilitative and habilitative services and devices as essential health benefits. Habilitative services and

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882, 886, Table 2 (2018) (examining age cohorts of 18-44, 45-64, and over 65).

<sup>50</sup> 42 U.S.C. §§ 18022(b)(1), 300gg-6.

<sup>51</sup> *Id.* § 18022(b)(1).

<sup>52</sup> *Id.* § 18022(b)(2); *see* 45 C.F.R. § 156.110.

<sup>53</sup> 42 U.S.C. § 18022(b)(4).

devices are provided to help an individual attain new skills not developed because of a disabling condition and then maintain or prevent deterioration of such skills. In contrast, rehabilitative services and devices are intended to help a person regain, maintain, or prevent/decrease deterioration of a skill or function that may have been lost because of a disabling condition.<sup>54</sup> Prior to the ACA, health plans would typically cover rehabilitative services, such as occupational, physical, or speech therapy to help individuals with an accident or illness *recover* their ability to walk, speak and function. However, habilitative services were generally excluded, as insurers often argued that such services were not medically necessary if they would not result in “improvement” or if an individual did not have some level of functional ability in the first place. Likewise, habilitative devices include durable medical equipment, such as walkers, ventilators, wheelchairs and glucose monitors, which help individuals maintain their health and live independently.

Another key category of “essential health benefits” is mental health and substance use disorder services (collectively, “behavioral health services”).<sup>55</sup> Prior to the ACA, 38% of health plans did not provide coverage for mental or behavioral health care services, and 45% of health plans did not provide coverage for substance abuse disorder services.<sup>56</sup> Though Congress had required group insurers to provide coverage for certain behavioral health benefits that was no more

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<sup>54</sup> See Patient Protection and Affordable Care Act; HHS Notice of Benefit and Payment Parameters for 2016, 80 Fed. Reg. 10750, 10811 (Feb. 27, 2015) (as codified at 45 C.F.R. § 156.115).

<sup>55</sup> 42 U.S.C. § 18022(b)(1)(E).

<sup>56</sup> Claxton et al., *supra* note 38, at 2.

restrictive than coverage for other medical benefits covered by the health plan, these requirements did not translate into comparable coverage for behavioral health services.<sup>57</sup>

The ACA extended the federal parity provisions to require behavioral health parity in the individual markets, and the inclusion of behavioral health services as “essential health benefits” provided additional strength to the parity requirements.<sup>58</sup>

### **E. Ban on Annual and Lifetime Limits**

The ACA also prohibits insurers from imposing lifetime or annual limits on the amount of essential health benefits they must cover.<sup>59</sup>

In the decade before the ACA, the majority (59%) of workers with employer-provided health plans faced a cap on lifetime benefits.<sup>60</sup> As a result, health insurance coverage could discontinue *forever* once the

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<sup>57</sup> See 29 U.S.C. § 1185a; 26 U.S.C. § 9812; Kirsten Beronio et al., U.S. DEPT OF HEALTH & HUMAN SERVS., OFFICE OF THE ASSISTANT SECY FOR PLANNING & EVALUATION, *Affordable Care Act Will Expand Mental Health and Substance Use Disorder Benefits and Parity Protections for 62 Million Americans* (2013), [https://aspe.hhs.gov/system/files/pdf/76591/rb\\_mental.pdf](https://aspe.hhs.gov/system/files/pdf/76591/rb_mental.pdf); Kirsten Beronio et al., *How the Affordable Care Act and Mental Health Parity and Addiction Equity Act Greatly Expand Coverage of Behavioral Health Care*, 41 J. Behav. Health Serv. Res. 410 (2014).

<sup>58</sup> 42 U.S.C. § 300gg-26.

<sup>59</sup> 45 C.F.R. § 147.126; see also Sarah Kliff, *The Obamacare Provision that Saved Thousands from Bankruptcy*, VOX (Mar. 2, 2017), <https://www.vox.com/policy-and-politics/2017/2/15/14563182/obamacare-lifetime-limits-ban>.

