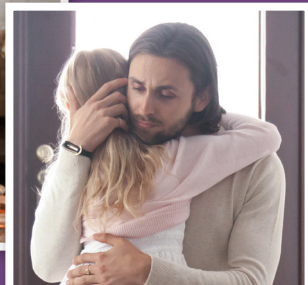
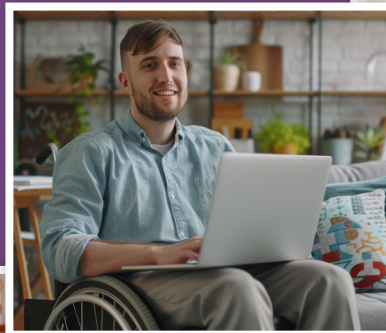


# ABLE TO SUCCEED

## A Policy Reform Agenda for Americans with Disabilities



by **RACHEL BARKLEY**  
NCPPR • ABLE AMERICANS



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## A Policy Reform Agenda for Americans with Disabilities



### ABLE AMERICANS

is a program of the

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# KEY FINDINGS

## ABLE TO SUCCEED:

### A Policy Reform Agenda for Americans with Disabilities

This report provides 45 policy solutions to address the problems listed below.

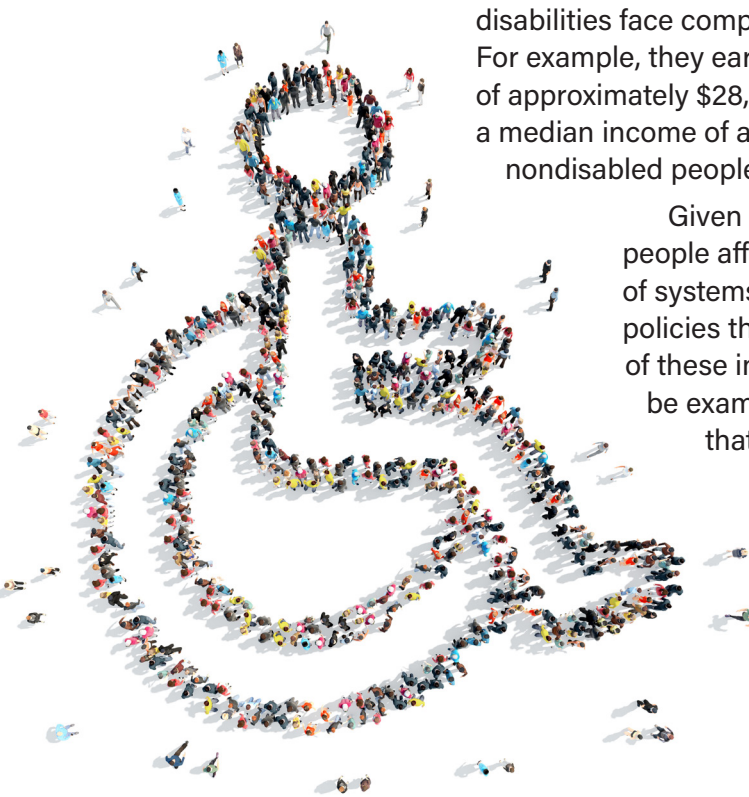
- The number of individuals with disabilities and their caretakers combined is **100 million Americans**. The vast web of government policies and programs that impact their lives should be examined to ensure that they are living up to the principles underpinning the American dream and standards of human dignity and equality of opportunity.
- Government programs and policies that serve people with disabilities are falling short. Key indicators do not paint a good picture of outcomes when we examine **independence, health outcomes, workforce participation, and barriers to marriage** for people with disabilities. We also need better program outcome studies to determine the impact of government programs and then adequately reform them.
- Adults with disabilities are **4 times** more likely to report their health to be fair or poor than people with no disabilities. People with disabilities face life-altering shortages and inability to access proper care.
- Only **40.6%** of persons with disabilities are participating in the workforce as of April 2024. That is nearly half of the rate of those without disabilities. Studies have shown that not working correlates with long-term negative mental and social health impacts, such as levels of stress, anxiety, depression, suicide risk, life expectancy, family relationships, community engagement and physical health.
- **25%** of individuals with disabilities in America live in poverty — more than twice the rate of individuals without disabilities.
- For people with physical disabilities, less than **5%** of housing nationwide is accessible for people with moderate mobility difficulties and less than 1% is accessible for wheelchair users.
- Avoidable emergency room visits that should have been candidates for mental health or substance abuse care are estimated to cost **\$8.3 billion** per year.
- Three areas of policy and programs must be addressed to improve outcomes: **Inequality under the law and in society, access to healthcare, and government barriers to work and independence.**

# Introduction

One in four adults in the United States live with a disability — 61 million people.<sup>1</sup> Disability can happen to anyone at any time, making it a minority that anyone can join. It is also the largest minority group in the world and a voting bloc that should be given attention.<sup>2</sup> Furthermore, caregivers form a secondary population affected by the challenges of disabilities with more than one in five Americans (21.3 percent) fulfilling a caregiver role at some time in the past 12 months.<sup>3</sup> The number of individuals with disabilities and their caretakers combined is 100 million Americans.

This population is likely to increase with an aging population.<sup>4</sup> According to Pew Research Center, “Older adults are significantly more likely than younger adults to have a disability. Some 46% of Americans ages 75 and older and 24% of those ages 65 to 74 report having a disability.”<sup>5</sup> People with disabilities face compounding challenges. For example, they earn a median income of approximately \$28,438, compared to a median income of about \$40,948 for nondisabled people.<sup>6</sup>

Given the number of people affected, the vast web of systems and government policies that impact the lives of these individuals should be examined to ensure that they are living up to the principles underpinning the American dream and standards of human dignity and equality.





# Principles

## That Should Drive Disability Policy

The Declaration of Independence is the visionary document that birthed the guiding vision for the nation and made America unique among nations. It espoused the driving and enduring principles that apply to all Americans: “We hold these truths to be self-evident, that all men are created equal, that they are endowed, by their Creator, with certain unalienable rights, that among these are life, liberty, and the pursuit of happiness.” All our rights are endowed by our Creator. There are no caveats about different abilities in that founding document.

The Founders did not create this notion out of thin air, it came from natural law tradition of unchanging moral truths, grounded in our human nature and knowable through the light of reason. In antiquity through both Jewish and Christian traditions, we are given the Imago Dei in the very first chapter of biblical text that tells us human beings are created in the image and likeness of God, therefore equal in their inherent worth and bestowed with intrinsic value.

The principles of human dignity and equality of opportunity, or the right to “the pursuit of happiness,” laid forth in the Declaration

should undergird all disability policy. These principles may seem self-evident, but unfortunately this is often not the case for people with disabilities. America has a long history of legal and policy inequality to overcome when it comes to the treatment of those with disabilities. To this day, antiquated laws remain on the books that treat people with disabilities as less than equal and force them into lives of subsistence. Downstream from these laws, society and culture often parrot many misperceptions about people with disabilities.

Beyond equality of opportunity and human dignity, as a polity, we are morally obligated to provide a minimum safety net when civil society is unable to provide one. The programs that are thus created by government to provide for the most vulnerable should be thoroughly measured for their success and outcomes. This, unfortunately, does not happen in our maze of safety net programs which are too often conflicted and riddled with disincentives, working against what we know helps people lead flourishing lives: work and family formation.

It is difficult to even know how many safety net programs there are — federal safety net spending is spread across at least 80 different programs which are housed in 14 different government departments.<sup>7</sup> At best, the social safety net makes poverty tolerable but not escapable for many in this country, as author Mauricio Miller has observed.<sup>8</sup> This is even more true of safety net programs that aid people with disabilities.

For example, many outcomes of disability programs are only measured in terms of enrollment or de-enrollment. This tells us nothing about what the programs do to improve lives. Instead, program outcomes should be measured against what disabled individuals

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*To this day, antiquated laws remain on the books that treat people with disabilities as less than equal and force them into lives of subsistence. Downstream from these laws, society and culture often parrot many misperceptions about people with disabilities.*

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can achieve with assistance, without assistance, and how effective and efficient programs are rather than just count how many people continue to remain on program rolls.

