



**DISABILITY POLICIES IN THE 21<sup>ST</sup> CENTURY:  
BUILDING OPPORTUNITIES FOR WORK AND INCLUSION**

House Energy and Commerce Committee Republicans  
Leader Cathy McMorris Rodgers

## EXECUTIVE SUMMARY

Energy and Commerce Republicans believe that more can be done to remove barriers that keep people with disabilities from living up to their full potential and contributing to their communities. We believe there are three priority areas on which to focus:

1. Ensuring access to long-term services and supports by eliminating waitlists for such care in Medicaid and making coverage options more affordable for those not covered by Medicaid;
2. Making communities and daily life more accessible for people with disabilities by supporting access to assistive technologies and enforcing accommodation requirements in the Americans with Disabilities Act (ADA) and section 504 of the Rehabilitation Act of 1973 (Section 504) in health care settings; and
3. Moving the workforce toward integrated employment by eliminating the subminimum wage for people with disabilities and providing supports and funding opportunities for accommodations in the workplace.

We welcome public comment on specific problems and solutions that Congress should address to improve the lives of those with disabilities.

## INTRODUCTION

The policies coming out of Washington, D.C. today threaten the ability of many Americans, and in particular those with disabilities, to reach their fullest potential. Instead of encouraging and supporting people with disabilities to live as independently as they are able, many of these policies make it more difficult to work or just easier not to work at all, due to the failures of a system that encourages poverty in exchange for access to key services and supports.

Work and engagement in one's community has strong associations with positive health outcomes. In part, these positive associations are driven by income and the increases in quality of life that come from having job security,<sup>1</sup> but having a job, attending school and other forms of community engagement also are associated with positive physical and mental health outcomes.<sup>2</sup>

As our economy recovers from the COVID-19 pandemic and Americans face high rates of inflation that threaten to undermine years of progress, Congress should reemphasize its commitment to reducing barriers to employment so that all Americans can have an opportunity to succeed. In doing so, Congress should prioritize efforts to support work and community engagement for those who have been forgotten in other economic advances, especially people with disabilities who experience unique challenges to participating in the work force. According to Bureau of Labor Statistics, only about 17.9% of people with disabilities were employed in 2020 compared to 61.8% of people without disabilities for that year. This equates to an unemployment rate of about 12.6% for people with disabilities for that year and about 7.9% for

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<sup>1</sup> Kim, von dem Knesebeck, "Is an Insecure Job Better for Health than Having No Job at All? A Systematic Review of Studies Investigating the Health-Related Risks of Both Job Insecurity and Unemployment - BMC Public Health", BioMed Central, September 29, 2015.

<sup>2</sup> Burton, Waddell, "Is Work Good for Your Health and Well-Being?", United Kingdom Department for Work and Pensions, 2006.

people without disabilities for that year. These trends for employment play out regardless of all demographic criteria, like age, race, and educational attainment, highlighting significant hurdles that people with disabilities face in participating in the workforce.<sup>3</sup>

America has led in efforts to address barriers to employment and inclusion in society for people with disabilities. The enactment of provisions like section 504 of the Rehabilitation Act of 1973 (Section 504), the Americans with Disabilities Act (ADA), and the Individuals with Disabilities Education Act (IDEA), have dramatically increased the opportunities for people with disabilities. However, employment and other opportunities for people with disabilities still lag and have even been exacerbated by the COVID-19 pandemic and its associated societal and economic fallout. This has caused many with disabilities to leave jobs because of preexisting medical conditions and lose supported employment services due to the risk of transmitting the virus.<sup>4</sup>

To continue improving the lives of people with disabilities, Congress must reevaluate our nation's safety net to ensure that it is working for those that need it and not holding them back from reaching their full potential. These programs are meant to ensure greater opportunities for independence and inclusion for people with disabilities, and central to the current system is Medicaid, a federal-state partnership that disproportionately provides health care services to people with disabilities. Covering an estimated 10 million people with disabilities,<sup>5</sup> or at least one in six of all people living with a disability,<sup>6</sup> Medicaid offers acute care services to those in need and offers a long-term care benefit, which helps beneficiaries remain independent and active in their communities and jobs. Medicaid's long-term care benefit, however, can be limited to either institutional settings or, for those that can get off waitlists, home and community-based services (depending on state decisions and budgets). Alternatively, for those who need long-term care and are not eligible for Medicaid, a private, long-term care insurance market exists, but the policies are expensive, and many individuals are better off paying out-of-pocket for their care or relying on loved ones to serve as caregivers. Without long term care services, people with disabilities can be isolated from their communities and loved ones, unable to pursue careers that would require additional support, or unable to get through their day.

Even when people with disabilities have the supports that they need to be active in their communities, the current landscape does not always accommodate their day-to-day needs. For instance, barriers to access to assistive technologies and inaccessible public spaces can make daily life difficult. Similarly, perverse laws, like the subminimum wage for people with disabilities, act as barriers for people with disabilities, preventing them from successfully participating in the workforce.

Energy and Commerce Republicans stand ready to solve problems that people with disabilities face. We want to learn about the challenges people with disabilities face and how we can address them to have the greatest positive impact. This will require learning from the successes and

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<sup>3</sup> Bureau of Labor Statistics, "Persons with a Disability: Labor Force Characteristics — 2020", February 24<sup>th</sup>, 2020.

<sup>4</sup> National Council on Disability, "2020 Progress Report on National Disability Policy: Increasing Disability Employment", Page 3, July 24, 2020.

<sup>5</sup> Medicaid and CHIP Payment and Access Commission, "Exhibit 14: Medicaid Enrollment by State, Eligibility Group, and Dually Eligible Status, FY 2019 (thousands)", MACStats: Medicaid and CHIP Data Book, 2010.

<sup>6</sup> Centers for Disease Control and Prevention, "Disability Impacts All of Us", CDC Disability and Health Infographics, September 16, 2020.

shortcomings of both Republican and Democratic policy proposals. The following outlines three major areas of focus:

1. Access to long-term services and supports,
2. Accommodations in the community, and
3. Barriers to integrated employment.

## **ACCESS TO LONG-TERM SERVICES AND SUPPORTS**

Long-term services and supports (LTSS) refers to a broad range of health and health-related services and supports needed by individuals for self-care due to a physical, cognitive, or mental disability or condition to help maintain or improve physical or social functioning and quality of life. LTSS includes a variety of services, ranging from services needed for bathing and dressing to modifying infrastructure to making buildings and homes more accessible to people with disabilities. Because of the personal and individual-specific nature of long-term care, there is also variety in where the services can be provided, ranging from community-based settings like homes to adult day cares or institutional settings like nursing homes.<sup>7</sup> There is no one-size-fits-all approach to LTSS, and thus the flexibility to receive the care that meets an individual's need is key to helping ensure their independence and ability to live an active life.

The need for LTSS is generally measured by the presence of functional limitations in the ability to perform basic personal care activities, known as activities of daily living (ADLs). ADLs refer to activities such as eating, bathing, using the toilet, dressing, etc. Similarly, instrumental activities of daily living (IADLs) may also be used to measure a person's need for LTSS. IADLs include activities such as preparing meals, managing money, shopping, housework, etc. It is estimated that 70% of individuals who reach the age of 65 develop limitations in ADLs that may result in a need for LTSS. As the population ages, the demand for LTSS is expected to increase.<sup>8</sup> For people with disabilities who struggle with ADLs, access to LTSS can be necessary for community engagement and work opportunities.

However, the ability to access LTSS varies significantly, and the cost of care is among the most significant barriers to access. The average out-of-pocket cost of LTSS depends on the level of care needed but ranges from an average \$47,836 per year for home health aide services, \$19,500 per year for adult day services, and as much as \$90,156 to \$102,204 per year for nursing home care.<sup>9</sup>

Most Americans who need LTSS in the U.S. rely on unpaid, family caregiving services or Medicaid for long-term care. If quantified, the value of these unpaid services would likely equal at least \$470 billion a year,<sup>10</sup> compared to Medicaid with an estimated \$180 billion a year in

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<sup>7</sup> Colello, "Overview of Long-Term Care Services and Supports", Congressional Research Service, December 30, 2019.

<sup>8</sup> Id.

<sup>9</sup> O'Neill Hayes and Kurtovic, "The Ballooning Costs of Long-Term Care", American Action Forum, February 18, 2020.

<sup>10</sup> RAISE Family Caregiving Advisory Council, "Recognize, Assist, Include, Support, & Engage (RAISE) Family Caregivers Act Initial Report to Congress", Page iv, September 22, 2021.

long-term care spending<sup>11</sup>. Other payers like Medicare and private insurance spend considerably less each year on long-term care services (around \$83 billion and \$33 billion, respectively<sup>12</sup>) due to these payers having either limited means to pay for long-term care, having restrictions on coverage for people with an existing disability, or offering long-term care products that are too expensive for the average American.<sup>13</sup> Given the importance of LTSS for people with disabilities, more must be done to address access to long-term care for Americans.

