



The Extra Costs of Living with a Disability in the U.S. — Resetting the Policy Table

October 2020

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Overview

Researchers at Stony Brook University, the University of Tennessee, National Disability Institute, and the Oxford Institute of Population Ageing estimate that a household containing 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.¹

The research, which was supported by the FINRA Investor Education Foundation, uses a statistical method known as the “standard of living approach” and is the first study applying this methodology to the U.S. population. This brief draws from the technical working paper and focuses on the policy implications of the research.²

Many means-tested public benefits in the U.S. impose asset and income limits, but do not take the additional costs of disability into consideration. The result is that many people with disabilities may be viewed as financially able and thus denied assistance even though the reality of their extra disability-related expenditures places them in a tenuous financial position.

¹ This estimate is an average taken from the four surveys incorporating the years 2015 to 2018.

² The working paper is available at: nationaldisabilityinstitute.org/reports/extra-costs-living-with-disability.

Background

Previous research has explored the effect that disability has on income. Working-age adults with disabilities are twice as likely as those without disabilities to have incomes under the poverty threshold. They are less likely to be employed than their peers without disabilities and, even among those who are employed, they have lower wages on average than those without disabilities.³ Additionally, family members often reduce the amount they work to provide informal support to family members with disabilities, thus further reducing the household income.⁴

Income is also front and center in U.S. public policies, as it is used to measure poverty and establish eligibility for means-tested public programs. However, financial stability is based not only on income, but also on the relationship between income and expenses. Because these income measures do not consider expenses or the additional costs associated with living with a disability, they understate the true level of economic hardship experienced by households that include a person with a disability.

The extra costs of disability fall broadly into two categories: indirect costs and direct costs.

Indirect costs include foregone earnings that people with disabilities incur because they face barriers to work, such as employment discrimination. They also include costs borne by family members who may reduce their amount of paid work, or take lower paying jobs that come with flexibility needed to provide care to a family member with a disability.

Direct costs are those expenditures people make because they have a disability. Within the disability community, these extra costs are well known. The largest extra costs are for personal assistance services and health care, where out-of-pocket costs for people with a disability are more than twice as high as those without a disability.⁵ On Twitter, individuals share their experiences about a variety of extra costs, such as the cost of ordering things when the in-person pickup option is not accessible, building a wheelchair ramp, acquiring and maintaining service animals, buying a more expensive car in order to accommodate a wheelchair, purchasing food for special diets, or paying more for housing in order to find a place that is accessible and convenient.

³ Lauer, E.A., Boege, S.L., & Houtenville, A.J. 2020. *Annual Disability Statistics Compendium: 2019*. Durham, NH: University of New Hampshire, Institute on Disability.

⁴ Lilly, M.B., Laporte, A., & Coyte P.C. 2007. Labor Market Work and Home Care's Unpaid Caregivers: A Systematic Review of Labor Force Participation Rates, Predictors of Labor Market Withdrawal, and Hours of Work. *Milbank Quarterly*. 85(4): 641–690.

⁵ Kennedy, J., Wood, E.G., & Frieden, L. 2017. Disparities in Insurance Coverage, Health Services Use, and Access Following Implementation of the Affordable Care Act: A Comparison of Disabled and Nondisabled Working-Age Adults. *INQUIRY: The Journal of Health Care Organization, Provision, and Financing*. 54: 1–10.

These direct extra costs may be aggravated by poverty. Living in a low-income neighborhood or lacking savings and access to credit can force people into more expensive ways of doing things. They may pay more for food because they live in a food desert or more for financial services because they rely on check cashing services, payday loan companies, or other subprime lenders.⁶

Direct costs vary dramatically from person to person according to personal circumstances, availability of unpaid supports, the type and severity of impairment, eligibility for in-kind benefits from government programs, and other factors. The costs are not fixed and may ebb and flow over the course of a lifetime. Costs may even vary depending on work status, since additional supports often are needed to facilitate working.

⁶ The Brookings Institution. 2006. *From Poverty, Opportunity: Putting the Market to Work for Lower Income Families*. https://www.brookings.edu/wp-content/uploads/2016/06/20060718_PovOp.pdf.