Some suggested metrics include significant health outcomes, increased workforce participation for those who are able to work, increased independence, and increased family formation. Government programs and policies that serve people with disabilities are falling short because these key indicators do not paint a good picture of outcomes when we examine health, work, independence and marriage for people with disabilities. Below are some examples of the current outcomes in these four key areas from various studies.

## Four Key Indicators of Outcomes

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### HEALTH

Adults with disabilities are 4 times more likely to report their health to be fair or poor than people with no disabilities (40.3% vs 9%).<sup>9</sup> The National Institutes of Health recently designated people with disabilities as a population with health disparities — meaning that there are “significant disparities in their rates of illness, morbidity, mortality and survival, driven by social disadvantage, compared to the health status of the general population.”<sup>10</sup> People with disabilities face life-altering shortages and inability to access proper care. For example, there are currently almost 700,000 people waiting for home and community-based services across the country with an average wait time exceeding 36 months.<sup>11</sup> For those who have mental health needs, without adequate in-home care options, nursing homes or residential treatment needed for mental disorders, mental health needs are instead being met by emergency rooms and even law enforcement, imposing a great cost to taxpayers and families.<sup>12</sup>





## WORK

While the number of people with disabilities in the workforce has increased in recent years, the gap in workforce participation versus nondisabled people is staggering: 40.6% of persons with disabilities are participating in the workforce as of April 2024.<sup>13</sup> That is nearly half of the rate of those without disabilities. Studies have shown that not working correlates with long-term negative mental and social health impacts,<sup>14</sup> such as levels of stress, anxiety, depression, suicide risk, life expectancy, family relationships, community engagement and physical health.



## INDEPENDENCE

Today, 25% of individuals with disabilities in America live in poverty — more than twice the rate of individuals without disabilities. There is a high correlation between crime and disabilities with 38% of prisoners in state and federal prisons have at least one disability, about 50% higher than the general population. Cognitive disabilities are the most common at 23%.<sup>15</sup> Further, individuals with disabilities are more likely to experience homelessness, with some estimates finding that nearly one quarter of individuals experiencing homelessness have a disability.<sup>16</sup> For people with physical disabilities, less than 5% of housing nationwide is accessible for people with moderate mobility difficulties and less than 1% is accessible for wheelchair users.<sup>17</sup> People with disabilities are subjected to unsafe or unsanitary situations, or even unwantedly institutionalized, because of the nationwide shortage of caregivers that is only increasing with an aging population.<sup>18</sup>



# MARRIAGE

When it comes to family formation, there are significant barriers to marriage for many people with disabilities. The overall first-marriage rate in the United States for nondisabled people ages 18 to 49 is 48.9 per 1,000. For people with disabilities, this indicator sinks to just 24.4 per 1,000 citizens.<sup>19</sup> Furthermore, in families where a child has a disability, the divorce rate could be as high as 87% given the lack of financial or caregiving support.<sup>20</sup>



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This report will outline the problems in government programs and policies that have contributed to these poor outcomes and injustices that fall short of the Declaration of Independence’s blueprint for the American Dream. Not addressing these problems is a failure to protect individual liberty and alleviate suffering for individuals with disabilities. It is also imposing a high cost to society through improper use of taxpayer dollars, an overcrowded healthcare system, increased homelessness and an undue burden on the criminal justice system. These problems, created by programs, regulations and laws, fall into three categories: Inequality under the law and in society, barriers to independence and work and access to care.



# WHAT ABOUT Waste, Fraud and Abuse of the System?

Many policymakers and thinkers reading this far may claim that the programs waste taxpayer dollars through fraud, mismanagement and abuse. Many on the conservative or libertarian side of the ideological spectrum argue that we should first focus on tightening eligibility rules and fraud prevention.

According to the Social Security Administration (SSA), the agency's fraud incidence rate is a fraction of one percent.<sup>21</sup> While SSA is likely not catching all of the fraud and abuse of the system, one should still ask: *Should the sole focus of conservative disability policy be focused on the small number of fraud cases or on the costs to society of the estimated 100 million people impacted by ineffective or even harmful disability policies?*

Rather than focus on the fraud in safety net programs, those interested in promoting the American Dream should do so by removing barriers to independence, work, marriage, health and a flourishing life for people with disabilities. If the focus of policymaking is turned toward making the systems better and measuring outcomes, fraud will also decrease as a result.

This does not mean that we should ignore the inefficient government programs for people with disabilities. The opposite is true. These programs and policies should be rigorously examined for their success in helping the most vulnerable and to use taxpayer funds responsibly. Unfortunately, this is not happening in any meaningful way across the board. Congress and the states must require the collection, reporting and analysis of program data that captures outcomes to pursue meaningful, evidence-based advances in the lives of people with disabilities.

# SECTION 1

## Inequality Under the Law and in Society

### BACKGROUND:

### History of Inequality Under the Law

For much of American history, people with disabilities have been viewed as less than human. The “impaired intelligence” or “feebleness” implied of many groups throughout history have been given as excuses to deny people their God-given rights. We can see this in parallel antiquated arguments utilized to deny African American slaves’ freedom and women the right to vote. The ideas espoused were the same at their root: A perverse idea that certain populations are unworthy of equality.

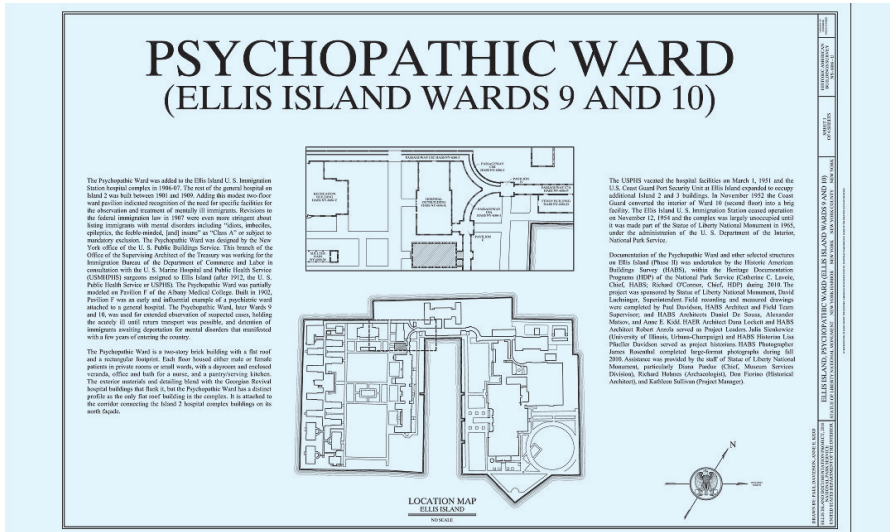
The laws perpetuating this kind of inequality for people with disabilities were sustained long after women’s suffrage was won. In the early 20th century, progressives led the eugenics movement, including infamous adherents such as Woodrow Wilson<sup>22</sup> and H.G. Wells.<sup>23</sup>

Margaret Sanger,<sup>24</sup> who popularized birth control and opened what would become the first Planned Parenthood in 1923, espoused the belief that certain classes and races were unfit to have families.

Eugenics also drove immigration laws that excluded those with physical or mental “abnormalities.” For example, an 1896 *Atlantic Monthly* piece espoused the “straining out” of



Margaret Sanger



The Psychopathic Ward of Ellis Island, New York Harbor, U.S. Immigration Station hospital complex (1906-07) facilities for the observation and treatment of mentally illimmigrants with mental disorders including "idiots, imbeciles, peileptics, the feeble-minded, [and] insane."

immigrants who were "deaf, dumb, blind, idiotic, insane, pauper or criminal who might otherwise become a hopeless burden upon the country."<sup>25</sup>

A lesser-known leader of the eugenics movement in the United States was Harry Hamilton Laughlin.<sup>26</sup> He was named an "Expert Eugenics Agent" to the House Committee on Immigration and Naturalization and a proponent of the forced sterilization laws for the "unfit." He had active ties to the Third Reich, and Adolf Hitler would later adopt his sterilization ideas for individuals with disabilities in Nazi Germany.