### **Access to LTSS Through Medicaid**

#### ***History and Background on Medicaid Coverage of LTSS***

Medicaid is the largest payer for long-term care in the U.S., paying for nearly half of all LTSS in the country and disproportionately covering the costs of care for people with disabilities.<sup>14</sup> Medicaid's role in covering long-term care has evolved dramatically since the program was established in 1965. Nursing home and institutional care was an original benefit of the program in 1965,<sup>15</sup> allowing for a growth in the availability of nursing home care through the 1960s and 1970s.<sup>16</sup> In 1981, Congress added home and community-based services (HCBS) waivers (section 1915(c) of the Social Security act) to the Medicaid program, giving states the option to cover LTSS under Medicaid in alternative, community-based settings as opposed to institutions or nursing homes.<sup>17</sup> The U.S. Supreme Court's decision in *Olmstead v. L.C.*, which held that the institutionalization of people who could be cared for in community settings was a violation of the ADA (as long as such resources are available), marked a tipping point in the country's efforts to deinstitutionalize long-term care and improve outcomes for people with disabilities in their communities.<sup>18</sup> Now accounting for over half of all spending by Medicaid on LTSS in the country, HCBS is vital to the goal of ensuring access to LTSS in communities.

LTSS through Medicaid, however, is contingent on the ability to meet statutory income and asset limits set by the states and the federal government. In most instances, eligibility for Medicaid coverage for seniors and people with disabilities is determined by eligibility for Supplemental Security Income (SSI), which limits total assets that a beneficiary can have to about \$2,000 for an individual and \$3,000 for married couples.<sup>19</sup> Over time though, Congress has seen the need for more flexibility to allow for further community engagement and work and has expanded opportunities to qualify for Medicaid. For example, the Katie Beckett Waiver excludes a parent's assets from a child's assets when considering a child with a disability's eligibility for Medicaid,<sup>20</sup> and buy-in pathways in the Ticket to Work and Work Incentives Improvement Act allow for

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<sup>11</sup> Colello, "Who Pays for Long Term Care Services and Supports?", Congressional Research Service, Pages 1-2, March 20, 2020.

<sup>12</sup> *Id.*

<sup>13</sup> *Id.*

<sup>14</sup> *Id.*

<sup>15</sup> 42 U.S.C. 1396a. State plans for medical assistance(9)(D).

<sup>16</sup> U.S. Congress, Senate Special Committee on Aging, *Developments in Aging, 1970*, S. Rpt. 92-46, Feb. 16, 1970, Washington, p. 42, cited from the American Nursing Home Association Fact Book, 1969-1970.

<sup>17</sup> 42 U.S.C. 1396n, § 1915.

<sup>18</sup> *Olmstead v. L.C. (Decided June 22, 1999)*.

<sup>19</sup> 42 U.S.C. 1382(a)(3)

<sup>20</sup> 42 U.S.C. 1396a(e)(2)

people with disabilities who work and have incomes that exceed traditional eligibility levels to remain eligible for Medicaid coverage if they pay premiums for their coverage.<sup>21</sup>

In addition to these pathways, Congress passed the Deficit Reduction Act of 2005 (DRA) to address the increasing need for long term care and continue improving access to care. DRA authorized states to offer certain additional HCBS services (section 1915(i) of the Social Security Act) and self-directed care (section 1915(j) of the Social Security Act) in a more flexible manner and established the Money Follows the Person Program (MFP) to provide funding for states to transition Medicaid beneficiaries from institutional settings to HCBS.<sup>22</sup> Additionally, DRA made a series of programmatic reforms to Medicaid to make sure it served those who truly need it by limiting eligibility only to those whose home equity is below \$500,000 and further limiting asset transfer rules.<sup>23</sup> The Affordable Care Act expanded section 1915(i) by establishing a new eligibility pathway for HCBS care. Under section 1915(i), individuals who earn up to 300% of the federal poverty limit (FPL), but do not meet the need threshold to qualify for institutional care, remain eligible for HCBS care.<sup>24</sup> Collectively, laws like these helped establish the current system that offers nearly two dozen eligibility pathways in Medicaid that states can offer for people with a disability to access LTSS.

### ***Barriers to Community & Work - Medicaid HCBS Waitlists***

While all forms of long-term care are essential to those who need it, access to HCBS care can be critical for people with disabilities, who would otherwise be able to live independently but for limitations on ADLs. In many instances, HCBS can bridge the gap towards independence for people with disabilities so that they can be employed and active in their communities.

*“A HCBS waiver has made it possible to be married to my bride while raising my two extraordinary daughters and providing for them financially. Even more than that, it has been a vital part of me realizing my potential, self worth and dignity as a human being.”*

*- Shawn Murinko, Spokane, WA.*

Medicaid, however, only requires coverage of long-term care in nursing homes and other institutional settings. HCBS care remains an optional service for states (this is commonly referred to as Medicaid’s “institutional bias”).<sup>25</sup> Nonetheless, there are several options for states to offer home and community-based services as an alternative to institutional care for Medicaid beneficiaries. Section 1915(c) allows for states to waive the requirement to cover institutional care and instead offer HCBS in a budget neutral manner. Additionally, states are permitted to offer HCBS care through optional pathways, such as the waivers available under section 1115, section 1915(i), section 1915(j), and section 1915(k).<sup>26</sup>

As an optional benefit, HCBS care is sometimes rationed or made available through waitlists so that states can manage their budgets and other federal Medicaid requirements. While a common practice, there are no statutory or regulatory requirements that define or describe waitlists. Nonetheless, according to the Congressional Research Service (CRS), 35 states reported having

<sup>21</sup> 42 U.S.C. 1396a(a)(10)(A)(ii)(XV) and 42 U.S.C. 1396d(v)

<sup>22</sup> Public Law No: 109-171, The Deficit Reduction Act of 2005, § 1915(i), § 1915(j).

<sup>23</sup> Public Law No: 109-171, The Deficit Reduction Act of 2005.

<sup>24</sup> Public Law No: 111-148, The Patient Protection and Affordable Care Act of 2010.

<sup>25</sup> 42 U.S.C., 1396a. State plans for medical assistance(9)(D).

<sup>26</sup> 42 U.S.C. 1315 and 42 U.S.C. 1396n

waitlists; 12 states and D.C. reported no such lists. The average wait time across all programs was just over 2 years. However, the average length of time an individual may spend on a waiting list varies by population and ranged from 4 months (people with HIV/AIDS) to 43 months (people with intellectual and developmental disabilities (I/DD)).<sup>27</sup> Furthermore, a disproportionate number of those on waiting lists are people with I/DD. People with I/DD constitute the highest per enrollee spending for section 1915(c) waivers, indicating there may be a connection between overall wait times and the costs of care for a waitlisted beneficiary.<sup>28</sup>

The trend for waitlists over time has only gotten worse, with waitlists growing by an estimated 10% each year. Among different populations, however, this trend varies. For those with I/DD, the rate continues to grow by 25% each year, while the waitlists for those with traumatic brain injuries has decreased by almost 51%.<sup>29</sup>

Waitlists are also a barrier for those living and receiving care in one state but wanting to move to another state where they would have to reenter a waiting list. These types of policies vary by state but can impact any beneficiary who needs to move across state lines, even if such a move is necessary for a job, medical care, or a required military relocation to a different duty station.<sup>30</sup> Waitlists are a prime example of how the safety net, over time, has failed to help those that need it most. Energy & Commerce Republicans want to reform access to LTSS and work to end waitlists in a fiscally responsible way that maintains the state-federal partnership that has been a hallmark of the Medicaid program.

## Requests for Information

### 1.1 Regarding Medicaid's institutional bias:

- A. How can Congress reduce or eliminate the institutional bias in Medicaid?
- B. What tools can Congress give to the Federal Government and states to help them enact policies to reduce or eliminate the institutional bias in Medicaid in the most cost-effective way? In your answer, please also address whether phasing in specific HCBS services as mandatory benefits over time or phasing in eligibility for such services by specific populations over time would be cost-effective solutions.
- C. Should waitlists be eliminated for certain classes of beneficiaries immediately (such as military or veteran families with disabled children) while other waitlist reforms are implemented over a longer period of time?
- D. Please provide any relevant data regarding the characteristics of waitlist populations, the costs of those individuals, and any other data relevant to waitlist reform.

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<sup>27</sup> Colello, "Waiting Lists in Medicaid Section 1915(c) Waivers", the Congressional Research Service, Pages 1-2, March 21, 2017.

<sup>28</sup> O'Malley Watts, Musumeci, Chidambaram, "Key State Policy Choices About Medicaid Home and Community-Based Services", Kaiser Family Foundation, 2020.

<sup>29</sup> O'Malley Watts, Musumeci, Chidambaram, "Key State Policy Choices About Medicaid Home and Community-Based Services", Kaiser Family Foundation, 2020.

<sup>30</sup> Military State Policy Source, "Allow Service Members to Retain their Earned Priority for Receiving Medicaid Home and Community-Based Services Waivers", 2020.

## ***Barriers to Community & Work – Out of Date Asset Limitations with Loopholes***

Key to accessing HCBS waitlists and other services in Medicaid is a state’s ability to balance demand for care with the available supply of such services. Medicaid coverage (albeit with waitlists for some care, like HCBS care) is available to anyone who qualifies for the program, including multiple pathways for seniors and people with disabilities who may need access to LTSS. The eligibility limits on assets, however, can be either too broad, allowing relatively wealthier individuals (who are not traditionally Medicaid beneficiaries) to receive Medicaid coverage, or too narrow, preventing those most in need from receiving care. Congress has tried to address this inequity through laws like the DRA, excluding the wealthy from accessing Medicaid coverage by limiting the types of assets that individuals can own and still qualify for the program and penalizing those who try to hide their assets to gain coverage.