A Realistic View of Extra Costs —

Edward Mitchell is from Jackson, Tennessee, where he lives and works with a spinal cord injury from a hit and run accident in 2003 when he was 17 years old. Edward earned a bachelor's degree and an MBA away from home and is a member of a bowling league and band. He now works at the Jackson Center for Independent Living and the Jackson Generals Minor League Baseball Team. To maintain an independent lifestyle, Edward and his family experience a significant amount of extra costs. These costs come in the form of home nursing, home modifications, dictation tools that help with writing, and car modifications that allow him to drive himself to work.

Edward lives with quadriplegia and uses a variety of assistive devices. He has manual and electric wheelchairs, which were covered in part by his father's private insurance plan. While that same insurance plan pays to have his wheelchair seat cushions replaced every two years, Edward and his family are responsible for the additional cost of repairs for things like scratches, joystick damage, and broken wheels. These costs can be considerable for a person with an active lifestyle. Edward also pays for and maintains a wheelchair-accessible vehicle. Although some modifications were covered by insurance or through the state Vocational Rehabilitation program, Edward paid \$50,000 out of pocket just to purchase the vehicle. He finds himself in the shop almost every other month with repair costs exceeding \$500. This is in addition to the income lost by taking off work to travel to the shop in Memphis. Edward cannot leave these costs unpaid because of the independence afforded him by this vehicle. "That could be your only mode of transportation to get around, especially in a rural town," he said.

PROFILE CONTINUED ON PAGE 11

How the U.S. currently addresses these extra costs

Unlike many countries, such as the United Kingdom and Sweden, the U.S. does not have an allowance program designed specifically to address the extra costs of disability. In fact, most public disability expenditures are focused on wage replacement and health insurance for working-age people who, based on a stringent disability determination process, are deemed “unable to work.”⁷ However, the extra costs have been recognized in legislation, administrative rules, tax code adjustments, customized budgeting for home and community based services, and provision of in-kind benefits.

Legislation

Congress explicitly recognized the extra costs when legislating the following programs:

- Low-income families with children with disabilities qualify for Supplemental Security Income (SSI) because, as Congress noted when passing the law in 1972, “Poor children with disabilities should be eligible for SSI benefits because their needs are often greater than non-disabled children.”⁸
- When extending Medicare benefits to Social Security Disability Insurance (SSDI) beneficiaries (1972), a Senate Committee on Finance Report noted that “[t]he disabled, as a group, are similar to the elderly in those characteristics—low incomes and high medical expenses—which led Congress to provide health insurance for older people.”⁹
- More recently, Congress passed the Achieving a Better Life Experience Act of 2014 (ABLE Act) and recognized these extra costs by allowing individuals to save for disability-related expenses in a tax-advantaged account that is not considered an asset when determining eligibility for means-tested public benefits.

⁷ Livermore, G., Shenk, M., & Stapleton, D. 2019. Federal and State Expenditures for Working-Age People with Disabilities in Fiscal Year 2014. *Journal of Disability Policy Studies*. 30(2): 111–117.

⁸ U.S. House of Representatives, Social Security Amendments of 1971, Report of the Ways and Means Committee on H.R. 1, H. Rept. No. 92-251, pp. 146–148 as cited in: Fremstad, S., & Vallis, R. (2012) Supplemental Security Income for Children with Disabilities. National Academy of Social Insurance. https://www.nasi.org/sites/default/files/research/SSI_For_Children_Disabilities.pdf

⁹ Senate Report No. 92-1230 (September 25, 1972), p. 37 as cited in: Social Security Administration, Legislative History of the Social Security Disability Insurance Program. www.ssa.gov/legislation/DI%20legislative%20history.pdf

Administrative adjustments

Other programs adjust for some of the extra costs in their administrative rules. For example, in general, eligibility for benefits provided by the Supplemental Nutrition Assistance Program (SNAP) requires that a household have gross income of less than 130 percent of the Federal Poverty Level (FPL) and a net income of less than 100 percent. The household must also have low countable assets. However, a household with a person who is elderly or has a disability (defined as receiving at least one type of state or federal disability benefit) is not subject to the gross income requirement and can deduct certain medical-related expenses (including attendant care) from the income calculation. In addition, these households are allowed \$3,500 in countable resources rather than the standard \$2,250. These rules may sound like minutiae, but they are an important way the U.S. recognizes some of the extra costs of disability.