Laughlin's work influenced atrocious laws in 30 states throughout our country that resulted in over 70,000 people, mostly black and individuals with disabilities, being forcibly sterilized. Even worse, these laws were upheld by the Supreme Court in 1927. In the case *Buck vs. Bell*, Justice Oliver Wendell Holmes Jr. infamously wrote that "three generations of imbeciles are enough."<sup>27</sup>

Under the state of Virginia's law alone, about 8,300 citizens were sterilized, and the state law was not repealed until 1974. The Supreme Court has not expressly overturned *Buck vs. Bell*; however, all state statutes have been repealed and many states officially apologized.

**BACKGROUND:**

# Landmark Disability Laws: 1973 Rehabilitation Act and the 1990 Americans with Disabilities Act

Slowly, reforms were made throughout the 20th century to bring about equality under the law for people with disabilities. The first landmark legislation was the passage of Section 504 of the 1973 Rehabilitation Act (RA) and culminating in the bipartisan American with Disabilities Act of 1990 (ADA). Both were driven by years of people with disabilities and parents of children with disabilities protesting unequal treatment, segregation and exclusion across the country.

Section 504 forbade organizations and employers receiving federal funds from excluding or denying individuals with disabilities an equal opportunity to receive program



**ADA.gov**  
U.S. Department of Justice  
Civil Rights Division

Home Topics Guidance & Resource Materials Law, Regulations & Standards Enforcement File a Complaint

**The Americans with Disabilities Act (ADA) protects people with disabilities from discrimination.**

Disability rights are civil rights. From voting to parking, the ADA is a law that protects people with disabilities in many areas of public life.

Give Us Feedback

The stated mission of the ADA is to assure equality of opportunity, full participation, independent living and economic self-sufficiency for persons with disabilities.

benefits and services.<sup>28</sup> It established for the first time under the law that discrimination and barriers in society do exist and that these barriers blocked people with disabilities from participating in society rather than just accepting their exclusion as a natural and expected societal consequence of disability.

Decades of regulatory guidance and lawsuits around Section 504 ensued, eventually leading to the more robust ADA. The Department of Health and Human Services built upon Section 504 with a final rule on May 1, 2024, that went further to strengthen civil rights protections based on disability in health care and human services.<sup>29</sup> This rulemaking addressed discrimination in medical treatment, added enforceable standards for accessible medical diagnostic equipment and ensured accessible web content and mobile apps.<sup>30</sup>

The ADA, signed into law by President George H.W. Bush, prohibits discrimination against individuals with disabilities and has three titles pertaining to employment, state and local government and public accommodations and commercial facilities.<sup>31</sup>

Building upon the ADA, in 2008, Congress passed the Americans with Disabilities Act Amendments Act (ADAA) that broadened the definition of disability to ensure that it encompassed impairments such as cancer, diabetes and epilepsy.<sup>32</sup>

The stated mission of the ADA is to assure equality of opportunity, full participation, independent living and economic self-sufficiency for persons with disabilities.<sup>33</sup>

This was a step forward in removing extant barriers and providing civil rights to people with disabilities, but as the remainder of this report will show, there is more work to be done to provide better outcomes in health, independence, workforce participation and marriage.

There are still some areas of law and regulation that need to be addressed to provide equality of opportunity and the pursuit of happiness to all people with disabilities: Particularly when it comes to their rights to life, accessing housing, accessing travel and the pursuit of marriage and family.

# Threats to the Right to Life

Disabled lives are under threat from many state laws and medical practices surrounding the beginning and end of life. At the beginning of a woman's pregnancy, she is often offered genetic testing to determine if the fetus carries any genetic disorders, such as Down syndrome, cystic fibrosis, Tay-Sachs disease or spina bifida.

In the post-*Roe vs. Wade* environment, many are using these tests to determine if they should abort their child early in pregnancy due to a possible disability. This is problematic because it sends the message that these lives are worth eliminating — a conclusion reached by Iceland when they declared Down syndrome nearly eliminated due to prenatal screening.<sup>34</sup>

In the United States between 1995-2011, it is estimated that 67 percent of Down syndrome lives were eliminated before birth. Even more worrying, a *New York Times* investigation found that noninvasive prenatal testing can be wrong 80-93% of the time, and these tests are not even FDA approved.<sup>35</sup>

At the end of life, the problems are just as troubling and are spreading through state statutes. Physician assisted suicide is legal in 10 states and the District of Columbia, and 19 states have pending legislation in 2024.<sup>36</sup> About 5,330 people in the U.S. died with medical assistance as of 2020. These laws allow an individual who receives a terminal diagnosis of less than six months the option to receive a prescription drug from a physician to end their life. However,



Physician assisted suicide is legal in 10 states and the District of Columbia, and 19 states have pending legislation in 2024.



the definition and timeline of “terminal” is terribly subjective and often wrong.

As Vincenzo Piscopo, President & CEO of the United Spinal Association points out, “Quadriplegics can become eligible for physician-assisted suicide based on a technicality that also qualifies many others who could live long, fulfilling lives — if appropriate medical care were available. That is, if you have six months to live in the absence of medical intervention, you are eligible. Therefore, diabetics and dialysis patients — who can live for decades with treatment — also qualify.”<sup>37</sup> This is not hypothetical. In countries where physician assisted suicide laws are lax, we see people with disabilities pressured to end their lives.

In Canada, the fiscal tradeoffs of long-term and palliative care costs appear to take precedence over the non-monetary value of a life in hospital administration.<sup>38</sup>

For someone who becomes a quadriplegic, the first year of health and living expenses is an average of \$1,064,716, and each subsequent year is an average of \$184,891, according to the Christopher & Dana Reeve Foundation.<sup>39</sup>

In 2019, the American Medical Association affirmed that, “It is the policy of the AMA that physician assisted suicide is fundamentally inconsistent with the physician’s professional role.”<sup>40</sup>

The medical profession should instead redouble efforts to ensure optimal treatment for pain and discomfort and encourage utilization of services and supports that enhance quality of life.





## THREATS TO THE RIGHT TO LIFE

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## Policy Areas for Consideration

- ✓ Prohibit the use of any federal funds for physician-assisted suicide.
- ✓ Enact state legislation that protects babies with disabilities from termination based solely on their disability status.
- ✓ Stop state legislation allowing physician-assisted suicide from enactment in other states and repeal state legislation in the existing states.
- ✓ Promote disability cultural competency requirements in medical training and education, and care.

# Housing Discrimination

In 1968, the Fair Housing Act (FHA) aimed to provide protections for people with disabilities against discrimination in government-funded housing programs and the renting, purchasing or financing of housing. This was reinforced in Section 504 of the Rehabilitation Act and a 1988 amendment to the FHA that took full effect in 1991.

Additionally, apartment and rental units fall under the protection of the ADA. All these laws call for “reasonable accommodations or reasonable modifications” such as allowing someone with a disability to transfer to a ground-floor unit, assigning an accessible parking spot or adding a grab bar to a tenant’s bathroom.<sup>41</sup> However, the FHA does not apply to single-family housing.

Despite these laws, less than 5% of housing nationwide is accessible for people with moderate mobility difficulties and less than 1% is accessible for wheelchair users.<sup>42</sup>

Unsurprisingly, the most common fair housing discrimination complaint is based upon disability.<sup>43</sup> With a rising national affordable housing shortage currently estimated at 7 million units, this means housing is both inaccessible and unaffordable.<sup>44</sup>

Apartments that are accessible tend to be in new builds, because only multi-family units built after 1991 are subjected to the requirements.

New builds are often much more expensive. For recipients of social safety net programs such as Supplemental Security Income (SSI), the antiquated \$2,000 asset limitation makes it impossible to secure decent housing.

**LESS THAN 5%**

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**LESS THAN 1%**

is accessible for  
wheelchair users.