<sup>60</sup> Gary Claxton et al., KAISER FAMILY FOUND. & HEALTH RESEARCH & EDUC. TR., EMPLOYER HEALTH BENEFITS: 2009 ANNUAL SURVEY 184 (2009), <https://www.kff.org/wp-content/uploads/2013/04/7936.pdf>.



limit had been reached. The ACA now prohibits both lifetime and annual limits on individual, small group, and employer coverage for essential health benefits.

This prohibition has profoundly affected people with disabilities, particularly those who require lifelong health services. Not surprisingly, people with disabilities, on average, utilize more health care and incur more medical expenses than people without disabilities.<sup>61</sup> The ACA has allowed those with chronic conditions to find stable insurance coverage that will not be suddenly and completely exhausted.<sup>62</sup> For people with disabilities requiring regular medical attention, the ACA's ban on lifetime and annual limits has dramatically reduced the likelihood of them or their families having to endure otherwise avoidable personal bankruptcy as a cost of obtaining needed medical treatment.

#### F. Non-Discrimination Requirements

Finally, the ACA expanded protections for disabled individuals through the expansion of non-

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<sup>61</sup> Kennedy et al., *supra* note 6, at 8, Table 5; Chaiporn Pumkam et al., *Health Care Expenditures Among Working-age Adults with Physical Disabilities: Variations by Disability Spans*, 6 DISABILITY & HEALTH J. 287, 294, Table 4 (2013); see also Catherine Zaidel et al., *Health Care Expenditures and Length of Disability Across Medical Conditions*, 60 J. Occupational and Envtl. Med. (2018), [https://journals.lww.com/joem/Fulltext/2018/07000/Health\\_Care\\_Expenditures\\_and\\_Length\\_of\\_Disability.9.aspx](https://journals.lww.com/joem/Fulltext/2018/07000/Health_Care_Expenditures_and_Length_of_Disability.9.aspx) (“The authors found that individuals with persistent disabilities had higher total medical expenditures but lower out-of-pocket expenses than those with temporary disabilities.”).

<sup>62</sup> See Joanne Volk, *Affordable Care Act's Ban on Lifetime Limits Has Ended Martin Addie's Coverage Circus*, GEORGETOWN UNIV. HEALTH POLICY INST. (Nov. 14, 2012), <https://ccf.georgetown.edu/2012/11/14/affordable-care-acts-ban-on-lifetime-limits-has-ended-martin-addies-coverage-circus/>.

discrimination requirements. Section 1557 of the ACA adopts and applies existing federal laws that prohibit discrimination on the grounds of disability, among others. It applies non-discrimination provisions broadly to: (1) any health program or activity, any part of which is receiving federal financial assistance; (2) any publicly-administered health program or activity; and (3) the state health care exchanges created by the ACA.<sup>63</sup>

In its implementing regulations, Section 1557 specifically prohibits discriminatory health plan benefit designs, a subtle and insidious form of discrimination against disabled people.<sup>64</sup> An issuer does so by, among other things, designing a plan that effectively discourages people with disabilities from enrolling or limits the scope of coverage in a way that effectively voids or reduces the benefit that a person may receive from the insurance. For example, a plan could exclude certain types of treatment centers from its provider network, thereby deterring people who rely on that type of treatment from enrolling in the plan.<sup>65</sup>

These provisions provide a powerful protection for people with disabilities, allowing them to seek redress from those who may want to exclude them from

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<sup>63</sup> PPACA § 1557 *codified at* 42 U.S.C. § 18116.

<sup>64</sup> *See* 45 C.F.R § 155.120(c). Section 1311 of the PPACA also prohibits discriminatory plan design. PPACA § 1311 *codified at* 42 U.S.C. § 18031.

<sup>65</sup> Elizabeth Guo, et al., *Eliminating Coverage Discrimination Through the Essential Health Benefit's Anti-Discrimination Provisions*, 107 Am. J. Pub. Health 253, 253 (2017), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5227931/pdf/AJPH.2016.303563.pdf>.

receiving the health care they need or to make it unfairly cost prohibitive.<sup>66</sup>

The critical importance of the ACA's non-discrimination requirements has been on full display in the ongoing COVID-19 crisis, ensuring that access to scarce medical resources may not be denied because of the existence or severity of an individual's disability. Although a number of states' plans for allocating scarce resources *have* contained such discriminatory considerations, following guidance issued by the HHS Office of Civil Rights and initial enforcement actions taken, many states are working with stakeholders to comply with the ACA and other applicable prohibitions on such discrimination.<sup>67</sup>

