











# Economic Justice Is Disability Justice

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The relevance of disability in the understanding of deprivation in the world is often underestimated....

—Amartya Sen¹

Disability<sup>2</sup> can be both a cause and a consequence of economic insecurity. It can be a cause when disability or illness spurs job loss, a reduction in earnings, substantial additional disability-related costs, obstacles to education and training, or possibly some combination of these and other drivers of deprivation and hardship. Meanwhile, disability can be a consequence of economic insecurity—since poverty and economic instability can impede access to health care and preventive services, while also increasing the chance that an individual lives and/or works in environmental conditions that are harmful to their health. As a result, disability and poverty go hand in hand.

Yet, despite the fact that more than one in four adults in the United States live with disabilities<sup>3</sup>—numbers that are rapidly rising to new heights as the COVID-19 pandemic has been a mass disabling event—U.S. economic policy conversations all too rarely include a disability lens. Indeed, until recently, the U.S. Census Bureau's annual report on income, poverty, and health insurance coverage did not even contain information on poverty among disabled people. It does

now, and according to the Census's Supplemental Poverty Measure (SPM), people with disabilities experience poverty at double the rate of nondisabled people; in 2019, 21.6 percent of disabled people were considered poor under the SPM compared with just over 10 percent for those without disabilities. The economic hardships people with disabilities face are prevalent in many aspects of life: disabled people are three times as likely as nondisabled people to experience food insecurity. And roughly half of U.S. adults who turn to homeless shelters have a disability.

# HOW MANY ADULTS IN THE UNITED STATES ARE DISABLED?

• Disability is a complex, multidimensional, and evolving concept, with varying definitions used in different contexts. Many surveys and national data sets are inconsistent in their definitions and analyses of disability. However, taken together, data from various surveys produced by the Census Bureau and other federal agencies can be used to estimate the number of adults in the United States who are disabled. Most of these surveys use a standardized set of six questions that ask about activities of daily living, including difficulty hearing, seeing, walking or climbing stairs, dressing or bathing, concentrating or remembering, and doing errands alone. The best estimates suggest that 61 million, or one in four U.S. adults, live with disabilities—numbers that are rapidly rising due to the COVID-19 pandemic, which has been a mass disabling event. An appendix to this report includes a more detailed discussion of defining and counting disability.

 $This \ report\ can be found\ online\ at:\ https://tcf.org/content/report/economic-justice-disability-justice/$ 

Barriers to employment—including denial of reasonable accommodations and other forms of disability discrimination by employers, which remain pervasive more than three decades after the Americans with Disabilities Act (ADA) was signed into law—are an important part of the picture.<sup>8</sup> While some people's disabilities may preclude full-time and/or traditional employment, millions of disabled people can and do work. Yet disabled workers in the United States face much higher rates of unemployment than their nondisabled peers.<sup>9</sup> And as new analysis in this report finds, a stark pay gap means that disabled workers who are employed were paid an average of 74 cents on the dollar in 2020 compared with nondisabled workers.<sup>10</sup>

It is critical to note that, due to a combination of structural as well as cultural ableism and racism, disabled people of color face multiple levels of marginalization in the United States, translating into even greater economic disparities and rates of poverty and hardship for Black and brown members of the disability community. For instance, in 2020, one in four disabled Black adults lived in poverty compared to just over one in seven of their white counterparts." LGBTQI+ disabled people face multilayered economic marginalization, as well: for instance, a 2021 study by the Williams Institute found that nearly 46 percent of LGBT individuals reported experiencing workplace harassment or discrimination due to their sexual orientation or gender identity at some point during their lives, with roughly one-third reporting such experiences within the past five years.<sup>12</sup> Future work by The Century Foundation will explore additional, critical intersections such as gender.

The United States has made important strides over the past half-century toward removing barriers to employment, education, social participation, and accessibility for disabled people. The ADA, signed into law in 1990 and most recently amended in 2008, prohibits discrimination on the basis of disability and mandates that people with disabilities have "equal opportunity" to participate in American life. The Rehabilitation Act of 1973, the predecessor to the ADA, bars any entity receiving federal funding from discriminating on the basis of disability.<sup>13</sup> The Individuals with Disabilities Education Act (IDEA),<sup>14</sup> enacted originally in 1975 and most

recently reauthorized in 2004, requires that children with disabilities be provided a "free appropriate public education," mandating access to an equitable educational experience; IDEA also provides significant funding for early intervention programs for infants and toddlers with disabilities and their families.

More recently, the 2014 Workforce Innovation and Opportunity Act (WIOA)<sup>15</sup> expanded access for people with disabilities to education and training programs, programs for transition-age youth and young adults transitioning to adulthood, vocational rehabilitation, and more. This reauthorization also refocused funding on youth, providing new requirements for coordination and a focus on competitive integrated employment opportunities. And key public programs such as Medicaid, Social Security Disability Insurance (SSDI), and Supplemental Security Income (SSI) have become cornerstones of our nation's social insurance and public assistance fabric, dramatically increasing access to health care, critical services and supports such as personal attendant care and direct service providers, and vital income support for disabled people and their families.

However, while we have made progress as a nation toward the goals underpinning the ADA, the unacceptable levels of poverty and hardship among disabled people that have persisted well into the twenty-first century make abundantly clear that much work remains. Moreover, while the economic crisis facing the U.S. disability community long predates COVID-19, the impact of the pandemic—which, as a mass disabling event, has spurred the largest influx of new entrants to the U.S. disability community in modern history<sup>16</sup>—has only made it clearer that we can no longer afford to ignore disabled people in our policymaking. Indeed, new polling<sup>17</sup> conducted by Data for Progress, in partnership with The Century Foundation's newly launched Disability Economic Justice Collaborative, finds that just 3 in 10 disabled voters believe that leaders in Washington care about people with disabilities.

In a positive trend, even prior to the pandemic, public awareness was finally beginning to grow in the United States that, with one in four Americans living with disabilities, every issue is a disability issue.<sup>18</sup> In one particularly noteworthy example, in the run-up to the 2020 election, for the first time in American political history, nearly every Democratic presidential candidate released a disability plan during the primary campaign.<sup>19</sup> And important reforms such as eliminating the loophole in federal labor law that allows people with disabilities to be paid subminimum wages are now included in both parties' platforms.<sup>20</sup>

Achieving economic justice for people with disabilities in the United States will require not only a redoubling of our national commitment to the unfulfilled goals of the ADA, other key disability civil rights laws and protections, and our social insurance and public assistance system, but also a collective commitment to applying disability as a lens across the entire economic policy agenda—and an intentional acknowledgment that we will never achieve true economic justice in this nation if we fail to achieve economic justice for people with disabilities.

While far from a comprehensive inventory of the economic picture for people with disabilities in the United States, this report offers a current snapshot of the economic crisis facing the U.S. disability community—and highlights several of the major systemic barriers and policy failures standing in the way of economic justice for people with disabilities and their families today. Future work by The Century Foundation's Disability Economic Justice Team, our partner the Center for Economic Policy Research, and the newly launched Disability Economic Justice Collaborative—which brings together two-dozen disability leaders, leading think tanks, and research organizations<sup>21</sup>—will highlight the policy solutions needed to chart a course to disability economic justice in the United States in the years ahead.

# Economic Insecurity Among People with Disabilities

In 1990, the ADA, which today remains the cornerstone of disability civil rights law in the United States, established four goals for disabled Americans: equal opportunity, independent living, full participation, and economic self-sufficiency. Despite three decades of progress, economic

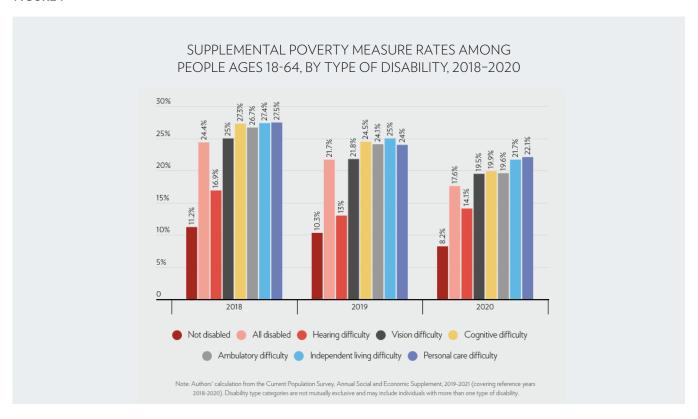
security has been the most difficult of the ADA's goals for the United States to realize and remains out of reach for an unconscionable share of America's disability community.

For starters, in recent years, the poverty rate for working-age<sup>22</sup> adults with disabilities in the United States has hovered at roughly twice the rate faced by working-age adults without disabilities. In 2019, pre-pandemic, nearly 22 percent of disabled working-age individuals lived in poverty, according to the Census's Supplemental Poverty Measure—more than double the roughly 10 percent of nondisabled working-age people facing poverty under the SPM.<sup>25</sup>

In 2020, nearly 18 percent of working-age disabled people lived in poverty under the SPM, compared with roughly 8 percent of nondisabled working-age people.<sup>24</sup> The poverty rate for people with disabilities declined between 2019 and 2020, though the percent drop was slightly less than for people without disabilities. The reduction in poverty occurred despite the COVID-19 economic crisis, reflecting not only the effectiveness of the large-scale antipoverty interventions authorized early in the pandemic, such as direct cash aid,25 but also these interventions' particular importance to disabled people. The roughly 18 percent of workingage disabled people living in poverty under the SPM in 2020 reflected a decline of nearly seven percentage points compared with the 2018 rate; this represents an almost 28 percent decrease within a span of just two years. The rate of poverty among nondisabled working-age individuals fell by three percentage points between 2018 and 2020, a nearly 27 percent reduction. Yet the disparity in poverty rates between disabled and non-disabled working-age people remains unacceptably large.