*“I was fortunate to be able to go from part-time to full time and get off of SSI. Many people aren’t able to do that because of their need for Medicaid. We shouldn’t be punished for wanting to work.”*

*- Debbie Melideo, Spokane,  
WA, Advocate*

Generally, Medicaid will disregard an individual’s car or home when reviewing assets. In addition, Medicaid often ignores assets owned by a spouse (the “community spouse”) if the individual would otherwise qualify for Medicaid on their own to access LTSS.<sup>31</sup> These rules are intended to protect individuals from becoming homeless in order to qualify for Medicaid, but they can be gamed by wealthier individuals who are not intended to qualify for Medicaid.

For example, under current law, individuals are not eligible for assistance if their equity interest in their home exceeds limits established in 2005, which are between \$500,000 to \$750,000.<sup>32</sup> However, these limits do increase with inflation. Today, the limitations are between \$600,000 to \$900,000.<sup>33</sup> Similarly, in 2014, the Government Accountability Organization (GAO) found that individuals could shield their assets by transferring them to family members or community spouses in the form of annuities, promissory notes, or personal care service contracts – all of which can be excluded when determining an individual’s assets.<sup>34</sup>

By contrast, the \$2,000 asset limitation for individuals and \$3,000 limit for married couples for SSI eligibility does not grow with inflation.<sup>35</sup> To remain eligible, an individual’s wealth (in real terms) must continue to diminish, even as inflation increases, in order to remain qualified for coverage and must be reduced if a qualifying couple chooses to get married (with the latter policy colloquially referred to as the “marriage penalty,” due to financial implications for people with disabilities associated with getting married rather than remaining single). Additionally, Medicaid requires states to pursue estate recovery after a beneficiary’s death on any asset from an individual who received LTSS through Medicaid, even if the asset was permissible under the

<sup>31</sup> Kaiser Family Foundation, “Medicaid Financial Eligibility for Seniors and People with Disabilities: Findings from a 50-State Survey”, June 14, 2019.

<sup>32</sup> 42 U.S.C. 1396p(f)

<sup>33</sup> Colello, “Financing for Long-Term Services and Supports (LTSS) in the United States: Overview, Medicaid History (1960s to 1990s), and Legislative Activity Since 2005”, Congressional Research Service, October 21, 2021.

<sup>34</sup> Government Accountability Office, “Financial Characteristics of Approved Applicants and Methods Used to Reduce Assets to Qualify for Nursing Home Coverage”, 2014.

<sup>35</sup> 42 U.S.C. 1396a(e)(2)



program.<sup>36</sup> The Medicaid and CHIP Payment and Access Commission (MACPAC) has recommended that this practice should be optional to discourage the targeting of assets of lower-income families.<sup>37</sup>

Given these stricter asset limits like those tied to the SSI eligibility pathways, the need to shield assets for individuals who may make slightly more than the qualifying amounts may be essential for a person with a disability to maintain access to LTSS. For example, accounts like ABLE accounts or Qualified Income Trusts, where deposits can be tax-exempt or disregarded for purposes of calculating income for Medicaid, can be useful tools to help people with disabilities to work and save for the future while also maintaining access to Medicaid's LTSS.

In particular, the recent success of ABLE accounts over the past decade shows the tremendous need for people with disabilities to have a means to work and save for the future with an estimated 75,000 people with disabilities holding an account with an average of \$6,000 saved and invested in each account.<sup>38</sup> This translates to about \$550 million or more saved by people with disabilities, with an estimated \$100 million of this having been spent on disability-related expenses.

Tighter eligibility standards are key to ensuring that Medicaid remains available to those in need without bankrupting states, but it's also become clear that standards that are too rigid for low-income Americans undercuts access to important care and stymies the ability to work, thus necessitating additional government interventions like the transformative ABLE accounts. In the coming years, it will be fundamental for Congress to reconsider how to balance these asset rules and how eligibility should be determined going forward.

### **Requests for Information:**

1.2 Medicaid is an essential program for those in need, and it should remain available only to those that need it. In regard to ensuring that Medicaid can remain available to just those that need it:

- A. What should Congress consider as we examine the current, allowable home equity amounts permitted by the DRA to qualify for Medicaid? Should Congress consider capping home equity values at \$500,000 (in 2005 dollars)? Should Congress consider resetting the \$500,000 to \$750,000 limit to 2022 dollars or some other level? Please provide any information on the impact of these changes or alternatives that will ensure Medicaid for those who need it.
- B. What steps should Congress consider to prevent wealthy individuals from shielding assets in order to qualify for Medicaid (including but not limited to the means highlighted in the 2014 GAO report, like exploiting annuities and promissory notes to shield gifts to family members)?

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<sup>36</sup> 42 U.S.C. 1396p(b)

<sup>37</sup> Chapter 3: Medicaid Estate Recovery: Improving Policy and Promoting Equity”, Report to Congress on Medicaid and CHIP, March 2021.

<sup>38</sup> Kennedy Miranda, “ABLE Act: What You Need to Know”, Social Security Administration, 2020, <https://blog.ssa.gov/able-act-what-you-need-to-know/#:~:text=As%20of%20the%20third%20quarter,save%20for%20their%20future%20needs.>

- C. What considerations should Congress consider when examining asset limits tied to SSI, like its lack of an inflation growth rate and marriage penalty?
- D. MACPAC recommends making estate recovery optional. The Committee is interested in feedback on this and other options to mitigate the burden of estate recovery for states and the families of beneficiaries. Please provide comments and data on the impact of this and similar proposals.
- E. Are there means to shield certain assets, like ABLE Accounts and Qualified Income Trusts, that Congress should consider expanding or making more flexible so that more beneficiaries can utilize them?

### ***Barriers to Community & Work – Complicated Pathways for Eligibility***

While Medicaid is reserved for those with low incomes, it does not need to be a program that holds people down in extreme poverty. Congress has taken steps over the past fifty years to develop additional eligibility pathways that allow for people with disabilities to maintain access to Medicaid’s LTSS at higher resource levels, as opposed to staying below SSI’s \$2,000 asset threshold. Today, there are over 20 potential pathways for eligibility for Medicaid for people with disabilities.<sup>39</sup> Of note are pathways through SSI, which allow those receiving SSI to also qualify for Medicaid coverage, the Ticket To Work eligibility pathway, which allows for people with disabilities to work and receive income above traditional Medicaid thresholds and pay premiums to maintain coverage as opposed to simply losing coverage, and the section 1915(i) pathway, which allows states to enroll people with disabilities into Medicaid at income levels up to 300% of the Federal Poverty Level (FPL) without asset limits.

Each eligibility pathway is unique, with different asset and income rules and thresholds, providing different opportunities for different populations to gain coverage. The results have been successful, with an estimated two-thirds of all people with disabilities on Medicaid qualifying for reasons beyond SSI coverage, which has helped move people with disabilities away from poverty and the low asset levels needed to qualify for SSI.<sup>40</sup>

*“My name is Christine Brown. I am a Clinical Research Assistant and Self Advocate Faculty at Ohio State University Nisonger Center and I have a disability. I like working because I like staying busy and like helping the community and being a tax paying Citizen. Once I turn 65, I will be forced to either quit work and keep my health care coverage, or to keep working and lose my health care coverage. The fact that I will be forced into a decision to leave the work I enjoy and due to an arbitrary age limit being forced to quit is wrong. Working is very important to me, but so is my health care coverage (that I help pay for). If the age limit is not removed, I will be at risk of losing the health care services that I need. I should be able to work for as long as I want to, without having to either sacrifice my health care coverage or my job.”*

*- Christine Brown, Cincinnati, OH*

However, the growing number of eligibility pathways has become a confusing patchwork to beneficiaries and case workers. For example, while 46 states have buy-in eligibility pathways, there is a significant gap between those eligible for the Ticket To Work eligibility pathway and those actually utilizing the pathway in most states. Many individuals currently enrolled in Medicaid through eligibility pathways with lower asset and income thresholds were unaware that

<sup>39</sup> Improving Opportunities for Working People with Disabilities”, Bipartisan Policy Center, January 2021

<sup>40</sup> Id.

there were opportunities to work and keep their Medicaid coverage.<sup>41</sup> Similarly, 18 states offer the state plan option services under section 1915(i), but only two states utilize the section 1915(i) eligibility pathway that was established by the ACA.<sup>42</sup> Caseworkers and government officials also may not understand the array of eligibility pathways that are available to potential beneficiaries, limiting the ability of beneficiaries to pursue more opportunities while maintaining Medicaid coverage.

The complexity of eligibility pathways can be challenging for beneficiaries, Congressional efforts to address this problem through additional pathways for people with disabilities can lead to even more confusion. Congress must ensure that all existing eligibility pathways are fully utilized and streamlined before creating new pathways.

### **Requests for Information:**

1.3 In regard to ensuring that Medicaid beneficiaries can better utilize the existing eligibility pathways, so that people with disabilities are not held back by bureaucracy and red tape:

- A. Should Congress reevaluate the asset eligibility requirements for SSI that allow for Medicaid eligibility? If Congress takes this approach, are there certain SSI-eligible populations, like those with I/DD, that should be exempted from SSI's eligibility thresholds?
- B. Should Congress keep the SSI eligibility pathway for Medicaid beneficial to people with disabilities or are other, existing pathways better suited to supporting the needs of people with disabilities? Please provide further information on the value of SSI benefits for people with disabilities relative to those gained by using alternative eligibility pathways that may otherwise allow for people with disabilities to have higher levels of income and assets.
- C. How can Congress revitalize and incentivize the Ticket to Work eligibility pathway? Should Congress update the law to allow those over 65 to participate? How can Congress streamline eligibility pathways and raise awareness and use of this option so that more beneficiaries who want to work can better utilize it?
- D. How can Congress use existing eligibility pathways to support people with disabilities? How can Congress streamline pathways to reduce confusion among beneficiaries and their family members and case workers? Instead of expanding eligibility to new beneficiary groups or increasing resource levels, how can Congress simplify eligibility pathways for states and beneficiaries so that they can more easily take advantage of the existing opportunities that may be available for them?