## HOUSING DISCRIMINATION

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### Policy Areas for Consideration

- ✓ Increase federal standards for minimum housing accessibility.
- ✓ Examine creating minimum accessibility requirements for new single-family housing builds.
- ✓ Ensure that land banks and new affordable housing projects are accessible.

# Travel Inequality and Access Issues

The ADA established accessibility requirements for public and private ground transportation, including buses, vans, rail cars and similar vehicles.<sup>45</sup> It established pedestrian protections, such as curb cuts in sidewalks, that made walkways usable for people with mobility aids. Unfortunately, the ADA does not cover all disability rights for air travel, which has knock-on effects in the real world. For example, from December 2018 to March 2022, the Department of Transportation reported 20,000 wheelchairs “lost, damaged or completely destroyed by airlines.” Reports show an average of 1,000 per month misplaced<sup>46</sup>. For many passengers with disabilities, this can mean months without use of their wheelchair.

In 1986, President Ronald Reagan signed the Air Carrier Access Act (ACAA). While the ACAA prohibits discrimination based on disability, it does not mandate accessible standards for travel such as accessible bathroom stalls or training of staff to handle equipment and understand the needs of people traveling with disabilities.

Bathrooms on most domestic-flight airplanes have not been required to be accessible, and thus are not accessible, leaving individuals with disabilities who are unable to walk or use the bathroom without caregiver assistance no way to use the bathroom in flight irrespective of flight time. Wide-body planes with two aisles, most often used for international flights, have been required to have accessible lavatories since federal rulemaking in 1990.<sup>47</sup> However, airlines have increasingly been using single-aisle aircraft for long-haul flights. In 2023, the Department of Transportation (DOT) issued a rule requiring airlines to make lavatories on new single-aisle aircraft with at least 125 seats large enough to permit a passenger with a disability and attendant, both equivalent in size to a 95th percentile male, to approach, enter, and maneuver within as necessary to use the aircraft lavatory beginning in 2033.<sup>48</sup>

Airlines have also not been required to provide space for wheelchairs onboard and almost always check wheelchairs at the gate. Thus, those unable to walk are left to the care of untrained airline staff. Many instances of airline staff dropping or severely injuring paralyzed travelers have been documented.<sup>49</sup>





## TRAVEL INEQUALITY AND ACCESS ISSUES

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### Policy Areas for Consideration

- ✓ Codify the DOT 2023 rulemaking in the ACAA to require all lavatories to be accessible for both passenger and an attendant.
- ✓ Reform the ACAA to ensure airlines train a minimum number of staff to assist people with disabilities and that they have adequate equipment to safely maneuver and transport disabled travelers within the airport environment.
- ✓ Reform the ACAA to mandate a minimum number of wheelchairs onboard aircraft of a larger size and ensure that proper precautions are put in place to protect wheelchairs stowed below the cabin.



## Barriers to Marriage and Family Formation

When many people consider their “pursuit of happiness,” it includes marriage and having children. Marriage boasts many benefits, including more meaning and greater life satisfaction.<sup>50</sup>

For those who do have children, marriage and a two-parent household greatly decreases the likelihood of poverty. Only 7% of families are poor if there are two married parents, whereas 32% are poor in single-parent households.<sup>51</sup>

Our policies should do all they can to encourage marriage, but unfortunately there are great barriers to family formation for people with disabilities who participate in the disability safety net that do not exist for others. For example, the many individuals with disabilities who depend upon social services such as Social Security Income (SSI), the asset limitation is \$2,000 for an individual and \$3,000 for a couple. The SSI income limitation is \$943 per month for an individual, and just \$1,415 for a married couple.

While Medicaid rules vary somewhat by state, the asset limit for married couples can be up to \$4,000. This means that for those who find a partner and wish to get married, but their potential mate owns a home, or their combined income puts them over the SSI limit, they risk losing their SSI or Medicaid Home and Community-Based Services (HCBS) caregiver. The comparable in-home care without Medicaid coverage could cost \$50,000-200,000 per year. Medicaid waiver programs in some states do not count the assets of the spouse, but Medicaid eligibility can be tied to SSI eligibility.

The marriage penalty incurred by asset limitations is another way individuals with disabilities remain impoverished.

Next, there is social stigma for those with disabilities who have children that is underpinned by many state child custody laws. The National Council on Disability in 2012 reported that parents with disabilities face discrimination based on their disability in custody cases and in accessing reproductive healthcare. It found that, “In every state, disability may be considered when determining the best interest of a child for purposes of a custody determination in family or dependency court. A nexus should always be shown between the disability and harm to the child, so that a child is taken from a custodial parent only when the parent’s disability is creating a detriment that cannot be alleviated.

In addition, prospective parents with disabilities have more difficulty when it comes to accessing reproductive health care such as assisted reproductive technologies, and they face significant barriers to adopting children.”<sup>52</sup>

There are 35 states that include disability as grounds for termination of parental rights.<sup>53</sup> The new 2024 Section 504 rulemaking made a positive step in addressing this with “requirements to ensure nondiscrimination in the services provided by HHS-funded child welfare agencies, including, but not limited to, reasonable efforts to prevent foster care placement, parent-child visitation, reunification services, child placement, parenting skills programs, and in- and out-of-home services.”<sup>54</sup>

## MARRIAGE AND FAMILY FORMATION



### Policy Areas for Consideration

- ✓ Increase asset and income limitations for married couples in SSI, SSDI and Medicaid for people with disabilities, particularly those who receive caregiver support through Medicaid.
- ✓ Assess all state custody laws for discrimination against parents with disabilities.

# SECTION 2

## ACCESS TO CARE

### BACKGROUND:

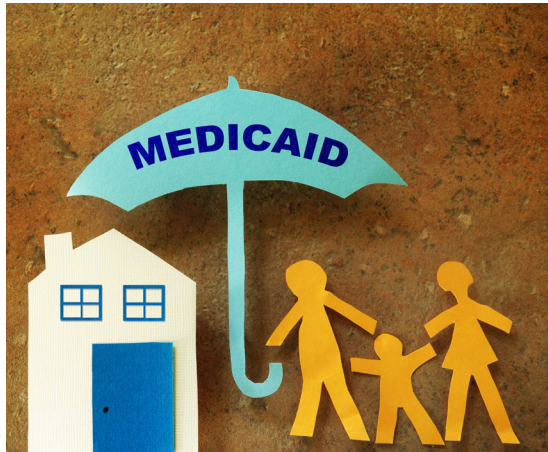
## Medicaid for Individuals with Disabilities

While the American healthcare system is a morass of complicated regulations and many problems, for the disability community it is even more perilous because often their everyday lives depend upon it. Many are largely dependent on government

healthcare programs, which unfortunately can have significant barriers to independence, marriage and work.

Over 10 million individuals with disabilities qualify for Medicaid based on a disability. Although many are eligible for both Medicare and Medicaid, most (6.2 million) do not have Medicare.<sup>55</sup> Over one-third of Medicaid beneficiaries who qualify on the basis of a disability do so through receipt of Supplemental Security Income (SSI).

The intent of Medicaid when established in 1965 was originally to serve the most vulnerable and needy, focusing on the elderly, disabled, pregnant women and children, but its scope has increased to include non-disabled childless adults earning up to 138% of the federal poverty limit since the passage of the Affordable Care Act.





# Barriers in Medicaid to Work, Independence, and Marriage

Many individuals with disabilities particularly rely upon caregivers who provide supports for daily living (such as cooking and hygiene), workforce participation and transportation. Medicaid covers these services through long-term care coverage in the form of institutional care or home and community-based service (HCBS) waivers.

According to a 2018 Congressional Revenue Service report, total Medicaid long-term service spending was \$154.4 billion in 2016, making Medicaid the largest single payer of long-term care.<sup>56</sup> Private insurance usually does not cover this kind of care, as it can run from \$50,000-\$200,000 per year in the private market. Thus, individuals with disabilities often find themselves reliant upon Medicaid as their sole health care option, which in turn provides major disincentives to work and marriage due to income and asset limitations and the absence of state portability of benefits.