Poverty rates also vary widely even among people with disabilities, depending on disability type. For example, as Figure 1 shows, working-age adults who face barriers to independent living (for example, running errands outside of the home) or caring for themselves (for example, showering, bathing) are consistently more likely to live in poverty than working-age adults with hearing or vision disabilities.<sup>26</sup>

FIGURE 1

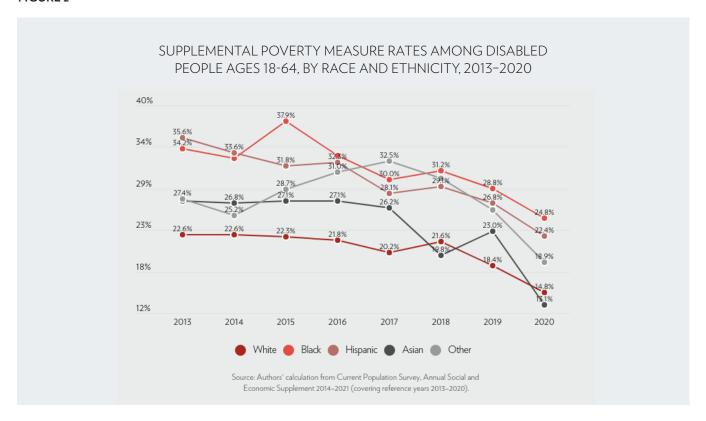


However, the share of those with hearing disabilities experiencing poverty actually rose between 2019 and 2020, even as it declined for other groups.

Although working-age people with disabilities overall have seen their poverty rates tick down in recent years, alarming racial disparities continue to persist within the disability community. Race and disability compound poverty in a significant way. As shown in Figure 2, disabled people of color ages 18 to 64 experience a higher rate of poverty relative to their white peers year after year. In 2020, one in four disabled Black adults lived in poverty compared to just over one in seven of their white counterparts. The Black-white poverty gap among working-age people with disabilities was only 1.6 percentage points smaller in 2020 than it was in 2013, representing a percent change of slightly less than 14 percent over seven years. Meanwhile, the Hispanic-white poverty gap for people with disabilities contracted by over 5 percentage points (an almost 42 percent reduction) during the same time period.27

In a deeper dive into Census poverty data, the authors have broken down 2017-19 data from the Annual Social and Economic Supplement (ASEC) of the Census's Current Population Survey (CPS), to show poverty rates among working-age disabled people by state, as displayed in Figure 3. The District of Columbia (Washington, D.C.) tops the list with the highest poverty rate among disabled people ages 18 to 64 anywhere in the nation at just under 36 percent. Maine and Mississippi also have comparatively high rates of poverty among disabled people, with approximately one in three disabled working-age adults living in poverty in those two states. Maine and Washington, D.C. also have the nation's widest gaps in poverty rates between people with disabilities and people without disabilities (25 and 23 percentage points, respectively). Conversely, Utah and Washington state have both the lowest poverty rates among working-age people with disabilities and the smallest gaps in poverty rates between disabled and non-disabled workingage people. Future work by The Century Foundation and our partners in the Disability Economic Justice Collaborative will include deeper state-by-state analysis.

FIGURE 2

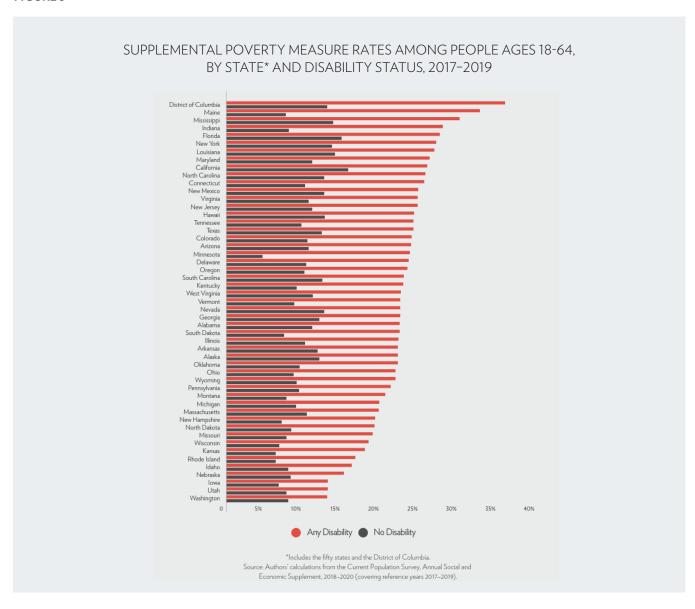


In addition to experiencing higher poverty rates, workingage people with disabilities aged 16-64 have a dramatically lower labor force participation rate than their nondisabled counterparts. In February 2022, the labor force participation rate for disabled workers was 36.6 percent compared to 76.9 percent for workers without disabilities.<sup>28</sup> While this marks a 9.6 percent increase in labor force participation among working-age adults with disabilities compared with February 2021, the share of disabled working-age people in the labor force is less than half that of nondisabled working-age people. Unfortunately, it remains all too easy for disabled people who want to work to be pushed out of the labor force. As discussed in the next section of this report, persistent discrimination, denial of reasonable accommodations, years-long waiting lists for the home and community-based services many need to live independently and to work, and a litany of other barriers all contribute to continued suppression of employment and labor force participation among working-age people with disabilities in the United States.

While hardly a pandemic-specific phenomenon, additional research shows that disabled workers in the United States were significantly more likely than nondisabled workers to lose employment early in the pandemic. Between March 2020 and August 2020, one in five workers with disabilities were dismissed from employment, compared with one in seven without disabilities.<sup>29</sup> While this disparity was likely driven in part by the fact that workers with disabilities in the United States are especially likely to work in the service and production sectors,<sup>30</sup> which were hit hard early on in the pandemic, even outside of pandemic times, workers with disabilities have frequently been among those "last hired, first fired."<sup>31</sup>

The economic effects of the COVID-19 pandemic have not been evenly distributed among working-age people with disabilities. People with disabilities are not a monolith, and employment impacts especially differ depending on the barriers a person faces to activities of daily living and whether an individual lives with one or multiple disabilities; over 40 percent of people with disabilities fell into the latter category in 2021. Given that more than half of working-age people with disabilities are not in the labor force, it is also helpful to consider employment levels in terms of the employment-

FIGURE 3



to-population ratio—which reflects the share of workingage disabled people who are employed—rather than labor force participation rates, which only reflect the minority of working-age disabled people who are in the labor force.

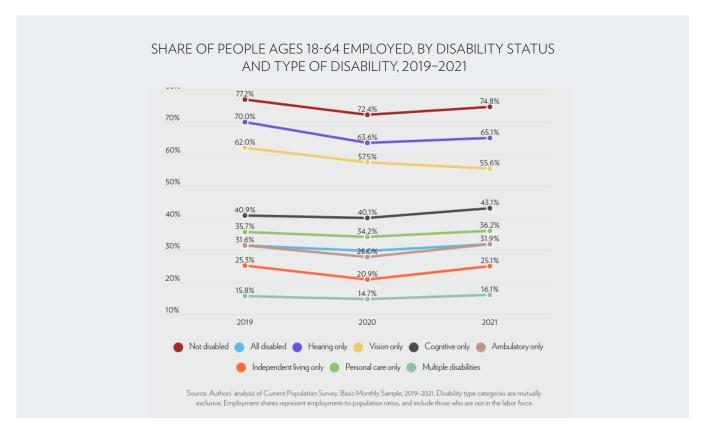
As shown in Figure 4, between 2019 and 2020, working-age people with one type of disability that affects "independent living"—that is, doing errands alone, such as visiting a doctor's office or shopping—experienced the largest percent drop in employment among working-age disabled people. The employment-to-population ratio for this group fell by 4.4 percentage points during this period, representing a 17.4 percent drop within just one year. Employment among

people whose only disabilities involved walking or hearing was also disproportionately affected during this period.

The employment-to-population ratio for all working-age people with disabilities returned to roughly 2019 levels by 2021. However, employment among people with hearing and vision disabilities remained short of pre-pandemic levels by approximately 7 and 10 percent, respectively.

The extent of pandemic employment decline for disabled people in the United States has also varied by educational attainment. Among disabled people between the ages of 25 and 64, those without bachelor's degrees experienced a

FIGURE 4



larger relative decline in their employment-to-population ratio between 2019 and 2020 than their counterparts with bachelor's degrees during the same period (Figure 5). The employment-to-population ratio for disabled working-age people without bachelor's degrees only just returned to 2019 levels in 2021, while the share of disabled people with bachelor's degrees who were employed was actually higher in 2021 than in 2019.

Though an imperfect measure, possession of a bachelor's degree can serve as a useful proxy for class. Formal education is strongly correlated with job quality, and economic outcomes for those with and without bachelor's degrees tend to differ significantly. This makes the lack of a bachelor's degree a reliable, if blunt shorthand for identifying members of the working class, who tend to have comparatively less societal power and autonomy. This understanding of class makes the disparities in employment outcomes between working-age disabled people with and without bachelor's degrees that much more concerning.