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<sup>41</sup> Gavin, B & McCoy-Roth, M., Gidugu, V., "Review of Studies Regarding the Medicaid Buy In Program", *Center for Psychiatric Rehabilitation*, 2011.

<sup>42</sup> Colello, "Financing for Long-Term Services and Supports (LTSS) in the United States: Overview, Medicaid History (1960s to 1990s), and Legislative Activity Since 2005", Congressional Research Service, October 21, 2021.

## *Access to LTSS Through Private Long-Term Care Insurance*

### *History and Background on Private Long-Term Care Insurance (LTCI)*

Nearly half of all coverage for LTSS in the United States is covered by Medicaid. Less than 10% of all long-term coverage payments are made through private plans and coverage.<sup>43</sup> This is in stark contrast to private health care insurance coverage, which accounts for a majority of all health insurance coverage provided in the United States.<sup>44</sup> Long-term care insurance (LTCI) also is not available to those that currently need LTSS.

Private health care insurance mechanics are somewhat similar to those of private LTCI. In both instances, insurers rely on developing risk pools where all individuals pay premiums to support care for those who need it, but healthy individuals disproportionately offset the costs of those needing care. In both instances, the larger the risk pool (and more importantly, the larger the population of healthy individuals in the risk pool), the lower the premiums are for everyone.

The differences between the systems for health care insurers and long-term care insurers lead to the challenges each industry has in attracting healthy individuals and creating stable risk pools. In the health insurance market, albeit with significant federal subsidization, more Americans choose to purchase health care insurance. This demand helps to attract healthy individuals to coverage and helps maintain a healthy market for health insurance.

Long-term care, however, is disproportionately needed by seniors and people with disabilities, as opposed to the broader population. Because the need for long-term care grows considerably as people reach age 65,<sup>45</sup> there is little demand from younger Americans concerned about an unlikely injury or disease requiring LTSS. The exception to this, however, is for younger Americans born with disabilities who may need LTSS throughout their lives. Because of this, risk pools for LTCI are much smaller than those for health insurance and much more likely to be comprised of older individuals and people with disabilities who either already need the services or may soon need such care. This causes high premiums for LTCI, with average premiums reaching \$150 to \$250 per month in 2020, discouraging healthier individuals from participating in the LTCI market. Instead, the high premiums encourage Americans to find alternate sources of long-term care coverage (either through Medicaid, family caregivers, or just paying out of pocket).

Additionally, the nature of the LTCI product itself differs from health care insurance because it can be tailored to meet the needs of individuals. The questions that an individual must answer when selecting an LTCI plan include: what specific daily benefit amount does the individual want the plan to pay out per day, does the individual want to purchase inflation protection (the cost of the daily benefit will increase by the time the individual needs to utilize the coverage<sup>46</sup>),

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<sup>43</sup> Colello, “Who Pays for Long Term Care Services and Supports?”, Congressional Research Service, Pages 1-2, March 20, 2020.

<sup>44</sup> Centers for Medicare and Medicaid Services, “NHE Fact Sheet”, CMS.gov, 2020.

<sup>45</sup> Colello, “Overview of Long-Term Care Services and Supports”, Congressional Research Service, December 30, 2019.

<sup>46</sup> Id.

how long does the individual want the daily benefit to be paid, and what is the length of coverage that the individual will need care, taking into account that some LTCI plans have waiting periods before care can begin.<sup>47</sup> Finally, LTCI plans can underwrite care and either charge different premium amounts based on an individual's initial health profile upon plan selection or even deny coverage if the individual is otherwise considered.<sup>48</sup> Together, the uncertainty over the need for care and the risks of medical underwriting can make LTCI even less attractive to healthier individuals, thus further exacerbating the risk issues for these markets.

Congress has tried to make LTCI more accessible, but those efforts either have not made significant improvements or have failed and had to be repealed. For example, in 1992, Congress established the Medicaid Long-Term Care Partnership Program, which allows for individuals to shield resources for purposes of Medicaid eligibility in amounts equal to the value of a LTCI plan that the individual owns. The program was designed to encourage individuals to pursue private LTCI first and only use Medicaid as a last resort if they use up their LTCI policy. The Partnership Program began as a compact among states that initiated the demonstration in the 1980s to create a bridge between Medicaid and LTCI. Congress aimed to expand further the use of these Partnership programs in the Omnibus Reconciliation Act of 1993 and the DRA by streamlining the process for establishing a Partnership program within a state, standardizing the resource disregard rules for qualifying plans, and clarifying what counts as a qualified LTCI under the program.<sup>49</sup> Today, Partnership plans account for at least 10% of all LTCI plans on the market, with that rate growing over time as more states adopt the program. Participation in Partnership plans, however, has been held back by limited awareness of the program and a lack of preparation for long-term care needs by seniors.<sup>50</sup>

Additionally, in 1996 with the passage of the Health Insurance Portability and Accountability Act (HIPAA), Congress established inflation protections for LTCI benefits at a rate of not less than 5%, in order to protect an individual's policy against the potential of inflation eroding the value of the purchased benefit. While inflation has now exceeded 9%, inflation was low for the last two decades. Thus, instead of mitigating the effects of inflation, these policies drove up the price of coverage without much benefit to beneficiaries.

Finally, the last major effort, and subsequent failure, of the past thirty years to support a LTCI market came in the Affordable Care Act (ACA). The Community Living Assistance Services and Supports (CLASS) Act was established in the ACA to provide a financing mechanism for LTSS for individuals with private, employer-sponsored insurance.<sup>51</sup> Established as Title XXXII of the Public Health Service Act (PHSA), the CLASS Act called for a process for the Secretary of the Department of Health and Human Services (HHS) to develop a program to provide a cash benefit that eligible enrollees with private insurance could use to purchase various LTSS (home modifications, assistive technology, accessible transportation, etc.).<sup>52</sup>

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<sup>47</sup> Id.

<sup>48</sup> Id.

<sup>49</sup> P.L. 103-66

<sup>50</sup> "Rising Demand For Long-Term Care Services and Supports For Elderly People", Congressional Budget Office, 2013, p. 29, <https://www.cbo.gov/sites/default/files/cbofiles/attachments/44363-LTC.pdf>

<sup>51</sup> Colello, Mulvey, "Community Living Assistance Services and Supports (CLASS): Overview and Summary of Provisions", Congressional Research Service, Pages 1-21, February 13, 2013.

<sup>52</sup> Id.

However, the CLASS Act’s implementation quickly fell apart due to failures in its design, which required flat rates and heavy subsidization of premiums for low-income recipients, raising significant concerns about the long-term sustainability of the program. Following actuarial analysis by HHS, it became apparent that the program could not be implemented. As a result, HHS informed Congress that the Department did not see a viable path forward for implementation that could meet the statutory requirements of the law to keep premiums for coverage at affordable rates, meaning the law needed to be repealed.<sup>53</sup> The CLASS Act was officially repealed in the 112th Congress by the American Taxpayer Relief Act of 2012, concluding the last major reforms enacted by Congress to LTCI.<sup>54</sup>

Since then, most efforts to expand access to LTCI have occurred through private market innovation and the development and adoption of new forms of private coverage options. Of note has been the rise of combination plans, offered by life insurers or through annuities, that allow for policy holders to use a life insurance policy to also cover long-term care costs. Given the association with life insurance, more Americans are familiar with and may be inclined to purchase these combination plans. Individuals also avoid the use-it-or-lose-it nature of LTCI, where remaining benefits in LTCI cannot be passed on to others after death, since the value for the plan can also be used for life insurance.<sup>55</sup> In 2018, over 400,000 combination policies were sold, marking a fourfold increase in the number of policies sold just four years prior in 2014. In that same year, these products totaled over \$4 billion in premiums and accounted for 87% of all new LTCI policy purchases.<sup>56</sup>

### ***Barriers to Community & Work – Unaffordable Long-Term Care Options***

Decisions around long-term care needs are personal. Every American should have the opportunity to pick the care that is right for them. Some may choose direct support professionals to assist with daily care needs, or nursing home or congregate care, and others may choose to rely on a family caregiver for daily help. However, even for those who may want LTCI, average Americans cannot afford care without relying on Medicaid (in 2021, premiums for seniors ranged as high as \$150 to \$250 a month,<sup>57</sup> and the average out-of-pocket cost for personal care aide services was \$47,836<sup>58</sup>).

*“I worry about my future and the future of those I care about with disabilities. I want to live a long, healthy life but long-term care options are expensive and complicated.”*

*- Kayla McKeon, NY,  
Self-Advocate with Down syndrome*

Furthermore, even for those who might be able to afford LTCI coverage, a private plan may not be feasible. People born with disabilities, like those with I/DD, cannot necessarily be insured under the current models for LTCI because the likelihood that they may need some degree of services delivered in any given year is high. Because of this, LTCIs are permitted to underwrite

<sup>53</sup> Id.

<sup>54</sup> Id.

<sup>55</sup> Mnuchin, Faulkender, “Long-Term Care Insurance: Recommendations for Improvement of Regulation”, U.S. Department of the Treasury, August 2020

<sup>56</sup> Id.