Tax code adjustments

The tax code recognizes extra costs by allowing certain deductions. People who are blind qualify for a larger standard deduction, and workers with disabilities may qualify for a deduction for impairment-related work expenses. All taxpayers who itemize are eligible to deduct medical care expenses that exceed 10 percent of adjusted gross income.¹⁰ This may be a particularly relevant tax advantage for people with disabilities who have high out-of-pocket medical care costs.

Self-directed services

The most direct adjustment for extra costs is conducted in Medicaid's Home and Community Based Waiver Services (HCBS). These vary by state and target population but are generally focused on providing health and human services (including personal care). This results in people with intellectual disabilities, mental illnesses, and/or physical disabilities who may otherwise need institutional care being able to live in their own home or community. Medicaid typically contracts with local agencies to deliver and manage these services. However, states have the option to offer HCBS participants (or their representatives) decision-making authority over service management and support.

Self-directed participants are allotted a customized budget developed through a planning process that is based on the individual's needs and preferences as established in the service plan. The use and availability of self-directed services vary by state. Overall, 13 percent of Medicaid HCBS participants use this option.¹¹ Despite its relatively low prevalence currently, this approach can serve as a model for accommodating the extra costs of disability.

¹⁰ According to [26 U.S. Code §213](#), the threshold for deducting medical expenses is 10 percent of adjusted gross income for taxpayers under age 65. Two temporary changes, the Tax Cut and Jobs Act of 2017 and the Certainty and Disaster Relief Act of 2019, reduced the threshold to the pre-2010 level of 7.5 percent through 2020. If Congress takes no action, it will revert back to 10 percent in 2021.

¹¹ Bradley, V.J. & Li, H. 2019, April. *Self-Direction: Are We There Yet? A Brief Status Report from the U.S. and Beyond*. Presented to Applied Self-Direction National Conference, Baltimore, Maryland.

Other in-kind services

Government programs also provide in-kind benefits for certain groups of people with disabilities. However, these supports are disjointed, idiosyncratic and only cover a small fraction of the extra costs. Many of these government programs are also means-tested (i.e., based on income). For example, Medicaid may include long-term care and home and community services, such as personal assistance services, for some enrollees based on their type and severity of disability. However, eligibility is contingent on having an income below 138 percent of the FPL with certain exceptions. Housing assistance is generally restricted to households with incomes less than 80 percent of the Area Median Income, and energy assistance is restricted to households with incomes less than 15 percent of the FPL.

How the extra costs of disability are estimated

In order to calculate the direct extra costs of living with a disability, the authors used the standard of living approach, which estimates the amount of additional income required to bring the standard of living of a household containing a person with a disability to the same level as a comparable household without a member with a disability. The main question driving this research was, “How much extra money would a working-age person with a disability need to spend on all activities to achieve the same standard of living they could achieve with no disability?”

The standard of living approach

The standard of living approach addresses this question using multivariate regression modeling that analyzes the underlying relationships among a standard of living indicator, income, and disability. Results tend to be sensitive to the measure of disability, standard of living, income, and control variables that are captured differently across surveys. To account for these differences, this research used four different surveys with slightly different measures and provided an average estimate of the extra costs of disability across the surveys.¹² The consistency of the four estimates gives greater assurance to the reliability and validity of the estimate.

This research approach measures out of pocket costs beyond what is covered by various health and social welfare programs that provide income and in-kind benefits. The extra costs are thus calculated as the household financial burden associated with living with a disability, even after considering various assistance programs and services.

¹² The four surveys included the FINRA Foundation’s [National Financial Capability Study \(2018\)](#), the [Financial Well-Being Survey \(2015\)](#), the [Survey of Household Economics and Decision-making \(2017\)](#), and the [U.S. Financial Health Pulse Survey \(2018\)](#).