Adding further still to an already bleak picture, on top of the enormous gap in overall labor force participation and the persistent divergence in employment, there are significant economic disparities between full-time and part-time workers with and without disabilities. As shown in Figure 6, nearly 8 percent of full-time workers with disabilities had incomes below the poverty line, compared with roughly 5 percent of full-time workers without disabilities. Nearly 22 percent of disabled part-time workers had incomes below the poverty line, compared to just over 15 percent of nondisabled part-time workers.

# Barriers to Employment and Economic Security for Disabled Individuals and Their Families

Despite advances in disability rights in recent decades, disabled people and their families continue to face a wide array of barriers to economic security. Ableist myths and stereotypes persist, and while a growing number of businesses have begun prioritizing disability inclusion in hiring, recognizing it as a win-win, many employers still

remain reluctant to hire people with disabilities—forcing many disabled people who want to work into unemployment and underemployment. While a widespread culture shift will not be achieved solely through policy change, many of the barriers to economic security facing people with disabilities in the United States are due to structural and programmatic failures that become visible when we center the perspectives and experiences of the disability community.

# Discrimination and Denial of Reasonable Accommodations

The ADA makes it illegal for an employer to discriminate against disabled individuals in regard to "job application procedures, the hiring, advancement, or discharge of employees, employee compensation, job training." Additionally, the ADA requires that employers provide reasonable accommodations that make it possible for disabled workers to succeed at work, so long as they do not negate the essential functions of the job or require an undue financial hardship to the employer. Careful research indicates that those workers with disabilities most likely to benefit from the ADA's protections—such as workers who face barriers that do not preclude full time and/or traditional work—did see employment gains after the passage of the ADA. 36

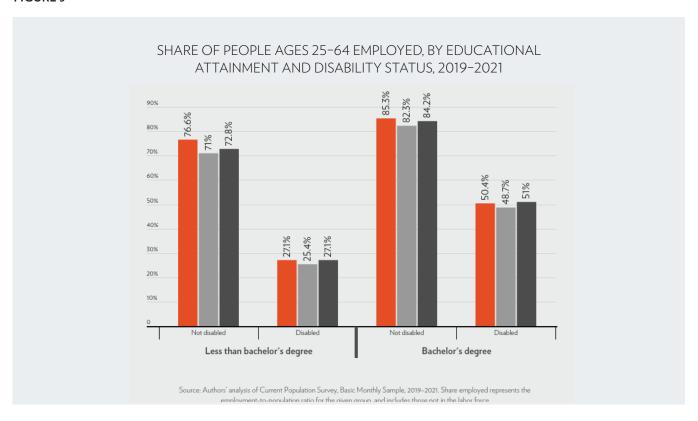
Nevertheless, employment discrimination against disabled workers in the United States remains pervasive in nearly all employment settings. A survey of disabled workers by the Center for Talent Innovation found that one in three experienced bias or discrimination in the workplace, including being insulted or excluded because of their disability. Meanwhile, hiring discrimination keeps many disabled workers out of jobs altogether; one recent experimental study found that resumes that were identical, other than listing either a spinal cord injury or autism as a disability, received 26 percent fewer responses for accounting jobs. Furthermore, disabled people of color face multiple layers of discrimination in the workplace, with ableism and racism conspiring to create even more significant barriers to employment as well as bias and poor workplace treatment

that can be even more substantial when experienced intersectionally.

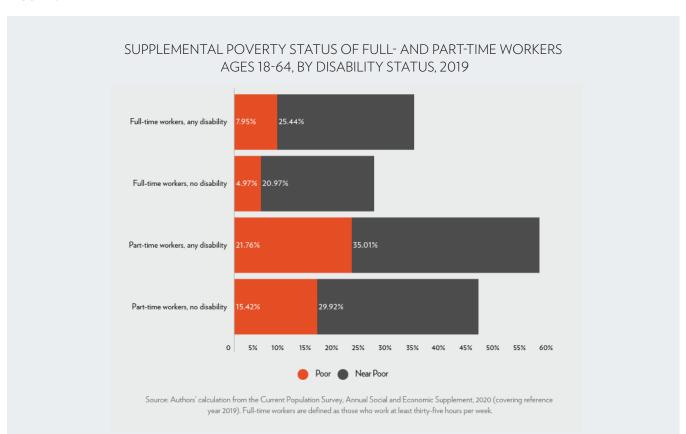
and unlawful Combating persistent employment discrimination against disabled workers—including through enforcement of the ADA and other disability civil rights protections—is critical to advancing disablity economic justice. In 2019, there were 24,238 disability employment complaints filed and resolved with the U.S. Equal Employment Opportunity Commission (EEOC). 39 Consistent and strong enforcement by EEOC is a key force for changing employer behavior and protecting disabled workers' rights, in addition to providing education and resources to employers on best practices for providing reasonable accommodations to workers with disabilities. The Department of Labor's Office of Disability Employment Policy (ODEP)<sup>40</sup> offers resources for workers and employers on access to and provision of accommodations generally, and specifically in light of the COVID-19 pandemic.

Moreover, the COVID-19 pandemic offers an immediate opportunity to realize the potential of "universal design" in employment settings. Universal design refers to the strategic decision to make the environment, services, systems, and entire operating structures usable by as many people as possible; curb cuts offer a classic example. As noted by the Department of Labor, the "key principles [of universal design] are simplicity, flexibility, and efficiency."41 Universal design can be used to expand access to workplace accommodations such as remote work, which became commonplace in many sectors during the pandemic. The improvements in workplace-related technology during the pandemic spurred by the necessity of social distancing demonstrated that for-profit and not-for-profit employers alike could be highly productive with workers in a variety of locations, aided by accessible technology and flexible schedules. Consistent with universal design, maintaining these innovations would benefit disabled Americans as well as many millions of others struggling to balance work and family, for example.

#### FIGURE 5

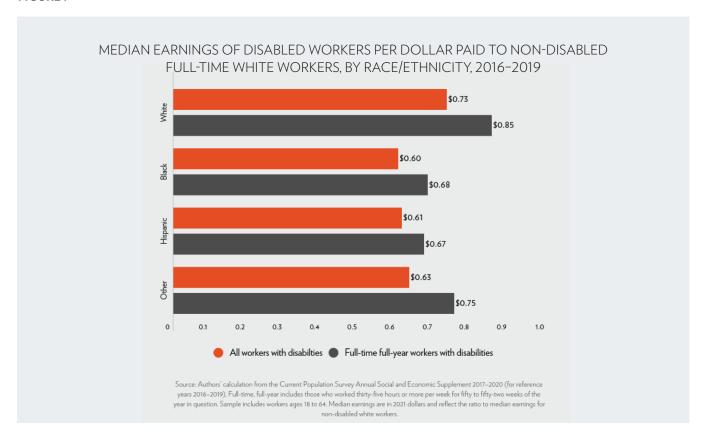


#### FIGURE 6



Subminimum Wage and the Disability Wage Gap

FIGURE 7



Although civil rights laws such as the ADA prohibit hiring and workplace discrimination, there remains a longstanding loophole in the Fair Labor Standards Act (FLSA) that enables employers to pay workers with disabilities less than the federal minimum wage. Section 14(c) of the FLSA was created in 1938.<sup>42</sup> This archaic and discriminatory provision has remained relatively unchanged for nearly a century, allowing employers to apply for certificates that enable them to pay disabled workers as little as pennies per hour of work. Minimal data are collected, making average pay difficult to understand—while keeping tens of thousands of subminimum wage workers in the shadows. In 2001, a federal watchdog estimated that more than half of all workers under 14(c) certificates earned \$2.50 per hour or less<sup>45</sup>—one-third of the federal minimum wage of \$7.25 per hour today, and just one-sixth the \$15 an hour that workers' advocates have called for in recent years. A more recent report suggests that the average subminimum wage may have ticked up slightly in recent years to \$3.34 an hour, with approximately sixteen hours a week worked for most disabled workers employed by a certificate holder. 44 Based on those more recent figures,

the typical disabled worker getting paid subminimum wages is paid about \$214 per month for sixty-four hours of work.<sup>45</sup>

As of January 1, 2022, approximately 1,200 employers across the United States currently have or have applied for a 14(c) certificate. Of those 1,200 certificates, 530 are pending, meaning employers do not report the number of workers with disabilities under the certificate because the application is in process. Thus, the number of workers nationally being paid these low wages is even more difficult to ascertain, although estimates suggest between 40,000 and 100,000. Subminimum wages—coupled with being stuck in segregated and noncompetitive employment in sheltered workshops—can trap disabled workers in a cycle of poverty and institutionalization by keeping independent living in the community as well as opportunities for economic security and competitive integrated employment out of reach.

Support has grown in recent years for phasing out or eliminating subminimum wages, including by bringing an end to the 14(c) loophole, as the Raise the Wage Act would do—alongside raising the federal minimum wage

and eliminating subminimum wages for tipped workers.<sup>49</sup> And in a sign of growing bipartisan consensus, eliminating subminimum wages for disabled workers is now a part of both the Republican and Democratic party platforms and was included in the bipartisan Transformation to Competitive Integrated Employment Act introduced in 2021.<sup>50</sup> Additionally, policy changes to create more equitable hiring and retention across all workforces as well as more inclusive cultures will be critical to address the earnings gap, as well as investments to further support and expand access to competitive integrated employment for workers with disabilities.