#### **IV. The ACA's Changes to Medicaid Provide People With Disabilities Better, and Sometimes Unprecedented, Access to Health Care.**

The ACA's expansion of Medicaid also foreseeably and intentionally benefited people with disabilities. Medicaid is an important source of health insurance

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<sup>66</sup> See, e.g., <http://www.chlpi.org/wp-content/uploads/2013/12/LA-Humana.pdf> (complaint against Humana in Louisiana).

<sup>67</sup> See, e.g., Press Release, Office of Civil Rights (HHS), *OCR Reaches Early Case Resolution With Alabama After It Removes Discriminatory Ventilator Triaging Guidelines* (Apr. 8, 2020), available at <https://www.hhs.gov/about/news/2020/04/08/ocr-reaches-early-case-resolution-alabama-after-it-removes-discriminatory-ventilator-triaging.html>; Press Release, Office of Civil Rights (HHS), *OCR Resolves Civil Rights Complaint Against Pennsylvania After it Revises its Pandemic Health Care Triaging Policies to Protect Against Disability Discrimination* (Apr. 16, 2020), available at <https://www.hhs.gov/about/news/2020/04/16/ocr-resolves-civil-rights-complaint-against-pennsylvania-after-it-revises-its-pandemic-health-care.html>.

coverage for such people, and the ACA's improvements to the Medicaid program—which are not dependent on the minimum-coverage provision—have had a substantial impact on their ability to access much-needed health care services.

### A. Medicaid Eligibility Expansion

Prior to the ACA, there were substantial gaps in Medicaid coverage that left individuals with disabilities without necessary services and care. To qualify for Medicaid, an individual generally had to have low income and meet one of several eligibility categories. Low-income children, parents or caretakers of children, children or adults with disabilities, and elderly adults were all eligible for Medicaid, but not *all* people with low income (and health care needs) qualified.<sup>68</sup>

The ACA expanded Medicaid eligibility to include all adults with income up to 138% of the federal poverty line.<sup>69</sup> Though the Court later ruled that the expansion of Medicaid was optional and up to individual states,<sup>70</sup> to date 36 states and the District of Columbia have expanded Medicaid eligibility to the limits allowed by the ACA.<sup>71</sup>

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<sup>68</sup> 42 U.S.C. § 1396a(a)(10)(A)(i); *see also* CTRS. FOR MEDICARE & MEDICAID SERVS., U.S. DEP'T OF HEALTH & HUMAN SERVS., BRIEF SUMMARIES OF MEDICARE & MEDICAID: TITLE XVIII AND TITLE XIX OF THE SOCIAL SECURITY ACT 24 (2019), <https://www.cms.gov/files/document/brief-summaries-medicare-medicaid-november-15-2019.pdf>.

<sup>69</sup> 42 U.S.C. § 1396a(e)(14)(I); 42 C.F.R. § 435.603(d)(4).

<sup>70</sup> *Nat'l Fed'n of Indep. Bus. v. Sebelius*, 567 U.S. 519, 587 (2012).

<sup>71</sup> KAISER FAMILY FOUND., STATUS OF STATE ACTION ON THE MEDICAID EXPANSION DECISION (2020), <https://www.kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act>.

Medicaid eligibility based solely on income is especially important for individuals with disabilities because it generally provides faster and more certain access to health insurance coverage, without being required to go through the delay and uncertainty of obtaining a formal disability determination for eligibility.<sup>72</sup> Moreover, Medicaid's narrow definition of "disability" is notoriously underinclusive of many people with chronic conditions and functional limitations who need health care services and support to access employment and to participate in their communities.