As mentioned in the above section, the income and asset limitations in Medicaid keep individuals with disabilities from marriage, but they also keep people from getting a job or a promotion if it means that they could lose their Medicaid-provided caregiver support. Working more hours or an increase in hourly pay can cause a Medicaid recipient to surpass the income eligibility threshold, and thus lose their vitally needed caregiver.

Congress passed the Balanced Budget Act of 1997, creating “Medicaid Buy-In” programs at the state level, designed to overcome the steep benefits cliff that people with disabilities face when taking a job or a pay increase that brings them over the program income or asset limitation. Today there are 45 states with Medicaid Buy-In programs, and these programs usually require working disabled people to “buy-in” to the state Medicaid program through premiums or copayments while allowing a higher income.<sup>57</sup> Despite these positive improvements, research has found that the programs can still be too confusing to provide economic security and overcome the Medicaid cliff as they enter the workforce.<sup>58</sup>

Lack of employment opportunities and job instability effects disabled individuals more than the general population. In order

to open up more job options, disabled people need the option to relocate to a different state. Unfortunately, those who receive long-term care support through Medicaid often cannot leave their current state because their Medicaid benefits will not follow them. Medicaid is a state-administered program and does not transfer when someone moves to another state and the wait lists and wait times to receive a HCBS waiver is prohibitive to moving.

The wait time to receive a Medicaid HCBS waiver averages 36 months. There were over 692,000 people on state wait lists for waivers in 2023.<sup>59</sup> People with intellectual or developmental disabilities make up about 75% of waiting lists, and seniors and adults with physical disabilities make up the other 25%. In the state of Florida, for example, nearly 25,000 people with disabilities are on the HCBS waitlist and families can expect to wait 7 or more years before getting waiver services.<sup>60</sup>

## **BARRIERS IN MEDICAID TO WORK, INDEPENDENCE, AND MARRIAGE**

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### **Policy Areas for Consideration**

- ✓ Re-allocate Medicaid funding formulas to boost Medicaid HCBS funding in states with the goal of decreasing wait lists.
- ✓ Study which state Medicaid Buy-In programs are most effective and apply best practices.
- ✓ Allow for Medicaid portability across states.
- ✓ Increase income and asset limitations for SSI and Medicaid and lengthen redetermination period for those with permanent disabilities.
- ✓ Remove any age limitations for ABLE 529 savings accounts.

# Caregiver Shortages and Burnout

The long wait list for HCBS waivers coupled with a shortage of employable caregivers can often mean that family members serve as caregivers for their disabled children, parents or other family members.

The number of caregivers increased from 43.5 million in 2015 to about 53 million in 2020, or more than 1 in 5 Americans.<sup>61</sup> This number will only increase as the population ages.

By 2030, an estimated 73 million people in the United States will be 65 years or older. In the U.S., 4.5 million paid direct care workers provide care for people in homes, residential care homes, nursing homes and hospitals.

By 2028, the need for paid direct care workforce is expected to grow by 1.1 million new jobs.<sup>62</sup> There is already a shortage of in-home care providers, which leaves people with disabilities in unhealthy or unsafe scenarios and at an increased risk of unwanted institutionalization.<sup>63</sup>



By 2030, an estimated 73 million people in the United States will be 65 years or older. In the U.S., 4.5 million paid direct care workers provide care for people in homes, residential care homes, nursing homes and hospitals.



Unpaid family caregivers typically forego or decrease their hours of outside employment, leading to income loss in the family. Almost 2 in 10 employed caregivers had to stop working, while 4 in 10 had to reduce their working hours to care for a loved one.

The average annual out-of-pocket cost for caregivers is \$7,200. It is a challenging job that brings not only financial strain, but also emotional and physical burdens.

Nearly 1 in 5 caregivers report only fair or poor health.<sup>64</sup> The shortages and burnout of both paid and unpaid caregivers are of great concern because the demand for in-home care is only increasing with an aging population.

## CAREGIVER SHORTAGES AND BURNOUT

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### Policy Areas for Consideration



- ✓ Provide higher Medicaid and Medicare reimbursement rates for caregivers and personal care assistants.
- ✓ Improve workforce data collection systems.<sup>65</sup>
- ✓ Research and assess programs and policies that promote self-directed services, which “allow participants, or their representatives if applicable, have decision-making authority over certain services and take direct responsibility to manage their services with the assistance of a system of available supports.”<sup>66</sup>
- ✓ Assess workforce training programs and licensing requirements in states to encourage a greater caregiver workforce.
- ✓ Increase the dependent care tax credit for caregivers of people with disabilities.



## Institutional or Residential Care Shortages

While in-home care is preferable to many individuals with disabilities because it keeps them connected to their community, it is not the best option for those with very complex medical needs or mental illness associated with their disabilities. However, there is an extreme shortage of beds available for inpatient care.

From the 1950s onward, there has been a move toward deinstitutionalization attributed to a variety of factors including disability civil rights, the *Olmstead v L.C.*<sup>67</sup> Supreme Court decision, President John F. Kennedy's policies and Medicaid financing formulas.<sup>68</sup> In 1955, about 560,000 Americans were committed to public psychiatric institutions. At present, there are fewer than 40,000.<sup>69</sup>

Many of these policy changes were sorely needed to reform a system that did not provide adequate protections against abuse of disabled individuals, such as the famed documentary by Geraldo Rivera documenting the squalid and inhumane conditions in 1972 at the Willowbrook State School for the developmentally disabled on Staten Island<sup>70</sup> and "Christmas in Purgatory,"<sup>71</sup> a grim photographic essay on the inhumane conditions suffered by institutionalized people with severe intellectual disabilities.

This was all before the ADA was passed and before the 1999 *Olmstead* Supreme Court ruling that reinforced disability rights to be integrated into the community. Today there are significant protections

for individuals that were not present during institutionalization of the 20th century. Thus, the disability community's continued advocacy for community integration need not come at the expense of adequate inpatient beds for those who have severe needs on the continuum of care spectrum.

This shortage of beds is felt most acutely for psychiatric care and is directly caused by a provision in Medicaid in place since 1965 that limits beds in "Institutions of Mental Diseases" (IMDs), which are specialized psychiatric hospitals. The law prohibits IMDs from billing Medicaid for care given to adults at a facility with more than 16 beds. The idea behind the law was for states to assume this cost and make psychiatric care more community-focused, however, the result was that hospitals stopped providing these services at their sixteenth bed.

The average among the 34 Organization for Economic Co-operation and Development (OECD) countries is 68 psychiatric beds per 100,000 people, while the United States' average of 25 beds per 100,000 people — near dead last in OECD countries.<sup>72</sup> As a result, emergency rooms, prisons, and, increasingly, the streets, have unfortunately taken on the burden of care for those with mental disorders. The cost to individuals is high because a prison environment is particularly harsh for disabled individuals or those with mental disorders,<sup>73</sup> where they also experience a higher rate of victimization.<sup>74</sup>

A 2016 report by the Treatment Advocacy Center found that 44 states and the District of Columbia have higher populations of mentally ill individuals in their jails and prisons than they do in their public psychiatric facilities.<sup>75</sup> It also costs more to house mentally ill inmates and seriously mentally ill inmates incur new charges by virtue of their disability while in prison or on parole.<sup>76</sup>



44 states and DC have higher populations of mentally ill individuals in their jails and prisons than they do in their public psychiatric facilities.



Furthermore, law enforcement resources are diverted to the streets to handle extreme psychiatric cases instead of those people receiving the medical care they need.

The cost to society is astronomical. According to the U.S. Department of Housing and Urban Development, people living in shelters are more than twice as likely to have a disability compared to the general population.<sup>77</sup>

On a given night in 2023, 31 percent of the homeless population reported having a serious mental illness.<sup>78</sup> Emergency rooms are above capacity with psychiatric cases, particularly with pediatric cases in the years since the COVID-19 pandemic.