While workers paid a subminimum wage are generally not included in general workforce demographic calculations,<sup>51</sup> even setting aside disabled workers paid subminimum wages, a significant disability wage gap remains. In 2020, workers with disabilities (ages 18-64) on average were paid 74 cents for every dollar paid to their nondisabled peers.

The disability wage gap is even more stark when broken down by race as shown in Figure 7. Black workers with disabilities who are working full time earn only 68 cents for every dollar paid to white workers without a disability, while Latino workers with disabilities who are working full time earn just 67 cents for every dollar paid to non-disabled white workers. Future research by The Century Foundation and our partners in the Disability Economic Justice Collaborative will further explore disparities at the intersections of race, gender, disability, and other lived identities.

# Challenges Facing Older Youth and Young Adults with Disabilities

Surveys of disabled youth find strong levels of self-belief, but low expectations that they will have the same opportunities for education and employment as their nondisabled peers. 52 As a result of landmark protections under the IDEA, children and young adults with disabilities under age 21 have the right to a "free and appropriate public education," including a broad array of services meant to ensure access to an equitable education. And while families with disabled children of all ages often face significant challenges in

accessing the educational services and supports their children need in order to thrive at school, the support that currently exists for older youth and young adults is particularly fractured and disparate.

Early adulthood is a critical time for young people to acquire training, education, and career experiences that can lead to personal and economic well-being.53 Yet youth with disabilities are significantly less likely than their nondisabled peers to be enrolled in post-secondary education, participating in job training, or employed.54 While WIOA—the nation's main workforce investment law-requires that states set aside 15 percent of their vocational rehabilitation funding for transitioning youth as detailed in the Services and Supports section later in this report, advocates and federal watchdogs alike have long called for better coordination between job training and educational institutions in the states as well as at the federal level.55 Such coordination would allow youth to have more opportunities to start paid work experience and job training, even before they lose IDEA protections at age 21 (though many lose IDEA services much earlier, upon high school completion).

Some interventions for transition-age youth have, for example, waived earnings disincentives for SSI benefits, to enable young adults to gain valuable early work experiences without risking access to vital income and health coverage. However, with the focus on youth in WIOA and the intention of thoughtful coordination between education partners, employers, and vocational rehabilitation (VR), the goal is to support youth with disabilities leaving secondary education to enter into postsecondary education or employment opportunities that lead to careers in integrated employment at competitive wages, and in turn, pave a path to economic stability and upward mobility. Unfortunately, that ideal is still out of reach for many—in large part due to a web of complex rules across interlocking programs that can be difficult for disabled youth and their families to understand and navigate, even when coordination is at its best.

# Added Costs of Living with a Disability

Living with a disability—or having a household member with a disability—often comes with significant additional out-of-pocket costs not covered by health insurance. For example, expenses such as adaptive equipment to make one's home and/or vehicle accessible, personal attendant care or direct service provider, home modifications, assistive technology for communication, food for medically directed diets, and special clothing and shoes can add substantially to an individual or family's budget and put economic stability even further out of reach. What's more, disabled people are substantially more likely to face unexpected medical expenses that further exacerbate economic insecurity.<sup>56</sup>

A growing body of research has begun to demonstrate the magnitude of these additional disability-related costs. Drawing on four nationally representative surveys, researchers from Stony Brook University, the University of Tennessee, the National Disability Institute, and the Oxford Institute of Population Aging estimate that households with a disabled adult need an average of 28 percent more income—an extra \$17,690 per year for a typical U.S. household—in order to achieve the same standard of living as a comparable household without a disabled member.<sup>57</sup> That research further suggests that America's Official Poverty Measure and Supplemental Poverty Measure both significantly underestimate poverty and hardship among the disability community. Accounting for additional disabilityrelated costs, the share of U.S. households with a disabled adult officially counted as poor in the United States would be ten percentage points higher than captured by official Census statistics—and 2.2 million more disabled people in the United States would be considered officially poor.<sup>58</sup>

# Lack of Access to Needed Supports and Services

As recently as a half century ago, disabled Americans lived in institutional settings by the hundreds of thousands. While the United States has fortunately charted a course toward deinstitutionalization and community living in the years since, thanks in large part to a landmark 1999 U.S. Supreme Court decision called Olmstead v. L. C.59—which

held that unjustified segregation of people with disabilities constitutes unlawful discrimination under the ADA—living independently and accessing necessary services and supports remain inextricably intertwined with economic stability and dignity for millions of people with disabilities today.

Unfortunately, the policies and programs that have been put in place to ensure access to community-based services and supports in the United States have suffered woefully from a history of disinvestment—and remain steeped in a system that still places a preference on institutional over community living. As a result, many disabled people remain warehoused in institutional settings despite their desire to live independently—or trapped on waiting lists for needed services such as home- and community-based services (HCBS) and accessible housing, and possibly relying on family or friends and living on the margins of society until those services become available. One of the results of this disinvestment, as discussed in the Overcriminalization section of this report, is that many disabled people have ended up inappropriately and unjustly ensnared in the criminal legal system, which houses a disproportionate share of people with disabilities today.60

Independent living is not just a matter of preference for most disabled people—surveys suggest 89 percent of people with disabilities would prefer to live in their communities instead of in institutional settings<sup>61</sup>—it is also a matter of health, dignity, wellbeing, and safety. Worth noting, the disability community has been ringing the alarm bells about the dangers of institutional settings since long before the COVID-19 pandemic began killing disproportionate numbers of disabled and older adults in nursing homes. As of February 2022, more than 200,000 residents and staff at U.S. nursing homes and other long-term care facilities have died from COVID-19, accounting for nearly one in four deaths from COVID-19 since the start of the pandemic.<sup>62</sup> In the words of Alice Wong, a prominent twenty-first century disability activist and founder of the Disability Visibility Project: "Disabled people know what it means to be vulnerable and interdependent. We are modern-day oracles. It's time people listened to us."63

HCBS provide the most extensive long term care and support for people with disabilities living in the community to have activities of daily living needs met. This might include support from a direct service provider for several hours a day. But HCBS are effectively only available via the Medicaid program and not through other health coverage. Although HCBS got a boost with the recent American Rescue Plan Act of 2021,64 it was unfortunately only a short-term-increase. While a significant, longer-term HCBS funding increase was promised in the Build Back Better Act,65 the stalling of that legislation means that individuals needing HCBS will continue to languish months and sometimes even years on long waiting lists, leaving them to either go without necessary services or be forced to seek institutional care while they wait for their rights under Olmstead to be realized.

Another challenge is that HCBS through Medicaid is only available to qualifying individuals with limited income and resources. Meanwhile, obtaining the same level of services through private coverage is cost-prohibitive even for wellto-do households, leaving most disabled workers stuck with the choice of impoverishing themselves in order to get the services they need to live independently or going without needed supports. To address this gap, a growing number of states allow qualifying residents who are not otherwise financially eliqible for Medicaid to "buy in" to the program by paying monthly premiums to receive needed services and supports—but not every state offers such a Medicaid buyin, and coverage varies significantly. Monthly income limits vary from under \$1,000 to more than \$4,500.66 By contrast, the typical cost of a personal care attendant or direct service provider can be tens of thousands of dollars in out of pocket costs each year.<sup>67</sup> Thus, if a disabled individual moves from one state to another while working and enrolled in their state's Medicaid buy-in program, they would need to re-enroll in the new state—assuming it offers a buy-in—and worse, may not qualify or receive the services they need depending on the new state's coverage and eligibility requirements.68 This can prevent disabled workers from being able to seek job opportunities across state lines and makes navigating employment and service systems even more challenging for disabled workers.

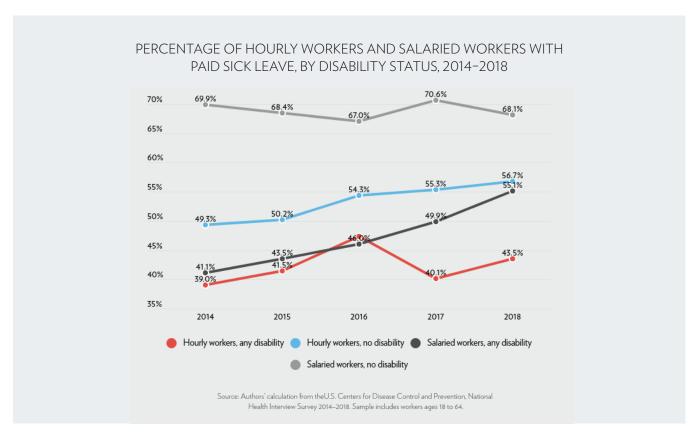
Access to employment and training supports is another important pathway to economic security for workers with disabilities, especially workers with intellectual and developmental and/or mental health disabilities. Each state has a vocational rehabilitation (VR) agency that is federally funded and is required to provide employment assistance to workers with disabilities. The approach taken by the VR system changed in 2014 with the reauthorization of the Workforce Innovation and Opportunity Act (WIOA), which shifted the focus toward youth with disabilities, starting earlier with career exploration and training. A 15 percent set-aside was created to specifically target funds for youth transition to employment.

Unfortunately, the changing economy has outpaced the change of VR. As a whole, the program has been unable to align with the changing job market and successfully shift the structure to support workers with disabilities moving into careers and jobs of the future, rather than productionfocused jobs that are quickly disappearing. In fiscal year 2021, states returned \$167 million<sup>69</sup> in unused funds to the Rehabilitative Services Administration (RSA). While those funds were repurposed to grants supporting phasing out 14(c), the returned funds demonstrate a challenge for states in leveraging their federal funding to support employment outcomes. To improve employment services, state VR agencies must align partnerships with employers, improve capacity within their agencies, and rethink their models of support to align with the workforce of the future, making concrete connections between federal investments and long-term employment outcomes—instead of churning disabled workers through their rolls month after month based on short-term measures of success that do not translate into long-term, stable employment.