Of all the changes brought about by the ACA, Medicaid expansion has most directly and substantially increased health care coverage for people with disabilities.<sup>73</sup> Research has shown that the expansion of Medicaid under the ACA has especially benefitted various marginalized populations, resulting in more people with health care coverage in expansion states as compared to the general population.<sup>74</sup> The ACA's Medicaid expansion is responsible for the largest portion of the decrease in

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<sup>72</sup> See Molly O'Malley Watts et al., *Medicaid Financial Eligibility for Seniors and People with Disabilities in 2015*, KAISER COMM'N ON MEDICAID & THE UNINSURED, 10 (2016), <http://files.kff.org/attachment/report-medicaid-financial-eligibility-for-seniors-and-people-with-disabilities-in-2015>;

MaryBeth Musumeci, *The Affordable Care Act's Impact on Medicaid Eligibility, Enrollment, and Benefits for People with Disabilities*, KAISER COMM'N ON MEDICAID & THE UNINSURED (2014), <https://www.kff.org/wp-content/uploads/2014/04/8390-02-the-affordable-care-acts-impact-on-medicaid-eligibility.pdf>.

<sup>73</sup> Stephan Lindner et al., "Canaries in the mine...": *The Impact of Affordable Care Act Implementation on People with Disabilities: Evidence from Interviews with Disability Advocates*, 11 DISABILITY & HEALTH J. 86, 89 (2016).

<sup>74</sup> Antonisse et al., *supra* note 23, at 3.

the percentage of people with disabilities who are uninsured, with 42.9% receiving insurance from Medicaid in 2017, an increase from 34.9% in 2009.<sup>75</sup>

### **B. Long-Term Care Services and Supports**

The ACA also provided additional flexibility for Medicaid to cover long-term services and supports (“LTSS”), which are often necessary to provide people with disabilities with services they and their families need. Crucially, the ACA encourages rebalancing Medicaid to provide appropriate LTSS in the individual’s own homes and communities rather than in institutions, as many people with disabilities strongly prefer—and as is their right under this Court’s decision in *Olmstead v. L.C.*<sup>76</sup> and under the ACA. The prospect of allowing people with disabilities to routinely receive care in their homes or communities rather than institutions has particular poignancy now, when a disproportionate percentage of COVID-19 deaths originate in institutionalized populations.<sup>77</sup>

“LTSS” refers to a variety of health and social services that assist people with functional limitations caused by chronic conditions or disabilities to live independently in their homes and communities. LTSS includes assistance with activities of daily living (e.g., eating, bathing, and dressing) and instrumental activities of daily living (e.g., housekeeping, preparing meals, and managing medication). While LTSS can be provided informally

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<sup>75</sup> 2017 DSR, *supra* note 3, at 56.

<sup>76</sup> 527 U.S. 581 (1999).

<sup>77</sup> Chidambaram, *supra* note 33.

by unpaid caregivers such as family or friends, it may also be provided formally by paid caregivers.

Traditionally, LTSS was provided in an institutional setting (e.g., a nursing home), but there has been a shift to providing it in the individual's home or in community-based settings (e.g., personal care assistant may come to one's private home or a group home), so as to afford individuals the choice to live in their communities. Under the ADA, individuals with disabilities have the civil right to choose to receive LTSS in the community, rather than in an institutional setting, where appropriate.<sup>78</sup>

People with disabilities of all ages are the primary population served by LTSS.<sup>79</sup> Medicaid is the primary payer for LTSS as other public and private health insurers do not offer such coverage.<sup>80</sup> All states are

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<sup>78</sup> See *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 607 (1999); 42 U.S.C. § 12101 et seq.

<sup>79</sup> U.S. DEPT OF HEALTH & HUMAN SERVS., OFFICE OF THE ASSISTANT SEC'Y FOR PLANNING & EVALUATION, AN OVERVIEW OF LONG-TERM SERVICES AND SUPPORTS AND MEDICAID: FINAL REPORT 5 (2018), <https://aspe.hhs.gov/system/files/pdf/259521/LTSSMedicaid.pdf> ("LTSS and Medicaid Report").