According to data gathered from 38 children's hospitals by the Children's Hospital Association, trips to emergency departments for mental-health treatment were 20% higher in 2022 compared with 2019. Children seeking help in E.R.s for suicide or self-harm soared 50% at those hospitals during the same period.<sup>79</sup>

It is estimated that about 1 in 8 visits to hospital emergency rooms involves a mental health or substance use condition.<sup>80</sup> These avoidable emergency room visits that should have been candidates for mental health or substance abuse care are estimated to cost \$8.3 billion per year.<sup>81</sup>

## INSTITUTIONAL OR RESIDENTIAL CARE SHORTAGES

### Policy Areas for Consideration



- ✓ Eliminate the Medicaid Institutions of Mental Diseases (IMD) exclusion.
- ✓ States and localities should increase funding for community residential facilities, which would be offset by lowered state expenditures on state prisons.
- ✓ Build upon Medicaid demonstration projects to increase reimbursement rates for Certified Community Behavioral Health Clinics and then study their effectiveness.<sup>82</sup>

# Medical Equipment Access and Quality

The good news is that technological advances of the past few decades have resulted in medical equipment that drastically improves the quality of life for individuals with disabilities. From cochlear implants in the 1970s to the promise of Neuralink<sup>83</sup> today, medical technology and equipment allows people with disabilities to be more active in the community, experience less pain and enjoy their lives.

The bad news is that the payment systems for medical equipment has not kept up with innovation or societal expectations. As previously discussed, many individuals with disabilities already face challenges to economic mobility, and the cost and access to good equipment for those who need it exacerbates this.

The high cost of this equipment leads most individuals to seek insurance coverage either through private insurance or Medicaid and Medicare. This is generally defined as “Durable Medical Equipment” (DME) and is subject to a confusing plethora of restrictions and regulations that private and government insurance must comply with under the law.<sup>84</sup>

As with many such complicated insurance regulations, insurers interpret them as they see fit and these definitions drive what is and is not covered. Additionally, novel technologies must go through the FDA’s expensive and often lengthy regulatory process in order to be covered by insurers.<sup>85</sup> Further, the cost of dealing with insurers or Medicaid bars new entrants into marketplace of manufacturers, dealers and repairers.





Typically, Medicaid or Medicare statute drives the industry standard. So, while an individual's life may greatly benefit from having a power-assist or seat lift on their wheelchair, insurance may arbitrarily deny this coverage based on DME standards.

Laws only allows for a new wheelchair every five years, so no matter how much a person utilizes their chair for daily activities, they must live with failing equipment until the arbitrary five-year mark rolls around. Delays and insurance denials have real costs, including missing work or school and experiencing secondary injuries such as pressure sores or torn rotator cuffs.



## MEDICAL EQUIPMENT ACCESS AND QUALITY

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### Policy Areas for Consideration

- ✓ Give consumers the "Right to Repair," to fix products they own with parts and repair manuals made available by the manufacturer, in federal or state law.
- ✓ Analyze opportunities to increase the scope of products covered by insurance.
- ✓ Require complex rehab technology companies to complete repairs within a reasonable period of time.

# Healthcare Bias

Quality healthcare is vital to a person with a disability, but unfortunately the healthcare system is rife with discrimination and disrespect for equal dignity.

A 2021 survey of over 700 practicing US physicians found 82.4 percent of physicians reported that people with significant disability have worse quality of life than nondisabled people. Only 40.7 percent of physicians were very confident about their ability to provide the same quality of care to patients with a disability and just 56.5 percent strongly agreed that they welcomed patients with disability into their practices.<sup>86</sup>

The COVID-19 pandemic demonstrated real effects of this when it came down to rationing of care and scarce resources. Hospitals create crisis of care protocols in such

situations, and at the beginning of the COVID-19 pandemic, some states explicitly allowed the denial of a ventilator to “individuals based on the presence of intellectual disabilities, including ‘profound mental retardation’ and ‘moderate to severe dementia’ and “people with spinal muscular atrophy who need assistance with activities of daily living” until the Department of Health and Human Services and the Office for Civil Rights intervened.<sup>87</sup> Pandemic restrictions also limited access to resources, supplies and staff, leaving many to struggle to access routine medical care.<sup>88</sup>

This kind of healthcare rationing can also be seen in the practice of using “Quality-Adjusted Life Years” (QALYS) to determine



Only **40.7 percent** of physicians were very confident about their ability to provide the same quality of care to patients with a disability.

insurance reimbursement and healthcare coverage of interventions or pharmaceuticals. This practice values an additional year of a “healthy” life over that of a person with a disability. This practice is more common in other countries that socialize the cost of universal healthcare, but it is finding its way into U.S. practices such as drug pricing.<sup>89</sup> This is a blatant disrespect for the equal dignity of human life.

A large step forward was made with the 2024 HHS final rule on Section 504 of the Rehabilitation Act to strengthening protections against disability discrimination in healthcare and human services. Among other protections, it “prohibits the use of any measure, assessment, or tool that discounts the value of a life extension on the basis of disability to deny, limit, or otherwise condition access to an aid, benefit or service.” It also “ensures that medical treatment decisions are not based on negative biases or stereotypes about individuals with disabilities, judgments that an individual with a disability will be a burden on others, or dehumanizing beliefs that the life of an individual with a disability has less value than the life of a person without a disability.”<sup>90</sup> While this rulemaking is positive, it should be codified into statute as well.

## HEALTHCARE BIAS



## Policy Areas for Consideration

- ✓ Ban QALYS from use in healthcare coverage and insurance reimbursement decisions.
- ✓ State crisis of care protocols should treat individuals equally in dignity and worth and medical providers should be trained accordingly.
- ✓ Promote disability cultural competency requirements in medical training and education, and care.

## SECTION 3

# BARRIERS TO WORK AND INDEPENDENCE

### BACKGROUND:

## Barriers that People with Disabilities Face in Employment and Independent Living

A chief goal of measuring the success of our programs and policies for people with disabilities should be to determine if programs are contributing to or detracting from their independence. Leading indicators show us that we are still failing that goal. Today, 25% of individuals with disabilities in America live in poverty — more than twice the rate of individuals without disabilities.

While not all people with disabilities are able to work, many face significant barriers to entering the workforce that can include a lack of education and training, physical barriers or a steep benefits cliff.

Though the number of disabled people in the workforce has increased in recent years, the gap in workforce participation with those who are not disabled is staggering: 40.6% of persons with disabilities are participating in the workforce as of April 2024,<sup>91</sup> only about half the rate of the nondisabled. Studies have shown that not working correlates with long-term negative mental and social



# A chief goal of measuring the success of our programs and policies for people with disabilities should be to determine if programs are contributing to or detracting from their independence.

health impacts.<sup>92</sup> Not working negatively affects levels of stress, anxiety, depression, suicide risk, life expectancy, family relationships, community engagement and physical health.

According to the U.S. Bureau of Labor Statistics (BLS) in 2021, 43.7 percent of persons with a disability who were not working reported some type of barrier to employment. A person's own disability, lack of education or training, the need for special features at the job and lack of transportation were among the barriers reported.<sup>93</sup>

The BLS study found that when it comes to education, 21.1 percent of people age 25 and over with a disability had a bachelor's degree or higher, compared with 41.0 percent for persons with no disability. More than half of people with disabilities receive some type of government assistance: 56.8 percent of persons with a disability received financial assistance within the past year from one or more of the following sources: Workers Compensation, Social Security Disability Income, Supplemental Security Income, Veterans Disability compensation, disability insurance payments, Medicaid, Medicare and other payments or programs. However, of those who were employed, only 23.8 percent receive assistance.

While a level of government assistance may be necessary in perpetuity for those who have a permanent disability that bars them from self-sustaining work and income, there must be some evaluation to determine when these programs cross the line and capture people with disabilities in a snare of long-term dependence and poverty.

We must also ensure that workplaces and community infrastructure are prepared to welcome and provide accommodations that allow people with disabilities to work. This goal of the ADA's passage, to "advance economic self-sufficiency" for people with disabilities, is yet unrealized. As President George H.W. Bush optimistically said when he signed the ADA, "Every man, woman and child with a disability can now pass through once closed doors into a bright new era of equality, independence, and freedom."