### Lack of Access to Paid Leave and Sick Days

Family, medical, and sick leave are critical components of a high-quality and supportive work environment for all workers, but are especially critical for workers with disabilities and families with a disabled member. Yet the United States is nearly alone among developed nations in lacking a national paid leave policy. Although the Family and Medical

FIGURE 8

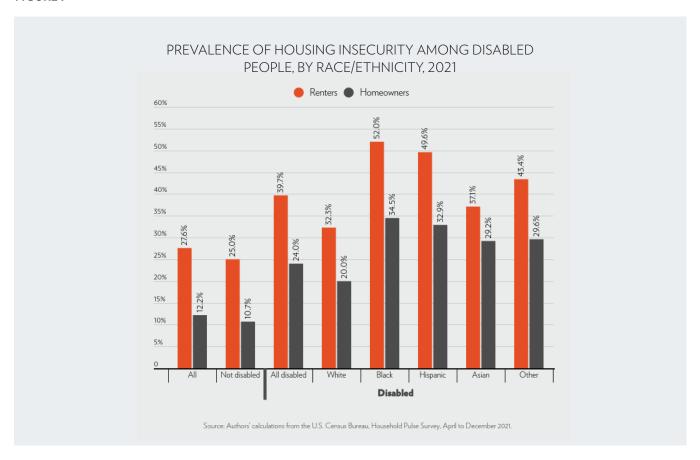


Leave Act (FMLA)<sup>70</sup> allows covered workers to take up to twelve weeks of leave during any twelve-month period if they experience a serious illness, need to care for a seriously ill family member, or to care for a new child, the leave is unpaid, and many low-income workers are forced to choose between lost wages and caring for themselves or a loved one. What's more, even the unpaid leave FMLA provides is out of reach for many disabled workers—particularly those working in low-wage sectors, for smaller employers, or with part-time or nontraditional employment arrangements.

As support for a national paid leave policy has gained significant momentum among voters across the political spectrum in recent years, a number of states and cities have joined those championing the provision of paid leave. At the time of writing, nine states and Washington, D.C. now offer paid family and medical leave<sup>71</sup> and fifty-four localities offer paid sick days.<sup>72</sup> However, paid leave remains unavailable to most workers with disabilities, particularly those who are paid hourly.

As Figure 8 shows, the share of disabled salaried workers with access to paid leave has steadily increased over time, with over half securing paid leave by 2018, up from just over 41 percent in 2014. But less than 44 percent of disabled workers paid by the hour had access to paid leave in 2018. Access to paid leave also increased much more modestly for these workers between 2014 and 2018. By contrast, among those without disabilities, 57 percent of hourly workers and 68 percent of salaried workers had access to paid leave in 2018. Among both salaried and hourly workers, the share of disabled employees with access to paid leave was approximately 13 percentage points below the share of non-disabled salaried and hourly workers with that benefit.73 It is worth noting that these calculations do not distinguish between part-time and full-time workers; many employers reserve benefits like paid leave for full-time employees, and disabled people are more likely than non-disabled people to work part time.74

FIGURE 9



# Insufficient Affordable, Accessible Housing

Economic security and safe, stable, and affordable housing are deeply intertwined. Fortunately, awareness of America's affordable housing crisis has grown significantly in recent years, as affordable housing has moved further and further out of reach for millions of low- and middle-income families—but rarely is the nationwide shortage of not only affordable but also accessible housing for disabled people and their families part of the conversation. In just one stark example, while the supply of affordable housing available to individuals and families eligible for the Housing Choice Voucher Program and Public Housing—the nation's main affordable housing assistance programs—is already woefully inadequate, just 5 percent of federally funded housing is required to be accessible to people with mobility disabilities, and just 2 percent for those with sight and vision disabilities.<sup>75</sup> Left with little recourse when affordable, accessible housing is out of reach, disabled people make up roughly half of people in the United States who are forced to turn to homeless shelters to keep a roof over their heads.<sup>76</sup>

In Figure 9, an analysis of the Census's Household Pulse Survey shows that one year after the onset of the pandemic, nearly 40 percent of renters with any disability experienced housing insecurity, in that they either deferred paying their rent or reported no or slight confidence in their ability to pay their rent next month. This is substantially higher than the national average of 25 percent. Disabled Black and Hispanic renters were especially likely to be housing insecure, at 52 percent and 50 percent, respectively. Disabled homeowners are also more likely to be housing insecure: 24 percent of disabled homeowners had either deferred payment on or had little to no confidence in their ability to make their next mortgage payment—more than twice the share of nondisabled homeowners.

## Food Insecurity and Other Material Hardship

In addition to housing, disabled Americans and their families face alarmingly high rates of food insecurity and other types of material hardships. As Figure 10 illustrates, 8.5 percent of adults in the last nine months of 2021 experienced food insufficiency, reporting that they sometimes or often did not have enough to eat in the past seven days. Among adults with disabilities, more than one in five reported food insufficiency—more than three times the rate of their nondisabled counterparts. Even more strikingly, just over half of adults with disabilities said they had substantial difficulty paying their monthly bills—nearly twice the national average of 27 percent.

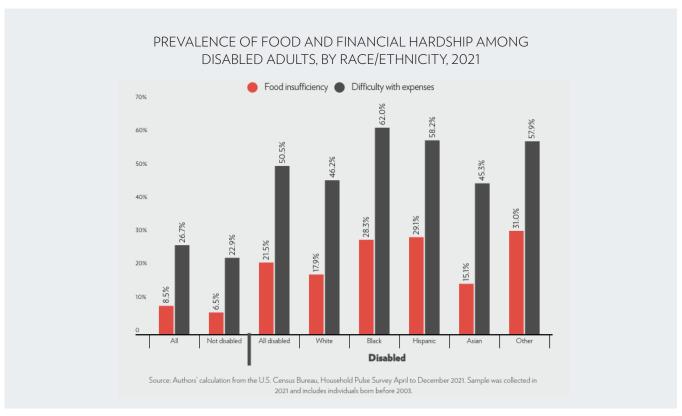
One in five households helped by Supplemental Nutrition Assistance Program (SNAP)—the main federal food assistance program, formerly known as Food Stamps—includes a non-elderly adult with a disability. SNAP has positive impacts on recipients' wellbeing as well as the national economy as a whole, including providing critical food assistance for millions of people with disabilities. Yet gaps in access and adequacy undercut SNAP's positive impacts, and too many disabled individuals struggling to put food on the table are left underserved. Moreover, SNAP households with people with disabilities are among those facing a looming "hunger cliff" when temporary pandemicera improvements to SNAP benefit adequacy and access end.

First, during the COVID-19 pandemic, SNAP benefits have been temporarily increased. When the federal Public Health Emergency Declaration (PHE) ends, the authority for issuing SNAP Emergency allotments will end, and most SNAP participants will lose \$82 a month in SNAP benefits. <sup>83</sup> For some older adults and people with disabilities who qualify for only the minimum SNAP benefit, their monthly benefits will drop even more substantially—from \$250 to \$20. "Absent the pandemic-era boost in monthly benefits, SNAP is generally inadequate to cover an individual or households' entire monthly food budget." In 2021, the Biden administration took an important step forward, boosting regular monthly SNAP benefits by roughly 21 percent<sup>84</sup>

for the typical household, by updating USDA's woefully outdated "Thrifty Food Plan," which forms the basis for calculating household benefits; for the first time since 1975, the purchasing power of SNAP allotments improved. Nonetheless, even with the adjustment the regular SNAP benefit remains inadequate to meet many disabled people's nutritional needs. The Closing the Meal Gap Act would improve SNAP benefits for people with disabilities by replacing the Thrifty Food Plan with the slightly higher Low Cost Food Plan as the basis for calculating SNAP benefits, increasing the minimum SNAP benefit, and improving the SNAP Standard Medical Deduction. So

Second, a rigid three-month (out of thirty-six months) time limit on SNAP receipt for so-called "able-bodied adults without dependents" has put SNAP out of reach for an unknown number of disabled people over the years due to improper eligibility screening and barriers in fully completing the documentation required to sufficient hours of work activities. While the Trump Administration's efforts to make that time limit even harsher failed,<sup>87</sup> and the time limit has been suspended during the pandemic, the time limit will return for many people after the Public Health Emergency Declaration expires.<sup>88</sup> The Improving Access to Nutrition Act would abolish SNAP's harsh time limits permanently.<sup>89</sup>

Additionally, limitations on how food assistance benefits may be spent have also served to undercut SNAP's impacts for people with disabilities. Online food ordering is especially important for disabled people, who are especially likely to face challenges accessing nutritious foods and foods for special diets, due to a combination of barriers to physical accessibility, transportation accessibility, and greater likelihood of living in food deserts. Online SNAP purchasing was piloted prior to March 2020 in only a few states, and then USDA accelerated its expansion given the urgent need to support SNAP consumers to safely purchase food remotely during COVID-19. Now online purchasing with SNAP benefits is available in forty-nine states and the District of Columbia. Nonetheless, it is still only available from a small fraction of SNAP-authorized retailers.