<sup>80</sup> Erica L. Reaves & MaryBeth Musumeci, *Medicaid and Long-Term Services and Supports: A Primer*, KAISER FAMILY FOUND. 3 (Dec. 2015), <http://files.kff.org/attachment/report-medicare-and-long-term-services-and-supports-a-primer>; see also Emily Rosenoff et al., *An Overview of Long-Term Services and Supports and Medicaid: Final Report*, U.S. Department of Health and Human Services Assistant Secretary for Planning and Evaluation Office of Disability, Aging and Long-Term Care Policy (May 2018) <https://aspe.hhs.gov/basic-report/overview-long-term-services-and-supports-and-medicare-final-report> ("Medicaid is the primary payer of LTSS"); Kaiser Family Found., *Medicaid's Role in Meeting Seniors' Long-Term Services and Supports Needs* (Aug. 2, 2016) <https://www.kff.org/medicaid/fact-sheet/medicaids-role-in-meeting-seniors-long-term->

required to provide coverage under Medicaid for nursing facility services, but home and community based services (“HCBS”) coverage is optional.<sup>81</sup> Medicaid LTSS expenditures include services and supports for seniors and people with a wide range of physical, intellectual, developmental, and mental disabilities.<sup>82</sup>

The ACA provides new and expanded options for states to offer LTSS in home and community-based settings to Medicaid beneficiaries.<sup>83</sup> That option is not only preferred by most people with disabilities but is also more cost-efficient than institutional services.<sup>84</sup> A number of new programs created by the ACA expand eligibility for and provide increased access to home and community based care.

#### 1. State Plan Home and Community Based Services Option

States have had the option to include home- and community-based services in their state Medicaid

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services-and-supports-needs/ (“Medicaid is the nation’s primary payer for LTSS for people with low incomes and is likely to continue to play a key role as LTSS financing reforms are considered.”).

<sup>81</sup> LTSS and Medicaid Report, *supra* note 79.

<sup>82</sup> *Id.* at 1.

<sup>83</sup> See 42 U.S.C. § 1396n.

<sup>84</sup> See, e.g., Arpita Chattopadhyay et al., *Cost-efficiency in Medicaid Long-term Support Services: The Role of Home and Community Based Services*, 2 SPRINGERPLUS 1 (2013), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3710567/>; see also Mary Sowers, et al., *Streamlining Medicaid Home and Community-Based Services: Key Policy Questions*, KAISER FAMILY FOUND. (Mar. 11, 2016) <https://www.kff.org/medicaid/issue-brief/streamlining-medicaid-home-and-community-based-services-key-policy-questions> (noting “the typically lower cost of HCBS relative to institutional care”).



plans without a waiver since 2005. However, the ACA expanded financial eligibility for HCBS and allowed states to target specific populations for coverage.<sup>85</sup> States could provide full Medicaid benefits, as well as home and community based services, to individuals who are not otherwise eligible for Medicaid and who meet certain financial and functional eligibility criteria.<sup>86</sup> These provisions benefit children and adults with significant mental health needs and people with intellectual and developmental disabilities.

## 2. Community First Choice Option

The ACA also created the Community First Choice Option, which allows applicant states to provide home and community based services to Medicaid enrollees, and increased the federal share of funding available to participating states by 6%.<sup>87</sup> States can provide these services to individuals who are eligible for the state's Medicaid program and whose income does not exceed 150% of the federal poverty line. Alternatively, if the individual's income is higher than this threshold but the individual has been determined to require an institutional level of care and is eligible for nursing facility services, then the individual is also eligible for HCBS.<sup>88</sup>

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<sup>85</sup> 42 U.S.C. § 1396n.

<sup>86</sup> 42 U.S.C. § 1915(i). Under the ACA, states can cover: (1) people up to 150% of the federal poverty line with no asset limit who meet functional eligibility criteria and who will receive HCBS; and/or (2) people up to 300% SSI who would be eligible for Medicaid under an existing HCBS waiver and will receive state plan HCBS. Watts, *supra* note 72, at 9.

<sup>87</sup> 42 U.S.C. § 1396n(k).

<sup>88</sup> 42 U.S.C. § 1396n(k)(1).