<sup>57</sup> “Long-Term Care Insurance Policy Costs- 21”, American Association for Long-Term Care Insurance, 2022.

<sup>58</sup> “Cost of Care Survey”, Genworth, 2021.

care and either charge different premium amounts based on an individual’s health profile or even deny coverage if the individual is otherwise considered uninsurable.<sup>59</sup> Changing those rules could destabilize the market further so that LTCI becomes unaffordable for any American who wants LTCI coverage.

Regardless of the ability to be covered though by LTCI, there are few federal incentives to support LTCI coverage. While Congress has established several incentives to purchase private health insurance, such as tax-exempt accounts like Health Savings Accounts (HSAs), and special tax treatment opportunities like the medical expense deduction and the exclusion for employer-sponsored insurance, there is no equivalent support for those who want to purchase LTCI coverage. This unequal landscape denies opportunities for people with disabilities, who might not necessarily be insurable by LTCI, with fewer other options to afford LTSS beyond limited means to utilize the medical expense deduction to offset both the costs of LTCI premiums and the delivery of LTSS,<sup>60</sup> and limited means to use HSAs, which can only be used to pay for long-term care costs if a patient is chronically ill, has the services prescribed by a doctor, and are medical (as opposed to allowing for home accommodations).<sup>61</sup> Nonetheless, these options either fail to provide more affordable alternatives to pay for LTSS, since they either limit the means to pay for services in a tax-exempt manner or, as is the case with the medical expense deduction, are disproportionately used by top income earners.

Additionally, the regulatory landscape discourages the development of more affordable LTCI coverage options. HIPAA rules fixed inflation requirements for LTCI at 5%, forcing upward pressures on costs for LTCI plans even though inflation has been low for the past twenty years.<sup>62</sup> Similar rules in the DRA require Partnership plans also to have inflation protection policies, while other rules in the DRA for Partnership plans limit the types of policies that can qualify under the program, pushing consumers into plans they may not want and at higher costs.<sup>63</sup>

### ***Barriers to Community & Work – Red Tape Stifling Innovation***

While most Americans do take active steps to plan for their futures and retirements, including setting aside funds for retirement in 401(k) plans and Individual Retirement Accounts (IRAs) and purchasing life insurance policies, few Americans take the steps to prepare for a potential need for long-term care. Even though premiums and the likelihood of denial for coverage increases as one ages, 10% of individuals ages 60-64 have LTCI coverage

*“When I needed to go to assisted living, I was fortunate enough to have my long-term care insurance and to have savings to help me pay for the care. I don’t know what I would have done if I hadn’t been able to save for this.”*

*- Alice Horn, Cincinnati, OH, Advocate*

<sup>59</sup> Colello, “Overview of Long-Term Care Services and Supports”, Congressional Research Service, December 30, 2019.

<sup>60</sup> Internal Revenue Service, “Topic No. 502 Medical and Dental Expenses”, IRS.gov, 2022, <https://www.irs.gov/taxtopics/tc502#:~:text=You%20figure%20the%20amount%20you,or%20function%20of%20the%20body.>

<sup>61</sup> Id.

<sup>62</sup> U.S. Department of the Treasury, “Long-Term Care Insurance: Recommendations for Improvement of Regulation”, Report of the Federal Interagency Task Force on Long-Term Care Insurance, 2020.

<sup>63</sup> Id.

compared to nearly 20% of individuals ages 80-84 with LTCI coverage.<sup>64</sup>

Creating a more sustainable LTCI market will require Americans to plan for futures that may include the need for LTSS. That planning should include consideration of opportunities to leverage other retirement planning avenues, like life insurance policies or 401(k)s, to cover the costs of LTSS. Organizations like the National Association of Insurance Commissioners (NAIC) also have taken steps to develop state regulatory models to encourage the uptake of other forms of long-term care coverage, as a way to push the innovation of new models further.<sup>65</sup>

Participation in combination plans and other types of coverage, like short-term coverage, however, are stymied by red tape. While 401(k)s and IRAs can be used to pay for retirement needs like long-term care, the need for long-term care may occur prior to retirement. In the event that an individual wants to use retirement savings prior to age 65, there are tax penalties for using savings, even when those savings may be necessary to pay for LTSS to keep an individual in the workforce and out of retirement.<sup>66</sup> Additionally, barriers to innovation are stifled by federal regulations that do not align with state level models<sup>67</sup> and by federal rules for the Partnership Program, which exclude combination plans and short-term plans from qualifying as eligible long-term care coverage if the policy doesn't meet the definition of a federally tax-qualified long-term care policy.<sup>68</sup>

### **Requests for Information:**

1.4 In order to increase uptake of LTCI among seniors and those who may benefit from such coverage and to reduce the costs of long-term care for those that do not qualify for Medicaid:

- A. Current law limits the ability to use tax-exempt accounts, like HSAs, for covering long-term care, only allowing for them to pay medical needs associated with long-term care. Should Congress expand the opportunity for HSAs and other tax-exempt accounts to be used in long-term care?
- B. If Congress considered expanding the use of tax-exempt accounts for long-term care coverage, should Congress consider limitations to the scope of potential services that such tax-exempt accounts can cover? Should Congress consider differentiating between the ability to use such accounts for one-time payments, like those for home modifications, as opposed to recurring payments, like those for the actual delivery of services?
- C. Should Congress repeal federal inflation protection requirements for LTCI plans, therefore allowing for states to set inflation protection rules?

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<sup>64</sup> Id.

<sup>65</sup> National Association of Insurance Commissioners, “Long-Term Care Insurance Model Act”, 2017.

<sup>66</sup> Internal Revenue Service, “Retirement Topics – Exceptions to Tax on Early Distributions”, IRS.gov, 2021, <https://www.irs.gov/retirement-plans/plan-participant-employee/retirement-topics-tax-on-early-distributions#:~:text=Generally%2C%20the%20amounts%20an%20individual,tax%20unless%20an%20exception%20applies.>

<sup>67</sup> National Association of Insurance Commissioners, “Long-Term Care Insurance Model Act”, 2017.

<sup>68</sup> 42 U.S.C. 1396p(b)



- D. Should Congress permit holders of retirement accounts like 401(k)s or IRAs to withdraw savings early to pay for LTCI premiums and other LTSS needs without early withdrawal tax penalties?
- E. If Congress considers permitting holders of retirement accounts, like 401(k)s or IRAs, to withdraw savings early to pay for long-term care, should Congress consider limitations on the scope of potential services for which such withdrawals may be used? For example, should Congress consider whether to differentiate between the ability to use such withdrawals for one-time payments, like those for home modifications, as opposed to recurring payments, like those for the actual delivery of services?
- F. Should Congress allow short-term plans and other combination policies under LTCI plans under the Partnership Program?
- G. Should Congress require the Department of the Treasury to update existing regulations for LTCI to be better aligned with models like the NAIC's LTCI models that may otherwise be out of sync with state regulations?

### **Access to LTSS Through Family Caregiving**

#### ***History and Background on Family Caregiving***

The bulk of long-term care in the United States is delivered by family caregivers, largely in an unpaid fashion. The value of these services may be as high as \$470 billion per year.<sup>69</sup> According to the Administration for Community Living, over 53 million people, or 1 in 7 Americans, support the health and quality of life of a loved one each year by serving as family caregivers in various capacities, disproportionately supporting those who do not otherwise have coverage for LTSS.<sup>70</sup> The needs for these 53 million Americans vary significantly. Ultimately, however, the challenges of supporting these populations are the same, relying on unpaid, and sometimes untrained, caregivers taking time out of their day, and potentially even missing work and sacrifice wages, in order to care for a loved one in need.

The aging population drives much of the demand for this care, and as the number of seniors in America continues to grow, the need for family caregivers or paid LTSS will increase over time. By 2040, there will be twice as many seniors in the country as there were in 2000, and as noted prior, an estimated 70% of all adults that reach the age of 65 will have a limitation in ADLs that may warrant the need for long-term care supports.<sup>71</sup>

For those with I/DDs, the need for family caregivers is acute, with as many as 75% of those with an I/DD relying on family caregivers to support ADLs. The I/DD population is unique from other populations that rely on long-term care because most in this population are either, or were, diagnosed with a disability as a child and have likely needed some sort of LTSS for most of their

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<sup>69</sup> RAISE Family Caregiving Advisory Council, "Recognize, Assist, Include, Support, & Engage (RAISE) Family Caregivers Act Initial Report to Congress", September 22, 2021.

<sup>70</sup> Id.