Findings

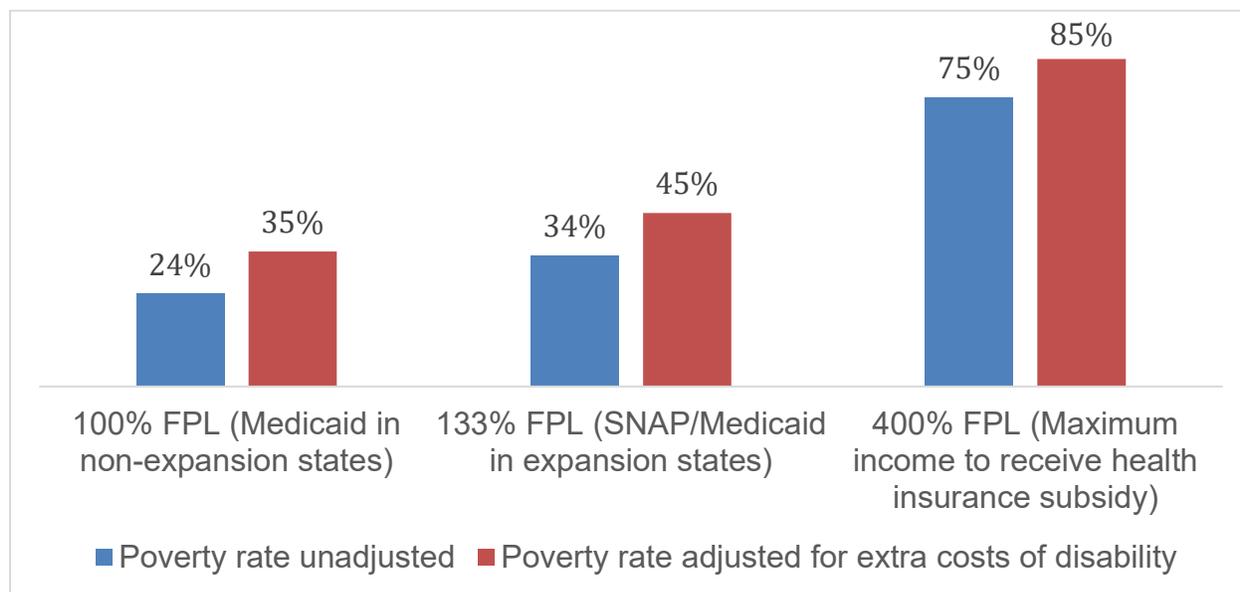
This approach shows that, in order for a person with a disability to have the same standard of living as someone without a disability, they would need more money.

Households containing an adult with a work-disability are estimated to require, on average, 28 percent more income (or an additional \$17,690 a year for a household at the median income level) to obtain the same standard of living as a comparable household without a member with a disability.

Poverty measures, such as the FPL, assume that a household including a person with a disability can achieve the same standard of living as a household not including a person with a disability when both have the same income. This research finding, which highlights the required expenses that only people with disabilities incur, challenges that assumption.

If we were to adjust the FPL for adults with disabilities for the additional costs of disability, as shown in Figure 1, the poverty rate for households including an adult with a work-disability would rise from 24 percent to 35 percent. With the population of adults with work-disabilities estimated at 20 million¹³ this would result in an estimated 2.2 million more people with disabilities counted as poor. This adjustment would also increase eligibility for the major health and social welfare programs, including SNAP, Medicaid, and access to the health insurance subsidy.

Figure 1. How the poverty rate for households with adults with work-disabilities changes when adjusting for the extra costs of disability



Source: Authors' analysis of March 2019 Current Population Survey data

¹³ U.S. Census Bureau (2019). 2018 American Community Survey 1-year Estimates Detailed Tables, Age by Number of Disabilities. Table Number C18108. Retrieved from <https://data.census.gov/cedsci/>.

Limitations and the need for additional research

This statistical approach provides us with a robust estimate of the average additional costs of disability and highlights the need for additional research to address the following questions that cannot be explored using the standard of living approach.

- This approach does not provide information on the types of expenses that are driving the costs.
- This estimate provides an average across all people with work-disabilities, but it cannot be used to identify the extra costs for each individual. These costs may vary widely.
- It does not provide information on how living with a disability affects the income of the individual or the family member. For example, if a family member reduces work hours to provide care, the lost income is not captured.
- As the research draws on cross-sectional data, the results are descriptive, and causal inferences cannot be interpreted. Differences between people living with long-term versus short-term disabilities also cannot be identified. Longitudinal research is needed.
- The research only estimates what people with disabilities spend on disability-related items and does not estimate what level of spending may be required to enable them to fully participate in activities in their home and community.

Policy Implications

Thirty years ago, the passage of the Americans with Disabilities Act (ADA) was influenced by research that revealed patterns and practices of discrimination in the fair and equal treatment of people with disabilities in the classroom, workplace, places of public accommodations, and even in the delivery of government services. Public policy—most often with bipartisan support—has defined “liberty and justice for all” in a pluralistic and inclusive sense so as to benefit individuals with disabilities.