For states with waiting lists of children in need of services, the ACA creates opportunities for them to expand their home and community care programs.<sup>89</sup> Five states have implemented the Community First Choice Option: California, Maryland, Montana, Oregon, and Texas.<sup>90</sup> Texas, for instance, now covers assistance with activities of daily living and household assistance, “habilitation” services that help people learn to accomplish daily living activities more independently, emergency response services, and service coordination in an individual’s home or community.<sup>91</sup>

The Medicaid waiver programs provide coverage for services, such as independent living skills, that are important for individuals with disabilities and can mean the difference between institutionalization or continuing to live in one’s home.<sup>92</sup> Invalidating the ACA would not only obscure the legal obligation for

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<sup>89</sup> Elizabeth Edwards, *Helping Those on HCBS Waiting Lists: Positive Impacts of the ACA*, NAT’L HEALTH LAW PROGRAM 4-5 (Feb. 14, 2017), <https://healthlaw.org/wp-content/uploads/2017/02/HCBS-ACA-WaitingListsFinal.pdf>; see also MaryBeth Musumeci, Priya Chidambaram, and Molly O’Malley Watts, *Questions About Medicaid Home and Community-Based Services Waiver Waiting Lists*, Kaiser Family Foundation (Apr. 4, 2019), <https://www.kff.org/medicaid/issue-brief/key-questions-about-medicaid-home-and-community-based-services-waiver-waiting-lists/>.

<sup>90</sup> Medicaid.gov, Community First Choice (CFC) 1915 (k), <https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/community-first-choice-cfc-1915-k/index.html> (last visited Apr. 22, 2020).

<sup>91</sup> Texas Health & Human Servs., Community First Choice, <https://hhs.texas.gov/services/health/medicaid-chip/programs-services/community-first-choice> (last visited May 4, 2020).

<sup>92</sup> Lindner et al., *supra* note 73, at 89.

states to meet the needs and expressed desires of disabled people, but would also decrease the options available for states to meet these obligations.<sup>93</sup> It would also eliminate federal statutory authority to approve and implement innovative programs that have provided much-needed LTSS to individuals with disabilities who are covered by Medicaid.

### C. Behavioral Health Parity

As set forth in Section III.D, behavioral health services were generally not covered by private health insurance.<sup>94</sup> The ACA expanded their availability by requiring behavioral health services to be included in Medicaid to the same extent as other medical benefits and to be provided to Medicaid-expansion adults and other adult populations.<sup>95</sup> This, too, is a substantial benefit to people with disabilities that invalidation of the ACA would remove.

\* \* \*

Taken together, the ACA's provisions have transformed the lives of people with disabilities. As Congress intended, the ACA has increased the availability of comprehensive health care, allowing those who previously did not have coverage to gain access to essential health services and supports. It has increased the affordability of coverage, significantly expanded access to and quality of services, and decreased healthcare disparities. Invalidating the ACA now would reverse all these gains and disproportionately harm an already marginalized group of Americans. Congress would

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<sup>93</sup> Edwards, *supra* note 89, at 4.

<sup>94</sup> Claxton et al., *supra* note 38.

<sup>95</sup> 42 U.S.C. § 1396u-7.

not have wanted to take away what it worked so hard to provide to people most in need. Therefore, should the Court deem the minimum-coverage provision invalid, it should sever it to preserve the remainder of the statute and the substantial benefits it provides to people with disabilities.

### CONCLUSION

For the foregoing reasons, *amici* respectfully suggest that the Court should reverse the holding of the Fifth Circuit.

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## **APPENDIX**

**INDIVIDUAL STATEMENTS  
OF INTEREST FOR *AMICI CURIAE***

**American Association of People with Disabilities.** The 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 over 60 million Americans with disabilities.

**American Civil Liberties Union.** The American Civil Liberties Union (ACLU) is a nationwide, nonprofit, nonpartisan organization with nearly 2 million members and supporters dedicated to the principles of liberty and equality embodied in the Constitution and our nation's civil rights laws. It is committed to an America free of discrimination against people with disabilities, where they are valued, integrated members of society with full access to education, homes, health care, jobs, and families. It files this brief to underscore the central importance of the Affordable Care Act in advancing those values.

**The ARC of the United States.** The Arc of the United States ("The Arc") is the nation's largest organization of and for people with intellectual and developmental disabilities ("I/DD"). The Arc promotes and protects the human and civil rights of people with I/DD and actively supports their full inclusion and participation in the community. The Arc has a vital interest in ensuring that all individuals with I/DD receive the protections and supports to which they are entitled by law.