Similarly, SNAP's outdated restrictions on purchasing hot and prepared foods have also presented additional barriers for the disability community, many of whom face challenges in preparing meals. States may seek permission to waive the hot prepared food restriction during disasters for all households, including people with disabilities and older adults.

States also have the option to operate the SNAP Restaurant Meals Program (RMP), that enables SNAP participants who have a disability, are 60 or over, or are experiencing homelessness to use SNAP benefits to purchase food at restaurants. This can provide critical food access for people with disabilities who may lack access to kitchens or cooking facilities, to ensure they can utilize their SNAP benefit. To date, however, only a handful of states have implemented the RMP.<sup>95</sup>

## Barriers to Accessible Transportation

Difficulties accessing reliable, accessible transportation present another major barrier to employment and economic

security among disabled people. A lack of accessible transportation also translates into challenges in navigating independent living, social connectedness, and community engagement. According to the 2017 National Household Travel Survey<sup>94</sup> conducted by the U.S. Department of Transportation, over 25 million Americans with disabilities age 5 and older reported difficulty accessing the transportation they need, and more than 3 million said they were homebound as a result. Of the 13.4 million workingage adults with disabilities who report difficulties with transportation, only one in five were employed.<sup>95</sup>

Disabled individuals are dramatically more likely to report being transportation insecure—that is, unable to safely and reliably get where they need to go, when they need to go there. Using a Transportation Security Index developed by Alexandra K. Murphy (University of Michigan), Alix Gould-Werth (Washington Center for Equitable Growth), and Jamie Griffin (University of Michigan), a 2018 survey<sup>96</sup> of adults 25 and older found that people with disabilities were more than twice as likely as people without disabilities to report some level of transportation insecurity. Around one in six people with disabilities were classified as severely

transportation insecure, compared to fewer than one in sixteen people without disabilities.<sup>97</sup>

The ability to freely move around can determine whether people with disabilities have autonomy over their own lives, and structural accessibility plays an important role. Unfortunately, many U.S. transit systems have a history of routinely depriving people with disabilities of meaningful access, 98 and the accommodations they claim to offer can be onerous or unreliable. For example, fewer than two thirds of pick-ups by Pace's paratransit services in Chicago were found to be on-time in 2017.99 In New York City, disability advocates have complained that the subway system will not reach 100 percent ADA accessibility until 2100, given the sluggish current rate of retrofitting. 100 And even stations that are supposedly "accessible" often aren't, likely because the Metropolitan Transit Authority has routinely failed to perform scheduled preventative maintenance on its elevators and escalators.<sup>101</sup> The blatant inaccessibility of the New York City transit system—the largest system in the United States<sup>102</sup>—has been the subject of multiple classaction lawsuits, but significant accessibility improvements have yet to materialize.103

Pandemic-related service cuts have only made the situation worse. Scaled-back bus and train schedules have meant long waits for riders throughout the country. In California, King Harris, who uses a cane, explained that a lack of accessibility options means that people with wheelchairs or walkers are often unable to board the first bus that arrives. For those who rely on public transit, he said, extended waiting times on triple temperature days mean "your food is easy to spoil when you go to the grocery store." 104 In New York, reliability metrics for the oft-plagued 105 Metropolitan Transit Authority's Access-A-Ride have reached their lowest level in years, even as ridership levels have nearly recovered from their pandemic slump. 106 As Lena Townsend, who has multiple sclerosis and relies on paratransit to get to doctor's appointments, lamented, "it's so frustrating, because if you have to be someplace on time, you often can't get there."107 Such stories are unacceptably familiar throughout the disability community.

Transportation barriers for people with disabilities are especially salient in low-density areas characterized by car-dependency and sprawl. Without access to other transportation options, those who are unable to drive, afford, or otherwise access a private vehicle will find their ability to participate in many daily and community activities significantly limited. Working-age people with disabilities who report transportation difficulties are more likely to live in zero-vehicle households, and less likely to drive even if they own a vehicle.<sup>108</sup> Car-centric development imposes mobility limitations that put independence largely out of reach for nondrivers, reducing their ability to maintain employment or complete tasks that require trips outside of their homes. For nondrivers with disabilities, lack of access to other modes of transportation can jeopardize independent care and increase their risk of developing or worsening secondary chronic conditions.<sup>109</sup> Car-dependent infrastructure also poses particular problems for older adults, especially those who are looking to age in place. Driving cessation is associated with greater dependency on public transportation or, in its absence, on family and friends for rides.<sup>110</sup>

# Inadequate and Difficult-to-Access Income Supports

While programs such as Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) provide critical income support to millions of disabled people, the survival income they provide remains out of reach for countless individuals with disabilities and families for a variety of reasons. America's Social Security disability programs utilize one of the strictest definitions of disability in the developed world and are notoriously difficult to successfully apply for, due to lengthy and complicated forms and a byzantine multi-step disability determination process that leaves many lost in red tape." Fewer than 4 in 10 applications are approved, even after all levels of appeal and nearly one in five beneficiaries die within five years of receiving benefits.<sup>112</sup> Indeed, it has become a truism among disability advocates that one essentially needs a law degree to get disability benefits.

Making matters worse, despite years of pleas from the disability community, the SSI application still cannot be completed fully online, necessitating an in-person visit at a Social Security Administration (SSA) field office or assistance from SSA's often difficult-to-access 1-800 number<sup>113</sup>—a significant barrier for many disabled people and older adults even before the pandemic spurred nationwide SSA field office closures. And due to a long history of disinvestment when it comes to SSA's administrative budget, long hearing backlogs can force disabled people to wait months and even years to be approved for needed benefits; underscoring the human cost of these unconscionable delays, thousands of people die each year waiting for disability benefits as a result.114 Meanwhile, disabled people are forced to wait even longer still for urgently needed income support and health insurance once being approved: outdated rules in Social Security Disability Insurance include a five-month waiting period for benefits, and an accompanying twenty-fourmonth waiting period for Medicare (the health insurance that comes with SSDI eligibility). The bipartisan Stop the Wait Act,<sup>115</sup> introduced most recently in 2022, would eliminate these cruel waiting periods.

Benefits can be so difficult for eligible individuals to access that during the height of the pandemic—a time when more people were in need due to rising economic hardship—new SSI applications and awards actually fell to historic lows. 116 Taking both SSI and SSDI together, estimates suggest that at least half a million disabled people were left behind by Social Security's disability programs during the first year of the pandemic alone<sup>117</sup> because benefits are so difficult to access. While the reopening of SSA's field offices will hopefully make it possible for more eligible individuals to access needed disability benefits, it is but one step in the right direction and will not address the litany of barriers disabled individuals face when it comes to demonstrating eligibility for SSI and SSDI. Notably, prior to the pandemic, studies suggested that roughly half of eliqible individuals were already not receiving SSI.118

Also worth noting, while the Biden administration announced in July 2021 that people facing disability due to "long

COVID" are covered under the Americans with Disabilities Act<sup>119</sup> because so little is currently known about the nature, trajectory, and duration of long COVID, there is currently little in the way of guidance to enable SSA's disability adjudicators to evaluate long-COVID-related claims.

Meanwhile, for those lucky enough to be able to successfully navigate SSA's disability claims process, benefits are so low they are inadequate to help many stay afloat. This is particularly the case when it comes to SSI, whose maximum monthly benefit is just \$841 in 2022120—equivalent to just three-quarters of the federal poverty level for an individual, and neither enough to protect an SSI recipient from living in poverty, nor sufficient to afford average fair market rent in any state in the United States.<sup>121</sup> Other outdated program rules such as limits on earnings and other sources of income that have not been updated for inflation since 1972,122 marriage penalties, and a cruel penalty for receipt of mutual aid—such as a couch to sleep on or even a bag of groceries further entrench poverty and material hardship among SSI beneficiaries. President Biden pledged to update SSI as part of his campaign disability plan, 123 and legislation known as the Supplemental Security Income Restoration Act of 2021124 would similarly take important strides toward bringing SSI into the twenty-first century.

While the monthly income support that SSDI provides is generally more substantial than SSI's sub-poverty benefits and while SSDI does not generally bring the types of rigid and outdated restrictions that SSI imposes—SSDI's disabled worker benefits average less than \$1,300 per month, and 90 percent of beneficiaries receive less than \$2,000 per month, 125 leaving the vast majority of SSDI beneficiaries low-income and facing significant economic insecurity. One particularly outdated SSDI policy limits how much beneficiaries can earn as they attempt to work part-time or to return to work. Individuals who earn more than SSA's "substantial gainful activity" level—set at \$1,350 per month in 2022 for nonblind individuals, 126 a level that does not begin to capture current costs of living for disabled people—risk losing not only SSDI's income support but also its accompanying health insurance through Medicare.

Worth noting, due to the immense strictness of the Social Security disability standard, most disabled people in the United States do not qualify for benefits. Those unable to meet SSA's rigid definition of disability generally have little recourse, as the United States lacks an income support policy for people with disabilities that do not rise to the level of SSDI or SSI eligibility—and the rest of U.S. income support policy has increasingly become work-based, with extremely limited exceptions for disability.<sup>127</sup> In one consequence, many older people with disabilities unable to continue working until their full retirement age end up forced to claim Social Security retirement benefits early, which subjects them to a lifetime benefit reduction of up to 30 percent, further diminishing already vulnerable retirement security. Noncitizens with disabilities face an even bleaker landscape, due to harsh immigrant restrictions in SSI and other programs, such as a "five-year bar" prohibiting access to a wide array of public benefits until qualifying noncitizens have satisfied a five-year waiting period.<sup>128</sup> And even U.S. citizens who are residents of U.S. territories are generally excluded from SSI eligibility.<sup>129</sup>

# Savings and Ownership Penalties

A major driver of inadequate savings among disabled people—as well as families with a disabled member—is that many U.S. income support programs include outdated eligibility rules that directly penalize savings and ownership. In one particularly egregious example, SSI includes asset limits that have barely changed since the program was signed into law fifty years ago. In 1972, SSI's asset limits were set at \$1,500 for an individual and \$2,250 for a couple. Unchanged since 1989, today, SSI's asset limits sit at \$2,000 for an individual and \$3,000 for a couple—though they would be about \$10,000 and \$15,000 respectively if they had been adjusted for inflation since 1972.