<sup>71</sup> Id.

lives. As a result, family caregivers for people with I/DDs must take on unique responsibilities, like assisting with schooling, that family caregivers for aging adults may not have to provide.<sup>72</sup>

The long-term care needs for people with an I/DD have only grown over the years, thanks to advances in medicine that have helped the average life expectancy for this population to stretch further into adulthood. Today, as many as 25% of people with an I/DD live with a family caregiver who is over the age of 60, setting up potential situations where family caregivers may also need long-term care supports.<sup>73</sup>

Finally, veterans, who may develop service-related disabilities in adulthood due to combat, also have unique needs. As of 2019, there were nearly 5 million veterans with service-related disabilities living in the United States. Compared to prior generations of veterans, an estimated 15% of post-9/11 veterans have paralysis or a spinal cord injury compared to only 6.3% of veterans from prior generations. These injured veterans are typically younger than their family caregivers who may still be in the workforce or only recently retired, creating situations that can disrupt the livelihoods of their family caregivers due to the sudden need for care.<sup>74</sup>

Because of the diverse populations and the array of disabilities of individuals who need care, the scope of services and intensity of hours for family caregiving ranges significantly. Estimates by the National Alliance for Caregiving (NAC) and AARP have found that nearly half of all family caregivers provide less than 8 hours of care per week, while as many as one-third of all family caregivers provide over 21 hours of care per week. Additionally, NAC and AARP found the need for this care skews heavily towards those with physical disabilities and that age often dictates the type of care needed. Younger adults are also more likely to need mental behavioral health supports and I/DD supports compared to older adults, who are more likely to need support for memory problems.<sup>75</sup>

Finally, it should be noted that family caregivers are not always unpaid. Over the years, Congress has authorized discretionary programs to support family caregivers, ranging from supporting their training to their respite care needs. Congress also has provided funding through Medicare and Medicaid by allowing for these programs to cover certain family caregiver services, such as Medicaid's ability to pay for HCBS care through a "self-directed model" that allows a beneficiary to hire a family caregiver as a HCBS provider<sup>76</sup> and through the availability of payment for respite care for family caregivers for Medicaid beneficiaries<sup>77</sup> and Medicare hospice beneficiaries.<sup>78</sup> However, the Medicaid benefit is limited only to those eligible for Medicaid and, at times, subject to waitlists for HCBS care. Addressing waitlists could provide more options for family caregivers but will only alleviate pressures for those who already qualify for the program.

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<sup>72</sup> Id.

<sup>73</sup> Id.

<sup>74</sup> Id.

<sup>75</sup> AARP, National Alliance for Caregiving, "Caregiving in the United States 2020", May 14, 2020.

<sup>76</sup> 42 U.S.C. 1396n(j)

<sup>77</sup> 42 U.S.C. 1396n

<sup>78</sup> 42 U.S.C. 1395x(dd)

## ***Barriers to Community & Work – Burdens on Family Caregivers***

Family caregiving is integral to long-term care in the United States and serves a role as a bridge for those who either do not need or cannot afford other coverage for LTSS. Because family caregiving is indispensable to the LTSS system, the burdens that family caregivers currently face cannot be ignored.

Because Americans rarely plan for long-term care, family caregivers can find themselves unexpectedly supporting a loved one. This can be disruptive to the lives of caregivers and, understandably, leave loved ones feeling overwhelmed. Reported stressors for family caregivers include challenges associated with managing time constraints, emotional and physical stress, financial strain, depression, and isolation. According to the American Senior Communities, 22% of caregivers report that their health has worsened because of caring for a family member, and those who assist loved ones diagnosed with a type of dementia reported the most amount of emotional stress.<sup>79</sup>

*“My name is Bill Krebs and having a job and being part of society is important to me. I have an intellectual disability. I believe that all people with disabilities should be able to work and have affordable healthcare. It is important to me that I not be forced at age 65 to choose between my job and affordable healthcare. When I am older I still want to have a job in my community, have affordable health care, and be able to support myself.”*

*- Bill Krebs, PA.*

According to the Administration for Community Living’s RAISE Family Caregivers Advisory Council, the sources of the burdens on family caregivers can be diverse but ultimately reduced through any of four interventions: awareness and outreach for family caregivers, engagement of family caregivers in health care and LTSS, services and supports for family caregivers, and financial and workplace security for family caregivers. Among these intervention opportunities include ideas like promoting awareness and normalizing the existence of family caregivers, because the experience of suddenly becoming a family caregiver can be overwhelming and isolating, supporting training opportunities for family caregivers, so that family caregivers can feel supported as they make decisions for their loved ones, taking efforts to ensure that family caregivers are included in the care continuum for their loved ones, so that they can help make informed decisions on appropriate treatment needs for their loved ones, and supporting respite care opportunities for family caregivers, so that they can focus on work or take mental health breaks from the stress of caring for a loved one.

### **Requests For Information:**

1.5 In order to build upon the existing infrastructure available to support family caregivers, including ensuring access to respite care and essential caregiving training:

- A. Should Congress make respite care available to more populations within Medicaid? If so, which populations?
- B. What discretionary programs for respite care are working? Which ones should be reviewed and reconsidered by Congress?

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<sup>79</sup> American Senior Communities, “The Challenges Facing a Family Caregiver”, October 14, 2015, <https://www.asccare.com/the-challenges-facing-a-family-caregiver/>.

- C. What discretionary programs for caregiver training are working? Which programs should be reviewed and reconsidered by Congress?

## **ACCOMODATIONS IN DAILY LIFE AND IN THE COMMUNITY**

Progress for Americans with disabilities has meant ensuring that the needs of daily life are increasingly accessible. In the worst of the COVID-19 pandemic, when isolation and lockdowns were common-place, work and life were reimagined to make working from home more manageable and allow for the delivery of goods and services like groceries to one's home more feasible.

Making things more accessible takes concerted efforts across the public and private sector. The passage of laws like the ADA and the advent of new innovations like assistive technologies came from intentional steps to ensure that people with disabilities are included in society. Additional public and private collaboration will be necessary to build upon these efforts.

### **Federal Efforts to Support Access to Assistive Technology**

#### ***Barriers to Community & Work – Coverage Limits for Affordable, Assistive Technology***

Technology can be a critical tool to help individuals with disabilities gain greater independence, participate in the workforce, and live healthier lives. Assistive technology devices are very diverse in terms of sophistication. Some are incredibly low tech, like seat cushions, while other devices may include artificial intelligence, text-to-speech, and speech recognition.<sup>80</sup> Nonetheless, assistive technologies at all capabilities can improve outcomes in schools by increasing academic engagement and enabling greater participation in classes and in the workplace by improving productivity and the ability to complete tasks.

The cost of procuring technologies, however, can be a burden. Most assistive technologies including prosthetic devices, orthotic braces, and physical and occupational therapy, are optional for states to cover under Medicaid. HCBS waivers may provide items not otherwise available through state plan benefits, like adaptive aids, specialized medical equipment, and personal emergency response systems.<sup>81</sup> However, states often must balance the need for expanded access to services under waivers with ensuring more basic access to such services for those who do not have access to any form of care.

Furthermore, while Medicaid can reimburse for assistive technologies, the Centers for Medicare and Medicaid Services has been unwilling at times to support waiver authorities for states to reimburse for assistive technologies that may have secondary purposes that are not necessarily medical in nature. For example, technologies like iPads or computers, with their associated applications, may have assistive capabilities to improve outcomes in school or work, but may be

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<sup>80</sup> Administration for Community Living, "How Technology is Creating New Employment Opportunities for People with Disabilities", <https://tinyurl.com/4vtfk8nx>

<sup>81</sup> Application for a 1915(c) Home and Community-Based Waiver: Instructions, Technical Guide, and Review Criteria, Centers for Medicare and Medicaid Services, January 2019, <https://www.reginfo.gov/public/do/DownloadDocument?objectID=104942301>.

used outside of school or work hours for extracurricular or social purposes. In these instances, Medicaid is unlikely to cover the initial purchase of such technology because the usage is not exclusively medically necessary.<sup>82</sup>

Outside of Medicaid coverage, people with disabilities can use ABLER Accounts to pay for assistive technologies. Established in 2014 under the Achieving a Better Life Experience (ABLE) Act of 2014, current law allows states to create tax-advantaged savings accounts for eligible people with disabilities to pay for qualified disability expenses.<sup>83</sup> Under the Tax Cuts and Jobs Act of 2017, individuals can make contributions up to \$15,000 per year.<sup>84</sup> There are limits to the use of ABLER Accounts. Notably, an individual has to be diagnosed with a disability prior to age 26 to open an ABLER account, excluding those who receive a diagnosis later in life.<sup>85</sup> Expanding this age will allow more people to take advantage of this program and decrease the cost of fees associated with opening an account.

## **Requests For Information**

2.1 In order to ensure greater access to more affordable assistive technologies:

- A. Should Congress consider authorizing Medicaid to reimburse for the cost of technologies that may have secondary uses that are not necessary or assistive, even if the primary usage is for assistive technology purposes? If so, what, if any, limitations should Congress consider when authorizing such flexibilities? Please provide any data on the cost effectiveness of such technologies.
- B. How should Congress consider the future for assistive technologies, and how should Congress address future technologies that may not necessarily be accommodated or adopted by payers?
- C. Should Congress consider increasing the allowable age for qualifying for ABLER Accounts?

## **Federal Efforts to Support Accessible Health Care**

### ***Background on Accommodations in Health Care Settings***

Wellness is fundamental to ensuring that individuals meaningfully can participate in their jobs and communities. The challenge of staying well for people with disabilities has its own unique set of challenges and goes beyond the need for long-term care. People with disabilities are disproportionately likely to need more acute care; for example, children with Down Syndrome are significantly more likely to have congenital heart defects,<sup>86</sup> people with cerebral palsy are

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<sup>82</sup> Id.

<sup>83</sup> Public Law No: 113-295, The Achieving a Better Life Experience (ABLE) Act of 2014, December 19, 2014.

<sup>84</sup> <https://www.irs.gov/newsroom/able-accounts-a-valuable-financial-solution-for-people-with-disabilities>

<sup>85</sup> Public Law No: 113-295, The Achieving a Better Life Experience (ABLE) Act of 2014, December 19, 2014.