**Association of University Centers on Disabilities.** The Association of University Centers



on Disabilities (AUCD) is a nonprofit membership association of 130 university centers and programs in each of the fifty States and six Territories. AUCD members conduct research, create innovative programs, prepare individuals to serve and support people with disabilities and their families, and disseminate information about best practices in disability programming, including community integration and prevention of needless institutionalization.

**Autism Society of America.** The Autism Society of America is the Nation's leading grassroots autism organization. It was founded in 1965 and exists to improve the lives of all affected by autism spectrum disorder. It does this by increasing public awareness and helping with the day-to-day issues faced by people on the spectrum and their families. Through its strong national network of affiliates, it has been a thought leader on numerous pieces of state and federal legislation.

**Autistic Self Advocacy Network.** The Autistic Self Advocacy Network (ASAN) is a national, private, non-profit organization, run by and for individuals on the autism spectrum. ASAN provides public education and promotes public policies that benefit autistic individuals and others with developmental or other disabilities. ASAN's advocacy activities include combating stigma, discrimination, and violence against autistic people and others with disabilities, promoting access to health care and long-term supports in integrated community settings, and educating the public about the access needs of autistic people. ASAN takes a strong interest in cases that affect the rights of autistic individuals to participate

fully in community life and enjoy the same rights as others without disabilities.

**Center for Public Representation.** The 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 over forty 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, including home and community based services under Medicaid. The Center has brought litigation in dozens of states across the country to expand access to Medicaid-funded home and community based services for people with disabilities, resulting in settlement agreements and court orders for statewide reforms of Medicaid-funded disability service systems. The Center also helps lead the disability community's advocacy to protect the Affordable Care Act and Medicaid. The Center is a national legal support center, providing training, and technical assistance to federally-designed protection and advocacy programs in each of the fifty states and territories under a contract with National Disability Rights Network.

**Disability Rights Education and Defense Fund.** The Disability Rights Education and Defense Fund (DREDF) is a national law and policy center that protects and advances the civil and human rights of people with disabilities through legal advocacy, training, education, and development of legislation and public policy. DREDF is committed to increasing accessible and equally effective health care for people with disabilities and eliminating persistent health

disparities that affect the length and quality of their lives.

**Disability Rights Legal Center.** The Disability Rights Legal Center (DRLC) is a non-profit legal organization that was founded in 1975 to represent and serve people with disabilities. Individuals with disabilities continue to struggle against ignorance, prejudice, insensitivity, and lack of legal protection in their endeavors to achieve fundamental dignity and respect. The DRLC assists people with disabilities in attaining the benefits, protections, and equal opportunities guaranteed to them under the Rehabilitation Act of 1973, the Americans with Disabilities Act, the Individuals with Disabilities Education Act, and other state and federal laws. Its mission is to champion the rights of people with disabilities through education, advocacy, and litigation. The DRLC is a recognized expert in the field of disability rights.

**Judge David L. Bazelon Center for Mental Health Law.** Founded in 1972 as the Mental Health Law Project, the Judge David L. Bazelon Center for Mental Health Law is a national non-profit advocacy organization that provides legal assistance to individuals with mental disabilities. Through litigation, public policy advocacy, education, and training, the Bazelon Center works to advance the rights and dignity of individuals with mental disabilities in all aspects of life, including community living, employment, education, health care, housing, voting, parental and family rights, and other areas. Expanding the availability of community-based mental health services has been central to the Center's mission and focus.

**Little Lobbyists.** Little Lobbyists is a family-led national organization founded in 2017 that advocates for children with complex medical needs and disabilities to have access to the health care, education, and community inclusion they need to survive and thrive. Medically complex children, by definition, have multiple pre-existing conditions. These children should not be denied access to health care because of unexpected increased premiums, annual/lifetime limits, or unaffordable health insurance as a result of their medical needs and disabilities. Through advocacy, education, and outreach, Little Lobbyists families share the stories of their children with complex medical needs and disabilities with policymakers, the media, and general public in order to show how real lives are impacted by laws and policies.