# The High Cost of Living with a Disability

Researchers estimate that households with an adult with a disability that limits their ability to work requires on average 28 percent more income (or an additional \$17,690 a year) to obtain the same standard of living as a similar household without a member with a disability.<sup>94</sup>

A person's financial stability comes not only from their income, but also from their living expenses. A person with a disability and their household incurs extra expenses such as caregiving, medical therapies, pharmaceuticals, medical devices and their maintenance, acquiring and maintaining service animals, dictation tools, more expensive adaptive vehicles, food for a special diet, grocery delivery, installing ramps or renovations to the home or more expensive housing that is accessible and convenient.

These costs vary widely depending on the person's type of disability and existing social supports. For those with disabilities that are lifelong and require a lifetime of caregiving and the inability to work at all, the material cost to families and caregivers can be very high. These families ought not also have the increased and undue burdens of redeterminations and asset limitations that keep them from providing long-term supports for their disabled dependents for life.

The IRS allows taxpayers to deduct out-of-pocket medical expenses that go above 7.5 percent of their Adjusted Gross Income (AGI). While the 2017 Tax Cuts and Jobs Act (TCJA) lowered this from a previous 10 percent threshold, this is still a high bar to meet for a population with a notably lower average income.

If both the cost of living is so much higher and the income levels are lower for people with disabilities, then the social safety net and the tax code should account for this.

The creation of the Achieving a Better Life Experience (ABLE) Accounts in 2014 by Congress was a positive step forward in allowing people with disabilities to save for expenses. It allows contributions to an ABLE 529 savings account up to \$18,000 per year without risking loss of benefits and can be used to pay for qualified disability expenses such as housing, education, transportation,

health, prevention and wellness, employment training and support, assistive technology and personal support services. Distributions are tax-free if used for qualified disability expenses.<sup>95</sup> Starting in 2026, to be eligible, the beneficiary must have a qualifying disability that started before the age of 46<sup>96</sup>.



## THE HIGH COST OF LIVING WITH A DISABILITY



### Policy Areas for Consideration

- ✓ When determining asset limitations for disability safety net programs, deduct disability-related costs from the means testing.
- ✓ Consider removing asset limitations and unduly burdensome redetermination processes for the permanently disabled who cannot work.
- ✓ Assess ways the tax code can be altered to provide targeted treatment for people with disabilities, such as lowering the threshold for deduction of itemized unreimbursed expenses below the current 7.5 percent of Adjusted Gross Income.
- ✓ Expanding the definition of “medical expenses” to include the costs of by trained technicians who aren’t medical professionals, such as nurses and doctors.
- ✓ Remove all age limitations for ABLE Accounts.



# The Disability Benefits Cliffs

Benefit cliffs are an unfortunate part of the American social safety net system and occur when an individual discovers that they will become worse off economically by earning more money. This occurs when the loss in benefits exceeds the additional take-home pay from a job or a pay increase<sup>97</sup>.

Nowhere are cliffs more pronounced than with disability benefits. When someone is receiving multiple benefits, such as a combination of SSI/SSDI, Medicaid and food stamps (SNAP), the cumulative worth of those benefits can be a very high dollar amount. The job or pay raise they would need to overcome the benefits cliff would need to cover the cost of their caregiver and private health insurance, cash assistance from SSI that is somewhere near \$1,000 per month, and food assistance that is around \$740 for a family of four. In many cases that number can exceed \$100,000 a year in income, an insurmountable entry point into the workforce for a person with a disability.

There is also an added layer of insecurity that comes with joining the workforce and losing benefits. A person with a disability may have waited for months and waded through a complicated bureaucratic system with the aid of a benefits lawyer to obtain benefits in the first place.

The varying eligibility and limitations of these safety net programs can be so complicated that the very risk of losing them may be enough to keep a person with a disability far from the path to work.

This is demonstrated by the limited success of The Ticket to Work and Work Incentives Improvement Act of 1999.<sup>98</sup> Ticket to Work funds community-based organizations to provide work incentives and training and allows an individual to keep their SSI/SSDI and Medicaid/Medicare benefits for up to 9 months with a gradual phase down while on the path to work. The program provides some combination of job coaching, job counseling, training, benefits counseling and job placement through a variety of approved providers.<sup>99</sup>

The outcomes of the program have not been overly promising: In 2021, the Government Accountability Office (GAO) estimated that 5 years after starting Ticket to Work, participants' average earnings were \$2,451 more per year than that of similar nonparticipants. However, the majority of participants remained unemployed 5 years after starting Ticket to Work.<sup>100</sup>





## THE DISABILITY BENEFITS CLIFFS

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### Policy Areas for Consideration

- ✓ Analyze why disability work incentive programs like Ticket to Work and Medicaid Buy-In are not utilized more widely or show long-term success.
- ✓ Simplify access to safety net programs by streamlining and consolidating the delivery of programs through “One Door,” like the successful Utah model.<sup>101</sup>
- ✓ Require state caseworkers to provide individual action plans that provide all beneficiaries with the available resources to find a secure path to work.
- ✓ SSDI assesses disability based on the vocational grid, which hasn’t been updated since the 1970s and still heavily relies on a physical, 40-hour a week occupation. It should be updated to include part time work and accommodations.

# Workplace Barriers and Unreliable Transportation

The earlier quoted BLS report found that the biggest barriers to work reported were a person's own disability, lack of education or training, the need for special features at the job and lack of transportation. Many of these problems can be addressed by features of a post-COVID-19 workforce: Flexibility and the ability to work remotely at least part time.



Before the pandemic, many individuals with disabilities requested such accommodations from employers and were looked down upon or denied, only to find that these were indeed workable requests when nondisabled individuals needed them. This cultural change in work provided a big boost to people with disabilities who struggle with transportation, chronic fatigue or health needs throughout the day.

People with disabilities are substantially more likely to work in a fully remote position, even after controlling for education, occupation, industry, and other individual characteristics. In particular, "a worker who reports any disability is 2.4% more likely to be full-remote than an otherwise similar worker. This represents a 22% increase in likelihood of being full-remote compared to the population-wide average of 10.7%."<sup>102</sup>

The GAO found that Vocational Rehabilitation programs that work to train disabled workers can do more to train employers.

Understanding the diverse needs of people with disabilities requires employer understanding. The GAO found that Vocational



Rehabilitation programs that work to train disabled workers can do more to train employers.<sup>103</sup> New technologies used to find employees, such as use of algorithms or artificial intelligence tools to sort through job candidates must also be trained not to discriminate against people with disabilities solely based on their disability.<sup>104</sup>

Finding ways to hire people with disabilities is not only good for individuals, but it is also good business. A 2023 report from Accenture found that companies that lead in disability saw 1.6 times more revenue, 2.6 times more net income and 2 times more economic profit.<sup>105</sup>

While providing more opportunities to work from home may help some with disabilities, many jobs cannot be done at home. A major barrier to being a reliable employee is transportation.

The ADA requires access to new or remanufactured transportation vehicles, including buses and vans, rail cars, automated guideway vehicles, trams and similar vehicles. However, these options are often inadequate. Of the nearly 2 million people with disabilities who never leave their homes, 560,000 never leave home because of transportation difficulties.<sup>106</sup> Public transportation has long been unreliable, especially in rural areas. However, ride-sharing and the potential advent of driverless vehicles have the potential to provide a cheaper, more customer-focused solution to this problem.

## WORKPLACE BARRIERS AND UNRELIABLE TRANSPORTATION

### Policy Areas for Consideration



- ✓ States should ensure that vocational rehabilitation providers work closely and provide training for employers in the state.
- ✓ Rather than only prioritizing funds for the public transportation system, states and localities should consider also subsidizing more accessible vehicles in ride-sharing fleets and/or provide individuals with disabilities ridesharing vouchers.

# Education and Training

Education for students with disabilities has come a long way. The federal Individuals with Disabilities Education Act (IDEA) of 1990 originally passed as the Education of Handicapped Children Act in 1975. It was modeled after the pioneering 1972 Massachusetts General Law Chapter 766.<sup>107</sup> Prior to the passage of the Education for All Handicapped Children Act, schools were educating just 1 in 5 children with disabilities. Some states even had laws in place excluding children who were blind, deaf, or had developmental delays from accessing education.<sup>108</sup>

IDEA has evolved over the years with the core goal to provide children with disabilities equal opportunities in education and integration into the community through the public school system.