<sup>86</sup> Centers for Disease Control and Prevention, "Data and Statistics on Down Syndrome", CDC.gov, 2020, <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/data.html>.

less likely to be able to walk independently,<sup>87</sup> and people with Multiple Sclerosis are at an increased risk for certain conditions like osteoporosis.<sup>88</sup>

Furthermore, these individuals and others with disabilities are likely to need specific accommodations just to receive necessary treatment and examinations. Titles II and III of the ADA and section 504 require that health care providers provide full and equal access to health care services and facilities for people with disabilities and make reasonable modifications to ensure such access unless the modifications would create an undue hardship on the owner of the facility. For example, a physician's office must have necessary accommodations to ensure that people with disabilities can readily be treated by, for example, having accessible, clear spaces for wheelchairs and adjustable examination areas to accommodate people with various needs, so long as the modifications would not require significant renovations to the building or require significant investments in capital.

The need for accommodations for people with disabilities goes beyond the physical accommodations that are called for in the ADA and section 504. Physician training or, at times, the lack thereof, to accommodate specific care needs for people with disabilities can be integral to an individual's care. For example, Deaf American Sign Language (ASL) users that are able to communicate with health care providers either through ASL or other means have increased appropriate utilization rate of preventive services.<sup>89</sup> Similarly, children with I/DD are more likely to have poor health care outcomes associated with a lack of formal training by their health care providers<sup>90</sup> and less likely to receive dental care due either a lack of a willingness to treat patients with disabilities (with less than 10% of all dentists treating patients with disabilities<sup>91</sup>) or a lack of accommodations to reduce sensory overload and anxiety.<sup>92</sup>

Congress has authorized a number of physician workforce training programs over the years, including section 741 of the Public Health Service Act, which previously authorized cultural competency training grants to support providers that care for people with disabilities.<sup>93</sup> Additionally, Congress has taken steps to support advocates for patients with disabilities who may not otherwise be able to advocate for themselves and ensure that accommodations are made in clinical settings by authorizing Medicaid to reimburse for personal care aide services while an individual is hospitalized so that the personal care aide can support the patient during the hospitalization.<sup>94</sup>

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<sup>87</sup> Centers for Disease Control and Prevention, "Data and Statistics for Cerebral Palsy, CDC.gov, 2020, <https://www.cdc.gov/ncbddd/cp/data.html>.

<sup>88</sup> National Multiple Sclerosis Society, "Advanced Care Needs", NationalMSSociety.org, 2022, <https://www.nationalmssociety.org/Resources-Support/Living-with-Advanced-MS#section-3>.

<sup>89</sup> McKee MM, Barnett SL, Block RC, Pearson TA. Impact of communication on preventive services among deaf American Sign Language users. *Am J Prev Med.* 2011 Jul;41(1):75-9.

<sup>90</sup> Ervin, David A et al. "Healthcare for persons with intellectual and developmental disability in the community." *Frontiers in public health* vol. 2 83. 15 Jul. 2014.

<sup>91</sup> Oregon Office on Disability and Health, "Oral Health for People with Disabilities", Oregon Health & Science University, 2020, <https://www.ohsu.edu/oregon-office-on-disability-and-health/oral-health-people-disabilities>

<sup>92</sup> Milano, Michael, DMD, "Oral Healthcare for Persons with Intellectual or Developmental Disabilities: Why Is There a Disparity?", *Compendium of Continuing Education in Dentistry*, Volume 38, Issue 11, 2017.

<sup>93</sup> 42 U.S.C. 293e

<sup>94</sup> 42 U.S.C. 1396(h)

## ***Barriers to Community & Work – Living a Healthy Life***

Fundamental to ensuring greater health care outcomes for people with disabilities will be ensuring accommodations in health care settings and developing a health care workforce that is more proficient in its understanding of the health care needs of people with disabilities. While the requirements of the law are clear, application of the law is not uniform. Anecdotal reports suggest a lack of availability to accessible examination beds and preventive screening technologies, making receiving services like pap smears and prostate exams difficult or impossible, risking health outcomes for people with disabilities. According to the National Council on Disability, there is little accountability for ensuring accessibility in health care facilities, and the Department of Justice (DOJ) and HHS have taken few cases or pursued few penalties in cases involving discrimination against people with disabilities in health care settings.<sup>95</sup>

The Departments have acted over the years to address a lack of accessible care. HHS’s website highlights examples of the Office of Civil Rights’ successes in securing auxiliary aids and sign language interpreters for patients who are deaf or hard of hearing in a New York facility,<sup>96</sup> or helping to establish service animal policies at a county department of social services in Virginia.<sup>97</sup> But the overall number of successes remains limited, and conversations with stakeholders indicates that accessible, ADA-compliant health care facilities remains a barrier to care thirty years after the passage of the ADA.

*“I was born with a congenital heart disorder for which I had four open-heart surgeries – three when I was baby and one when I was 10 years old. As I grew, my heart could not keep up with the rest of my body and – as a result – I would have episodes of vasovagal syncope. While I was at Northern Virginia Community College, the doctors realized there was nothing that could be done surgically to help my heart. My only option was a new heart. They concluded that I would be a good candidate for a heart transplant. They could have – based on my Down syndrome diagnosis – denied me access to a new heart. This is a practice that is all too common for people with Down syndrome and other people with disabilities. The denial of organs to people with disabilities is tantamount to the determination that their lives are valued less than others. This denial is really rooted in fear, ignorance, and a lack of exposure to the lived experiences of people with disabilities. It also means that doctors and hospital transplant teams that deny organ transplants to people based solely on their disability have been ADA non-compliant even though Section 504 demands that they be in compliance. Some doctors are concerned that patients with intellectual and developmental disabilities might not be as capable of handling post-operative care, but if they have a strong support network then there should be fewer worries about post-operative care.”*

*- Charlotte Woodward, VA, Self-Advocate with Down syndrome*

Even with the enforcement of key accommodation laws, accessibility to health care has backslid in recent years due to the actions in response to the COVID-19 pandemic. In much of 2020 and 2021, people with disabilities were left in precarious positions with limited personal protective

<sup>95</sup> National Council on Disability, “The Current State of Health Care for People with Disabilities”, 2009, <https://ncd.gov/publications/2009/Sept302009#Americans%20with%20Disabilities>.

<sup>96</sup> “Voluntary Resolution Agreement Between Office for Civil Rights, Region II and Catskill Regional Medical Center”, Office for Civil Rights, <https://www.hhs.gov/civil-rights/for-providers/compliance-enforcement/examples/catskill-regional-medical-center/index.html>.

<sup>97</sup> “U.S. Department of Health and Human Services Office for Civil Rights Letter of Findings”, Office for Civil Rights, <https://www.hhs.gov/civil-rights/for-providers/compliance-enforcement/examples/disability/virginia-dss-letter-findings/index.html>.

equipment and few options to receive services like LTSS or other health care services that required in-person care. While telehealth was a silver lining during the pandemic, increasing access to care for those homebound or without access to LTSS and supports to get to medical care, it is not a perfect solution. As a result, people with disabilities either did not receive care or took risks in order to receive essential services.<sup>98</sup>

Creating an accommodating health care setting is challenging. Purchasing new equipment or updating existing equipment can be expensive, and providers may have concerns about treating certain patients with disabilities due to their relatively higher rates of anxiety and agitation when receiving treatment or may be unaware of ways to support patients during their treatments. Furthermore, a general unfamiliarity with laws like the ADA among providers creates uncertainty among providers and a chilling effect in the willingness to take on patients with disabilities, with as many as 69% of providers expressing concerns that they were at risk of ADA lawsuits.<sup>99</sup>

Nonetheless, the impacts of accommodations in health care settings can have profound impacts on patients. For example, sensory adaptations in dental facilities, like using ambient lighting and comforting pressure from wraps (not dissimilar to that from weighted blankets), were shown to reduce anxiety significantly among children with Autism Spectrum Disorder receiving dental care.<sup>100</sup> In addressing issues like anxiety among children with Autism Spectrum Disorder when they get medical care, a patient with a disability is not only more likely to be happier and more comfortable but is more likely to be able to finish their full course of treatment and receive subsequent care. Additionally, successful interventions can improve outcomes for patients and encourage more provider to treat patients with disabilities.

### **Requests For Information:**

2.2 Health care accommodations must be accessible to all Americans, regardless of whether they have disabilities or not. In order to ensure federal protections that support accommodations to health care:

- A. Should Congress strengthen oversight requirements at HHS and DOJ to ensure compliance with the law? Should Congress increase penalties for failure to meet accommodation requirements? What limits, if any, should be placed on such oversight authorities and penalties?
- B. Should Congress provide funding to make physical or sensory accommodations? If so, how much is needed to do so? How much should be supported by private dollars? What data exists about the costs necessary?
- C. How should Congress address support for training health care professionals on how to accommodate people with disabilities? Should medical schools and other continuing

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<sup>98</sup> National Council on Disability, “The Impact of COVID-19 on People with Disabilities”, 2021, [https://www.ncd.gov/sites/default/files/NCD\\_COVID-19\\_Progress\\_Report\\_508.pdf](https://www.ncd.gov/sites/default/files/NCD_COVID-19_Progress_Report_508.pdf).

<sup>99</sup> Iezzoni LI, Rao SR, Ressler J, et. Al., “US Physicians’ Knowledge About the Americans With Disabilities Act And Accommodation Of Patients With Disabilities, Health Affairs, Volume 41,” Number 1, 2022.

<sup>100</sup> Cermak, Sharon A et al. “Sensory Adapted Dental Environments to Enhance Oral Care for Children with Autism Spectrum Disorders: A Randomized Controlled Pilot Study.” *Journal of Autism and Developmental Disorders* vol. 45,9 (2015): 2876-88.



medical education opportunities be responsible for ensuring providers are educated on such issues? Are federal funds needed for such efforts?