Public policy should encourage, not penalize, saving for the future, as the importance of emergency savings to protect against financial shocks has been well documented. Accordingly, in a recent trend, policymakers at the federal level and in states across the United States have taken steps to reform counterproductive asset limits in income support programs.<sup>152</sup> Asset limit reform has gained the backing of

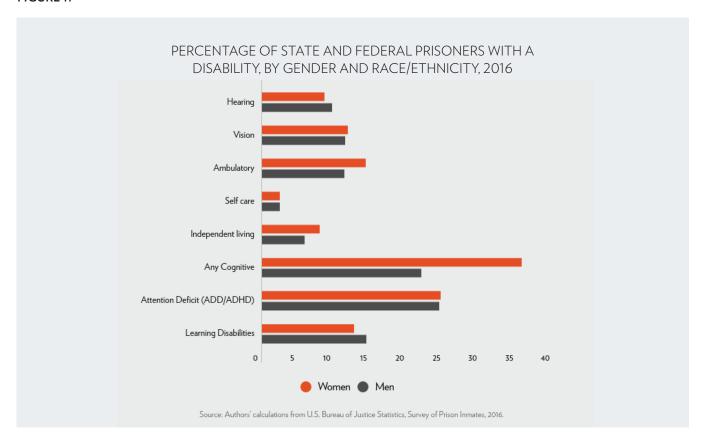
a wide range of stakeholders, including within the business community, such as JP Morgan Chase. While this type of reform was urgently needed long before COVID-19 hit U.S. shores, the pandemic threw into stark relief how dangerous it is to prevent economically fragile individuals and families from having even modest emergency savings. While more than six in ten Americans support eliminating SSI's asset limits altogether, the SSI Restoration Act mentioned above would at least raise SSI's asset limits to \$10,000 for an individual and \$20,000 for a couple, while importantly excluding retirement accounts from counting against those limits, so that SSI recipients and their families are no longer forced to choose between survival income today and retirement security tomorrow.

# Overcriminalization of Disability

As discussed above in the Services and Supports section of this report, while deinstitutionalization is widely regarded as a positive development, this shift has never been accompanied by the public investment necessary to ensure that community-based alternatives to institutional care were made available. In one tragic result, while the number of Americans with disabilities living in institutions has declined dramatically, many have instead been swept up into the criminal legal system over the years, often due to minor infractions such as sleeping on the sidewalk, or as the result of a police response gone wrong. 135 Meanwhile, stories abound in which law enforcement and court personnel's denial of reasonable accommodations has led Deaf and disabled people—particularly those with communication disabilities to be wrongfully ensnared in the criminal legal system due to communication barriers. 136 Indeed, federal and state jails and prisons are now home to three times as many people with mental health disabilities as state psychiatric hospitals. 137

People with disabilities are dramatically overrepresented in the nation's prisons and jails today. According to the Bureau of Justice Statistics, people behind bars in state and federal prisons are nearly three times as likely to report having a disability as the nonincarcerated population, while those in jails are more than four times as likely.<sup>158</sup> Nearly half of all incarcerated women reported having a disability in 2016 (see

#### FIGURE 11



### FIGURE 12

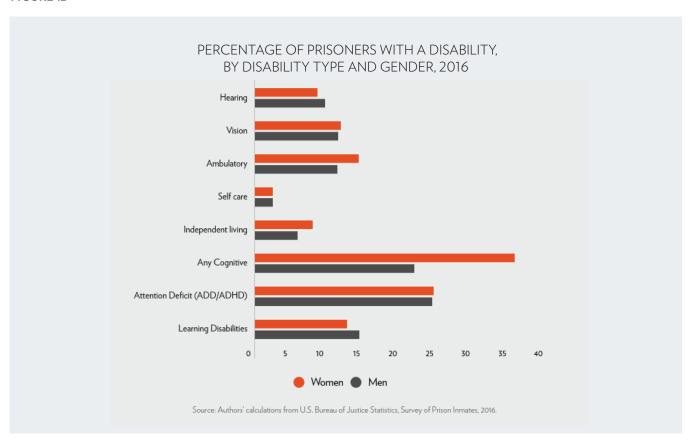


Figure 11). Roughly 38 percent of incarcerated men reported disabilities in 2016.

A detailed breakdown of these data by disability type (see Figure 12) suggests that the higher prevalence of women with disabilities behind bars was driven mostly by the high rate of incarcerated women with cognitive disabilities<sup>139</sup>—the most common disability type behind bars. Approximately 36 percent of incarcerated women and 22 percent of incarcerated men reported a physical, mental, or emotional disability resulting in serious difficulty remembering, concentrating, and making decisions. And one-quarter of imprisoned women indicated that they had at some point been diagnosed with Attention Deficit Hyperactivity Disorder (ADHD).<sup>140</sup> Due to data limitations, the authors are not able to further disaggregate available data on disabled people behind bars by race/ethnicity and disability type. But it is clear that decades of overcriminalization of Black and brown people in the United States have been especially disastrous for disabled people within these groups. One study found that while the cumulative probability of arrest was generally higher for disabled young people than nondisabled young people, the risk of arrest was disproportionately higher for young Black people with disabilities compared to disabled young people of other races or ethnicities.<sup>141</sup>

The mass incarceration of disabled people not only is unjust and immoral, but also further compounds the already immense barriers to economic security faced by disabled people in the United States, by adding the additional barrier of a criminal record—which on its own can present additional, often lifelong obstacles to housing, employment, education, and virtually every pillar of economic stability. Adding to this litany of structural failings and barriers, many reentry programs are not even accessible to returning citizens with disabilities. 145

# Lack of Access to Justice

Difficulty accessing legal representation in civil matters—together with insufficient accessibility in many of the nation's courts—act to further compound many of the barriers to economic security discussed throughout this report. Chronic

underfunding of civil legal services in the United States over many years, combined with a private legal market that is largely cost-prohibitive for low- and moderate-income people to access, leaves countless disabled people to fall into what is often called America's "justice gap" each year—the share of individuals eligible for free legal services who are turned away for lack of adequate resources. A 2015 study by the National Center for State Courts found that three-quarters of all civil proceedings involve at least one unrepresented party. A

Having access to legal representation can be the difference between a disabled person being able to maintain safe and stable housing and losing the roof over their head; accessing vital income support versus facing wrongful denial; and generally being able to enforce their rights under the ADA and other disability civil rights laws and regulations instead of having their rights trampled with no recourse. Particularly for people with intellectual and developmental, cognitive, and/ or mental health disabilities, their disabilities may interfere directly with the rigid bureaucratic demands of many public programs intended to serve them, and without assistance from legal services, many would be unable to access or maintain their benefits. Without adequate access to free or low-cost legal representation, systemic problems such as employment discrimination and illegal denial of reasonable accommodations will remain pervasive, and many disabled people will remain unable to enforce civil rights that have been on the books for decades.

While establishing a right to counsel in certain civil matters is an idea with great promise that has gained traction in recent years in cities and states—and slowly, at the federal level—only one state, Washington, explicitly authorizes appointment of counsel for litigants with disabilities as a form of reasonable accommodation under the ADA. Meanwhile, while Title II of the ADA applies to state and local courts, a lack of awareness about what the ADA requires—or that it even applies to them—is the norm more than the exception throughout America's courthouses. Few states require training of judges and court personnel on the ADA and disability rights in the courts. Few states courts' written correspondence and websites specify how to request

reasonable accommodations or how to file a complaint about denial of disability access—and many court websites themselves are inaccessible to people with disabilities. In fact, some state courts' ADA pages categorically deny the possibility of providing counsel as an accommodation for a disabled person, notwithstanding the ADA's requirement of a case-by-case analysis. Many states' courts do not provide auxiliary aids free of charge to disabled litigants to ensure they are able to effectively communicate with court personnel—and many courts even prohibit disabled people from bringing their service animals into court. Iso

# Conclusion

Achieving the as-yet unrealized promises of the ADAand finally breaking the persistent link between disability and poverty in the United States—will require applying a disability lens across the nation's economic policymaking. While far from comprehensive, this report intends to kickstart that process by offering a detailed picture of the economic crisis facing the U.S. disability community more than thirty-one years after the signing of the ADA, and highlighting policy gaps and failures resulting from the failure to consider disabled people in policy design. Future work by The Century Foundation's Disability Economic Justice Team—and our partners in The Century Foundation's newly launched Disability Economic Justice Collaborative, which brings together two-dozen disability leaders, leading think tanks, and research organizations—will address the policies we need to ensure disability and poverty no longer go hand in hand and make economic justice a reality for disabled people in the United States.