**Mental Health America.** Mental Health America (MHA) is the nation's leading community-based nonprofit dedicated to addressing the needs of those living with mental illness and promoting the overall mental health of all Americans. MHA's programs and initiatives fulfill its mission through advocacy, education, research and services. MHA's national office and its 200-plus affiliates and associates around the country work every day to protect the rights and dignity of individuals with mental health conditions and advocate for increased access to mental health services and supports.

**National Association of Councils on Developmental Disabilities.** The National Association of Councils on Developmental Disabilities (NACDD) is the national nonprofit membership association for the Councils on Developmental Disabilities located in every State and Territory. The

Councils are authorized under federal law to engage in advocacy, capacity-building, and systems-change activities that ensure that individuals with developmental disabilities and their families have access to needed community services, individualized supports, and other assistance that promotes self-determination, independence, productivity, and integration and inclusion in community life.

**National Association of the Deaf.** The National Association of the Deaf (NAD), founded in 1880, is the oldest civil rights organization in the United States, and is the nation's premier organization of, by and for deaf and hard of hearing individuals. The NAD is a non-profit membership organization with a mission of preserving, protecting, and promoting the civil, human and linguistic rights of 48 million deaf and hard of hearing individuals in the country. The NAD endeavors to achieve true equality for its constituents through systemic changes in all aspects of society including but not limited to education, employment, and ensuring equal and full access to programs and services. Serving all parts of the USA, the NAD is based in Silver Spring, MD. For decades, the NAD has advocated for equal access for deaf and hard of hearing people within the health care and health insurance systems.

**National Council on Independent Living.** The National Council on Independent Living (NCIL) is the oldest cross-disability, national grassroots organization run by and for people with disabilities. NCIL's membership is comprised of centers for independent living, state independent living councils, people with disabilities and other disability rights organizations. NCIL advances independent living and the rights of people with disabilities. NCIL

envision a world in which people with disabilities are valued equally and participate fully.

**National Disability Rights Network.** The National Disability Rights Network (NDRN) is the non-profit membership organization for the federally mandated Protection and Advocacy (P&A) and Client Assistance Program (CAP) agencies. The P&As and CAPs were established by Congress to protect the rights of people with disabilities and their families through legal support, advocacy, referral, and education. There are P&As and CAPs in all 50 states, the District of Columbia, Puerto Rico, and the U.S. Territories (American Samoa, Guam, Northern Mariana Islands, and the U.S. Virgin Islands) and the Native American Consortium which includes the Hopi, Navajo and San Juan Southern Piute Nations in the Four Corners.

**National Down Syndrome Congress.** Founded in 1973, the National Down Syndrome Congress is the leading national resource for advocacy, support, and information for anyone touched by or seeking to learn about Down syndrome, from the moment of a prenatal diagnosis through adulthood. A member-sustained, 501(c)(3) organization, representing the approximately 350,000 people in the United States with Down syndrome and their families, our programs provide individuals with Down syndrome the opportunities and respect they deserve so they can live the life of their choosing.

**National Federation of the Blind.** The National Federation of the Blind (NFB) is the oldest, largest and most influential membership organization of blind people in the United States. With tens of thousands of members, and affiliates in all fifty states, the District of Columbia, and Puerto Rico, the

ultimate purpose of the NFB is the complete integration of the blind into society on an equal basis. Since its founding in 1940, the NFB has devoted significant resources toward advocacy, education, research, and development of programs to ensure that blind individuals enjoy the same opportunities enjoyed by others. Due to the fact that many of its members have preexisting health conditions in addition to their blindness, full access on terms of equality to affordable health care is an important issue for the NFB.

**Paralyzed Veterans of America.** The Paralyzed Veterans of America (PVA) is a national, congressionally chartered veterans service organization headquartered in Washington, DC. PVA has nearly 17,000 members, all of whom are military veterans living with catastrophic disabilities. PVA's mission is to employ its expertise, developed since its founding in 1946, on behalf of armed forces veterans who have experienced spinal cord injury or a disorder (SCI/D). PVA seeks to improve the quality of life for veterans and all people with SCI/D through its medical services, benefits, legal, advocacy, sports and recreation, architecture, and other programs. PVA advocates for quality health care, for research and education addressing SCI/D, for benefits based on its members' military service and for civil rights, accessibility, and opportunities that maximize independence for its members and all veterans and non-veterans with disabilities.