Under the IDEA, school districts are required to evaluate students with disabilities and determine which students are eligible for IDEA services. Then, schools working with parents and Individualized Education Plan (IEP) teams develop an IEP for each child to determine what IDEA services to provide. Parents can appeal the accommodations made for their children, if necessary, but the litigation can be costly and burdensome.

While the IDEA has provided crucial K-12 education for children with disabilities, the next step in preparing children with disabilities for the transition to adulthood with life and employment skills for post-secondary education and employment is lacking.<sup>109</sup> Students with disabilities are more likely to not graduate than nondisabled students. During the 2018-19 school year, 68.2 percent of disabled students graduated high school compared with 85.8 percent of nondisabled



students. Students with disabilities are also more likely to drop out of postsecondary education. In a study from the 2011-12 school year, 25.1 percent of disabled students dropped out after one year with no certificate or degree, compared with 13.5 percent of nondisabled students<sup>10</sup>. The low employment participation rate of people with disabilities was covered earlier in this report.

While many IDEA-funded public schools are staffed with skilled special education counselors and teachers who can provide needed skills integrated into the broader school's programming, not all district schools may be equipped for each disabled child's needs. Parents of children with disabilities should be free to move their IDEA funding to the right school or training program that gives their child the best opportunities to succeed in life.

For adults, State Vocational Rehabilitation (VR) programs are the main source of government workforce training providers. Many states and programs currently measure effectiveness by simply reporting a starting salary in the year after someone exits a vocational rehabilitation service, but more information is needed to know how they are truly helping long-term with the \$2.5 billion spent on the program annually. Findings from a 2017 study demonstrate that while persons receiving VR services are more likely to obtain employment, only 18% are working competitively, often for minimum wage.<sup>11</sup>

## EDUCATION AND TRAINING

### Policy Areas for Consideration



- ✓ Pilot state Micro-Educational Savings Accounts that follow the child with IDEA funds for a customized learning experience and better transition to post-secondary education or the workforce.<sup>12</sup>
- ✓ Require states to collect follow-the-person data on outcomes of Vocational Rehabilitation programs.
- ✓ Integrate Vocational Rehabilitation services into the broader social safety net casework and IDEA IEP plans.





# Top Policies to Consider

- ✓ Eliminate the Medicaid Institutions of Mental Diseases (IMD) exclusion and build upon Medicaid demonstration projects to increase reimbursement rates for Certified Community Behavioral Health Clinics and then study their effectiveness.
- ✓ Reform the Air Carrier Access Act (ACAA) to ensure safety and access.
- ✓ Increase asset and income limitations in SSI, SSDI and Medicaid for people with disabilities.
- ✓ Reallocate Medicaid funding formulas to boost Medicaid HCBS funding in states with the goal of decreasing wait lists, study how to increase effectiveness of Medicaid Buy-In programs and allow Medicaid portability across states for people with disabilities.



# CONCLUSION

While great strides have been made in the past 50 years particularly in providing equal protection and civil rights under the law, it is time to assess the policies and programs that impact people with disabilities.

Current outcomes indicate that people with disabilities fall far behind their nondisabled peers in nearly every indicator of wellbeing. There is great potential to remove government barriers and program disincentives that are holding people with disabilities back. It will require a serious study of existing program outcomes to see what is successful in bettering health outcomes, providing more pathways to education and work, increasing independence and removing barriers to marriage and family formation.

Additionally, we have the opportunity to embrace creative solutions that empower people with disabilities to take advantage of new technologies and private innovations that will improve the lives of the largest minority group in the world.

Those who undertake these reforms are not just doing the right thing, but they will gain the appreciation of an underserved voting bloc who are waiting for their policymakers to acknowledge the challenges they face every day. Not only is this a moral imperative, but it is also timely, as the challenges set forth will only grow in the coming years with an aging population.

To learn more about Able Americans please visit:

[www.AbleAmericans.us](http://www.AbleAmericans.us)



## ABOUT THE AUTHOR

### **RACHEL BARKLEY**

Rachel is the director of Able Americans a program of the National Center for Public Policy Research. She is an experienced coalition and community builder at the state and national level. She recently started her own small business, RK Barkley Consulting, to help organizations move forward policies that advance freedom and promote human dignity through coalition building and policy strategy. She is also the executive director of the Alliance for Opportunity, a multi-state project to move 1 million people out of poverty to live flourishing lives.

Just three weeks after having their first baby and turning 30 in 2019, Rachel was diagnosed with a rare spinal cord tumor that threatened her life. The tumor and surgery to remove it made her a part of the disability community overnight as a quadriplegic with a spinal cord injury (SCI).

Previously, Rachel worked as External Relations Senior Advisor for Rep. Cathy McMorris Rodgers (WA-05), Director of Outreach for the U.S. House of Representatives Conference Chair and as Director of Coalitions and State Outreach for the largest caucus in Congress. In her roles, she partnered with outside think tanks, advocacy groups, trade associations and state leaders to advance legislation and coordinate messaging strategies.

Rachel got her start at a national non-profit for state policy think tanks, the State Policy Network (SPN), where she worked as a liaison between state and national organizations. She served on the board for a DC charter school start-up and on the advisory council for Pepperdine University School of Public Policy's American Project.

Rachel is originally from Ocala, Florida, and graduated from the University of Florida with dual degrees in Public Relations and Political Science. She lives with her husband and three children near Washington, DC.

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## DR. MARK MOSTERT

Mark P. Mostert, Ph.D., is senior researcher at Able Americans, the National Center's project to support Americans living with intellectual, developmental and physical disabilities.

Mark received his undergraduate degree from the Johannesburg College of Education (South Africa), an M.Ed. in special education from the University of South Alabama and a Ph.D. in special education research from the University of Virginia.

Mark has an extensive academic background as researcher, author and presenter, both nationally and internationally. He spent 35 years in academia, the last twenty at Regent University where he was full professor of special education while directing the doctoral program in special education. He also served as the director of the Institute for the Study of Disability and Bioethics, and as web content director of the award-winning *Useless Eaters* website.

Mark has served as a disability consultant to several member nations at the UN on topics related to disability policy and practices. He resides in Virginia Beach, where he pursues his lifelong love of opera and classical music.



## LESLIE FORD

Leslie Ford is a Former White House Domestic Policy Advisor and Special Assistant to the President and founder of Ford Policy Solutions

Ford previously served in the Trump Administration in the White House as a Domestic Policy Advisor and Special Assistant to the President from 2018 to 2020. In that role, Ford had broad responsibility for the development of the Administration's welfare and anti-poverty strategic agenda and oversaw the execution of policy at the Assistant Secretary level throughout the Administration as well as the interagency policy coordination process. She also worked with leading anti-poverty practitioners and Congressional policy leaders. She focused on advancing reforms to the U.S. social safety net programs so that all Americans can access meaningful work that enables them to move toward self-sufficiency and greater control of their futures.



Before her work in the White House, Ford was a Legislative Advisor to Sen. Mike Lee (R-Utah) on Capitol Hill. She oversaw the development of 22 pieces of legislation and more than 50 amendments on significant bills to advance health and welfare reforms. Ford started her career at the Heritage Foundation in 2011 as a Research Assistant focusing on religious liberty, civil society and poverty studies. Her work has been featured in the Wall Street Journal and National Review. Ford received a bachelor's degree from Franciscan University of Steubenville. She has four children and lives with her husband in Virginia.

## **MEREDITH RAYMOND, MSW**

Meredith Raymond is a Policy Analyst at U.S. Department of Health and Human Services. She is a subject matter expert on a variety of issues including caregiving, health equity, and disability employment.

A disability advocate, Meredith previously worked at a Center for Independent Living where she led a nursing home transition program and launched a case management department that supports people to live independently and fully participate in their local communities.

Meredith holds a master's degree in social work from Washington University in Saint Louis and bachelor's degree from the University of Florida.



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