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## **Notes**

- 1 Amartya Sen, The Idea of Justice (2009).
- **2** This report uses person first and identity first language throughout. The intentionality behind this choice is to honor the preferences, cultures, and identities within the disability community.
- **3** U.S. Centers for Disease Control and Prevention, "Disability and Health Overview," Accessed April 2022, https://www.cdc.gov/ncbddd/disabilityandhealth/disability.html.
- 4 Throughout this report, the authors use the Supplemental Poverty Measure (SPM), a more comprehensive measure than the Official Poverty Measure (OPM). While neither measure adequately captures the cost of a basic standard of living today in the United States, the SPM counts assistance from both cash and non-cash economic security programs such as Social Security disability benefits, food assistance from the Supplemental Nutrition Assistance Program (SNAP), the Earned Income Tax Credit (EITC), housing assistance, and other key antipoverty programs. The SPM also subtracts federal and state income taxes, federal payroll taxes, and certain expenses (such as out-of-pocket medical expenses and the cost of child care) from household income when calculating what resources a family has available to buy basics such as food, clothing, and shelter. Under the SPM, a household is considered poor if its resources fall below a poverty threshold (\$28,881 for a two-adult, two-child family renting in an average-cost community in 2019) that accounts for differences in family composition and geographic differences in housing costs. For more information on the SPM, see Liana E. Fox and Kalee Burns, "The Supplemental Poverty Measure: 2020 Current Population Reports," United States Census Bureau, September 2021, https://www.census.gov/content/dam/ Census/library/publications/2021/demo/p60-275.pdf.
- 5 See Figure 1 and accompanying discussion.
- 6 See Figure 10 and accompanying discussion.
- 7 Tom Temin, "New center from HUD and HHS helps people with disabilities find

housing," Federal News Network, January 19, 2022, https://federalnewsnetwork.com/management/2022/01/new-center-from-hud-and-hhs-helps-people-with-disabilities-find-housing/.

- 8 42 U.S. Code § 12101-12213.
- 9 See Figures 4 and 5 and accompanying discussion.
- 10 It is worth noting that this pay gap does not capture subminimum wages paid to tens of thousands of disabled workers under an archaic loophole in federal wage and hour law known as 14(c), as those workers are not generally captured in federal wage and hour statistics. For a more detailed discussion, please see the section below, "Subminimum Wage and the Disability Wage Gap."
- 11 See Figure 2 and accompanying discussion.
- 12 Caroline Medina, Lindsay Mahowald, Thee Santos, and Mia Ives-Rublee, "The United States Must Advance Economic Security for Disabled LGBTQI+ Workers," Center for American Progress, November 3, 2021, https://www.americanprogress.org/article/united-states-must-advance-economic-security-disabled-lgbtqi-workers/.
- 13 "The Rehabilitation Act of 1973," U.S. Equal Employment Opportunity Commission, accessed April 5, 2022, https://www.eeoc.gov/statutes/rehabilitation-act-1973.
- 14 "IDEA Individuals with Disabilities Education Act," U.S. Department of Education, accessed April 5, 2022, https://sites.ed.gov/idea/#.
- 15 "Workforce Innovation and Opportunity Act," Employment and Training Administration, U.S. Department of Labor, accessed April 5, 2022, https://www.dol.gov/agencies/eta/wioa.
- 16 While it is difficult to ascertain the precise number of people in the Uhited States who are newly disabled due to COVID-19, one 2022 estimate by the Center for American Progress Disability Justice Initiative suggests that the number of disabled people in the United States increased by roughly 1.2 million between the start of the pandemic in March 2020 and the end of 2021. See Lily Roberts, Mia Ives-Rublee, and Rose Khattar, "COVID-19 Likely Resulted in 1.2 Million More Disabled People By the End of 2021," Center for American Progress, February 9, 2022, https://www.americanprogress.org/article/covid-19-likely-resulted-in-1-2-million-more-disabled-people-by-the-end-of-2021-workplaces-and-policy-will-need-to-adapt/.
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134 "Voters Overwhelmingly Support Strengthening Supplemental Security Income (SSI) Finds TCF and Data for Progress Poll," Data for Progress and The Century Foundation, May 2021, https://production-tcf.imgix.net/app/uploads/2021/05/27090206/21.5\_1PAGER\_SSI\_v1.pdf.

135 For a more detailed overview of the over-representation of disabled people in the United States criminal legal system—and the policies needed to end the criminalization of disability in the United States, please see Rebecca Vallas, "Disabled Behind Bars," Center for American Progress, 2016, https://www.americanprogress.org/article/disabled-behind-bars/.

136 See Ibid.

137 See Ibid.

138 See Ibid.

139 Some examples of cognitive disabilities include Down syndrome, autism, dementia, intellectual disabilities, and learning disabilities.

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141 Erin J. McCauley, "The cumulative probability of arrest by age 28 years in the United States by disability status, race/ethnicity, and gender," American Journal of Public Health 107, no. 12 (2017), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5678390.

**142** For a detailed overview of how criminal records have come to serve as major drivers of poverty and inequality in the United States, see Rebecca Vallas and Sharon Dietrich, "One Strike and You're Out," Center for American Progress, 2014, https://www.americanprogress.org/article/one-strike-and-youre-out/.

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**144** "Justice Gap Report," Legal Service Corporation, https://www.lsc.gov/our-impact/publications/other-publications-and-reports/justice-gap-report.

145 "The Landscape of Civil Litigation in State Courts," National Center for State Courts, November 2015, https://www.ncsc.org/\_\_data/assets/pdf\_

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# Appendix: Economic Justice Is Disability Justice

APRIL 21, 2022 - REBECCA VALLAS, KIM KNACKSTEDT, HAYLEY BROWN, JULIE CAI, SHAWN FREMSTAD, AND ANDREW STETTNER

# **Defining Disability**

Disability is a complex and evolving concept, with varying definitions used in different contexts. For most of the twentieth century, disability was viewed solely in individual and medical terms as intrinsic to individual persons. Due largely to the efforts of disabled people and the international disability rights movement, disability has increasingly come to be understood in dynamic social terms—and as an identity. In contrast to the dated medical model, disability is increasingly viewed as an interaction between the individual and the societal structures that create barriers to living independently and engaging equitably. As disability rights activist Rachel Hurst writes: "disability is the outcome of social barriers [...] it is society that has to change to prevent discrimination and promote rights."

Disability crosses all ages, races, genders, sexual orientations, and religions. Disability is a part of many people's identities and lives from birth onward, while others may join the community later in life as they age. Indeed, it is the only protected class that individuals can become part of at any point in their lives.

Although not yet ratified by the United States, the Convention on the Rights of People with Disabilities<sup>2</sup> adopted by the United Nations General Assembly in 2006, specifies in the opening purpose statement that disabled people include those "who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others." The ADA similarly defines disability broadly as "a physical or mental impairment that substantially limits one or more major life activities" or "being regarded as having such an impairment."

Importantly, the COVID-19 pandemic appears to be one of the largest mass disabling events in U.S. history, vastly expanding the disability community due to the entry of people with disabilities resulting from long COVID. President Biden made clear in July 2021 that people facing disabilities due to long COVID may be covered by the ADA definition of disability and thus included in that protected class.<sup>3</sup>

In contrast to the broad definitions used by disabled individuals and civil rights legislation, disability is sometimes equated with eligibility for certain income support programs such as SSDI and SSI. As discussed in the Income Supports

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section of this report, those programs share a definition of disability that is much narrower and more directly connected to work capacity, including only those individuals who, because of a "physical or mental impairment" expected to last at least one year or to result in death, are unable to return to any of their past jobs or to do any work that exists in the national economy at a level in which they could do "substantial gainful activity"—that is, they could earn \$1,350 per month in 2022.4 Because this definition is so narrow and does not reflect the costs and reality of being disabled in the calculation, only a fraction of people with disabilities in the United States qualify as disabled (and are thus eligible for disability benefits) under the Social Security disability standard

# How Many People in the United States Are Disabled?

Many surveys and national data sets are inconsistent in their definitions and analyses of disability. However, taken together, data from various representative individual and household surveys produced by the Census Bureau and other federal agencies can be used to estimate the number of adults in the United States who are disabled. Most of these surveys use a standardized set of six questions that ask about activities of daily living, including difficulty hearing, seeing, walking or climbing stairs, dressing or bathing, concentrating or remembering, and doing errands alone. Some federal surveys have additional questions that can be used to identify disabled people—such as whether a person receives SSDI or SSI or is unable to work due to a disability—but these are typically not included when federal agencies produce overall disability statistics.

The best disability estimates are likely to come from surveys that: (1) are conducted by trained interviewers; (2) allow individuals to self-identify whether or not they have a disability and do not rely on "proxy" responses from other household members; and (3) have large sample sizes that are representative at national and state levels.

Both the Behavioral Risk Factor Surveillance System (BRFSS),<sup>5</sup> sponsored by the CDC and several other federal

agencies, and the National Health Interview Survey (NHIS),6 conducted by the National Center for Health Statistics at the Centers for Disease Control and Prevention (CDC), meet these criteria. According to the BRFSS, which directly interviews over 400,000 adults a year, about 61 million adults, or one in four adults, are disabled. This means that at least one in four adults answered yes to at least one of the standard six questions asked about difficulties with daily living tasks.

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# Notes

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- https://www.whitehouse.gov/briefing-room/statements-releases/2021/07/26/fact-sheet-biden-harris-administration-marks-anniversary-of-americans-with-disabilities-act-and-announces-resources-to-support-individuals-with-long-covid/.
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