- D. How have telehealth and other remote monitoring technologies been used to improve accessibility to health care services for people with disabilities? How did the utilization of such services during the pandemic improve access to care or mitigate a worsening of access to care? What should Congress consider when examining future extensions of telehealth and remote monitoring authorizations?

## **BARRIERS TO INTEGRATED EMPLOYMENT**

As Congress looks to reduce barriers to employment, ensuring all Americans who are willing and able to work have access to competitive, integrated employment will be necessary.<sup>101</sup> For the past thirty years, the federal government and the private sector have worked together to increase the number of people with disabilities in inclusive educational environments and employment. To reduce barriers to accessing integrative employment opportunities, Congress must end the practice of paying people with disabilities subminimum wages and provide support for employers to ensure greater accommodations in the workplace.

### **Subminimum Wage**

#### ***Barriers to Community & Work – Discriminatory Minimum Wage Laws***

Under section 14(c) of the Fair Labor Standards Act, employers can apply for special certificates from the U.S. Department of Labor (DOL) to pay individuals with disabilities less than the federal minimum wage. There is no minimum floor for the hourly wage that an employer can pay an individual with a disability under these certificates.<sup>102</sup>

Several independent federal agencies have called for the phase out of the section 14(c) subminimum wage. The National Council on Disabilities (NCD) issued a report in 2012 recommending a phase out section 14(c) certificates and an enhancement of existing resources to create new mechanisms to support people in competitive integrated employment and other nonwork settings.<sup>103</sup> In 2020, the U.S. Commission on Civil Rights called for the phase out of section 14(c) subminimum wage, finding that it has “limited people with disabilities participating in the program from realizing their full potential while allowing providers and associated businesses to profit from their labor.”<sup>104</sup> Fifteen states have either phased out section 14(c) certificates or are in the process of doing so.

While the original intent of section 14(c) certificates was to increase employment opportunities for individuals with disabilities, it has become clear that these certificates are having the opposite effect and are preventing these individuals from reaching their full potential. In its 2012 report

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<sup>101</sup> Department of Labor, Competitive Integrated Employment (CIE), <https://www.dol.gov/agencies/odep/program-areas/integrated-employment>.

<sup>102</sup> The Fair Labor Standards Act of 1938, § 14(c).

<sup>103</sup> Young, “Subminimum Wage and Supported Employment”, National Council on Disability, Pages 1-46, August 23, 2012.

<sup>104</sup> U.S. Commission on Civil Rights, “Subminimum Wage: Impacts on the Civil Rights of People with Disabilities”, November 15, 2019.

titled “Subminimum Wage and Supported Employment,” NCD found that sheltered workshops (section 14(c) certificate holders) are ineffective at transitioning people to integrated employment and that individuals who had previously been in sheltered workshops do not show a higher rate of employment, as compared to those who went straight to competitive integrated employment<sup>105</sup>.

### **Proposed Solutions:**

Rep. Bobby Scott and Rep. Cathy McMorris Rodgers proposed the Transformation to Competitive Integrated Employment Act (TCIEA), which would gradually phase out section 14(c) certificates over a five-year period and include a competitive grant program for both section 14(c) certificate holders and states so that certificate holders can transition their business models and offset any cost that may be associated with providing wraparound services.<sup>106</sup> These wraparound services could be anything from supported employment services, job coaches, nonwork activities, or other ways for individuals with disabilities to continue to have meaningful engagement during the day.

*“My entire life I have been told to surround myself with people who see my value and remind me of my worth. To pay one less money based on a diagnosis devalues the individual and their ability.”*

*- Mika Hartman, MS, parent advocate*

### **Employment Accommodation Supports**

#### ***History and Background of Current Landscape for Employment Accommodations***

In most instances, the costs of hiring a person with a disability is largely the same as that for hiring a person without a disability. The exception to this comes when accommodations have to be made for a person, whether those accommodations are to ensure that the physical space is ADA-compliant or are for purchasing assistive technologies or other personal assistive services to support the employee.

Accommodations are usually one-time expenditures and often have little to no cost. However, when they do have costs, the typical accommodation costs about \$500 or less.<sup>107</sup> These costs can increase by up to \$1,500 if the employee needs personal assistive services, but the respective needs can vary by individual.<sup>108</sup> Depending on the size of the employer and the potential costs of the accommodation, employers may be forced to consider factors for the employment of a person with a disability that goes beyond their qualifications for the job.

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<sup>105</sup> Young, “Subminimum Wage and Supported Employment”, National Council on Disability, Pages 10-11, August 23, 2012.

<sup>106</sup> Scott, Rodgers, H.R. 2373, the Transformation to Competitive Integrated Employment Act.

<sup>107</sup> Social Security Administration, “Money Mondays: The (Low and No) Cost of Reasonable Accommodations”, ChooseWork.SSA.gov, <https://choosework.ssa.gov/blog/2017-07-10-mm-the-low-and-no-cost-of-reasonable-accommodations>.

<sup>108</sup> Office of Disability Employment Policy, “Personal Assistive Services”, U.S. Department of Labor, <https://www.dol.gov/agencies/odep/program-areas/employment-supports/personal-assistance-services>.

For employees who become disabled on the job and seek to return to work, employers may be able to cover the costs of the accommodations through either short-term or long-term disability insurance, but no such coverage is available for employers looking to hire new employees who already have disabilities. Ultimately, the ADA requires reasonable accommodations to be made for employees, whether the employee had the disability prior to their initial employment or not.

### ***Examples of Success***

There are a number of success stories across the public and private sector for supporting the accommodation needs for people with disabilities. For example, the Department of Defense (DOD) operates the Computer/Electronic Accommodations Program (CAP) to ensure access to assistive technologies and other associated accommodation needs for DOD employees with disabilities and wounded, ill, and injured service members. The program, established in 1990, receives about \$7 million per year,<sup>109</sup> and is able to meet over 7,500 accommodation requests, reportedly helping save the Department an estimated \$613,000 through reduced costs and increased efficiencies.<sup>110</sup> Nonetheless though, the National Council on Disability found that the CAP runs out of funds annually by July or August due to the overwhelming demands from the program.<sup>111</sup>

Similar efforts are made throughout the private sector across a number of industries, demonstrating that employers can successfully invest in supporting employees with disabilities. For example, Starbucks offers training opportunities for people with disabilities to gain skills to be baristas or succeed in retail jobs.<sup>112</sup> Others, like AT&T, utilize recruitment programs that specifically seek to hire college graduates with disabilities and have established programs to ensure accommodations are available for employees.<sup>113</sup>

### **Requests For Information:**

3.1 In order to make workplace accommodations more affordable and accessible for employers so that workplaces can be accessible to all workers:

- A. Should all federal departments and independent agencies be required to have accommodation programs similar to DOD's Computer/Electronic Accommodations Program?
- B. Should Congress consider tax credits or tax deductions for employers to support workplace accommodations? If yes, what restrictions, if any, should be made on how

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<sup>109</sup> "Fiscal Year 2022 President's Budget: Defense Human Resources Activity", 2021, [https://comptroller.defense.gov/Portals/45/Documents/defbudget/fy2022/budget\\_justification/pdfs/01\\_Operation\\_and\\_Maintenance/O\\_M\\_VOL\\_1\\_PART\\_1/DHRA\\_OP-5.pdf](https://comptroller.defense.gov/Portals/45/Documents/defbudget/fy2022/budget_justification/pdfs/01_Operation_and_Maintenance/O_M_VOL_1_PART_1/DHRA_OP-5.pdf).

<sup>110</sup> "CAP Annual Report", 2021, [https://www.cap.mil/Documents/CAP\\_FY20\\_Annual\\_Report\\_Final\\_1.pdf](https://www.cap.mil/Documents/CAP_FY20_Annual_Report_Final_1.pdf)

<sup>111</sup> National Council on Disability, "NCD letter regarding DoD Computer/Electronic Accommodations Program", 2020, <https://ncd.gov/publications/2020/ncd-letter-dod-cap>.

<sup>112</sup> "Starbucks Commitment to Access and Disability Inclusion", Starbucks, 2021, <https://stories.starbucks.com/press/2015/starbucks-commitment-to-access-and-disability-inclusion/>

<sup>113</sup> "Recognized for Paving the Way", AT&T, 2013, [https://about.att.com/newsroom/recognized\\_for\\_paving\\_the\\_way.html](https://about.att.com/newsroom/recognized_for_paving_the_way.html).

such tax credits or deductions are used? Similarly, should such tax credits or deductions be limited to small employers or other categories of employers?

## **Conclusion**

As the United States continues its recovery from a deadly pandemic and ever-rising inflation, it may seem that things are only getting worse for Americans and not better. But it's times like these where our country should reaffirm its commitments to helping those in need by making the United States freer and more accessible to all Americans and ensure that our safety net is functioning for those who need it most.

Now is the time to ensure that people with disabilities have every opportunity to participate in their communities, just as those without disabilities already can. This means making LTSS more affordable and accessible, reducing barriers to assistive technologies and ADA-compliant health care settings, and creating greater opportunities for fair accommodations in the workplace. This is not an exhaustive list, however, and is why Energy and Commerce Republicans are interested in receiving feedback on what next steps Congress should consider to further support Americans with disabilities.

Every American deserves their God-given right to live and work free and independently, and Congress should remove barriers to independence for disabled individuals and ensure that an infrastructure is in place that supports the needs of Americans to live to their fullest potential.