Research indicating the substantial extra costs that people with disabilities face suggests more work is needed to further the goals of the ADA.

This will require fresh thinking about resetting eligibility rules for public benefits, changing the tax code, and improving vehicles for financial planning.

Implications for the social safety net

Current definitions of poverty that are commonly used for benefit means testing do not take into consideration the extra costs of living with a disability. Such a consideration requires resetting the policy table to be sensitive to the reduced value of income and assets due to disability costs related to healthcare, housing, transportation, technology, and other daily living needs.

The ADA protections against discrimination have reduced physical, communication, and attitudinal barriers to full participation in community. The section of the law that remains the most unrealized is the promise of “advancing economic self-sufficiency.”

Recalculating the means testing of public benefits eligibility for Social Security, Medicaid, food, and housing assistance in a way that factors in the extra costs of living with a disability can help advance economic self-sufficiency.

More research should be undertaken to factor the determination of extra costs of living with a disability as a new amended calculation of one or more of current public benefits. Research should explore the impact of an “extra cost” supplement or allowance for individuals with varying types of disabilities. Such a supplement could offset the extra costs of disability and greatly enhance the financial security of households with disabilities.

Implications for the tax code

The tax code holds a number of possible options for the distinct treatment of individuals with disabilities. The current medical expense deduction (Section 213) already includes individuals who itemize unreimbursed expenses that exceed 10 percent of adjusted gross income (7.5 percent from 2017–2021). From a policy reset standpoint, should individuals with disabilities who meet the ADA definition of disability have a lower threshold due to the amount of extra costs? Should taxpayers with disabilities be allowed to take a deduction for medical or other disability-related expenses in addition to the new higher standard deduction even if they do not itemize?

Implications for financial planning

The research findings will also benefit financial planners designing special needs trusts and calculating structured settlements. In both situations, knowledge of the “extra cost” factor may more accurately support an informed design of trusts supplemented by ABLE accounts and/or the purchase of disability insurance, which could help families meet the financial needs of children and/or adults with disabilities.

An additional policy area to consider would be amending the ABLE Act of 2014 to take into consideration the magnitude and variation of the extra costs faced by ABLE account holders. The current annual allowable contribution for ABLE accounts is \$15,000. Based on the findings of this study, this ceiling does not even cover the average extra expenditures, much less the extraordinary extra costs faced by some. ABLE accounts are modeled on the College 529 Plans, which do not specify a contribution limit. Instead, Congress allows families the freedom to ensure their 529 balances do not exceed the expected cost of qualified higher education expenses. Should we reconsider the annual allowable contribution limit to an ABLE account if an individual provides documentation of expenditures related to their disability?

This research also highlights that extra expenditures occur over the course of an individual's life, regardless of when the disability began. If the goal of the ABLE Act is to provide individuals and families with a mechanism to save for these expenditures, Congress should modify the eligibility requirement that an individual must have a qualifying impairment that began before the individual turned 26 in order to open an account. This important change would expand access for individuals with disabilities and improve the overall sustainability of ABLE programs by increasing the number of accounts.

Resetting the policy table for greater equity

Whatever the measure of poverty that is used, individuals with disabilities are more likely to be poor than their nondisabled peers.¹⁴ This research suggests that the extra costs are a substantial factor behind this inequity. Resetting the policy table for greater equity will require recognition across the public benefits space and the tax code of the significance of the extra cost factor (28 percent more income, or \$17,690 per year in 2020). Ignoring that factor will only perpetuate the financial insecurity experienced by people with disabilities and their families.

¹⁴ Brucker, D.L., Mitra, S., Chaitoo, N., & Mauro, J. 2015. More Likely to Be Poor Whatever the Measure: Working-Age Persons with Disabilities in the United States. *Social Science Quarterly*, 96(1): 273–296. doi: 10.1111/ssqu.12098

A Realistic View of Extra Costs —

(STORY CONTINUED FROM PAGE 3)

One of Edward's goals is to move out of his mother's home and live on his own. In his current home, his family had to cover the cost of bathroom modifications, which include an overhead lift system to help with bathing. He also requires a large, adjustable Flex-a-Bed to allow him to sleep comfortably, which insurance has refused to cover for several years. Edward understands that for "anybody that's in a chair, especially if they don't have good health, any little thing can take [you] out." For that reason, he invests money in extra catheter supplies, cranberry pills, an overall healthier diet, and an expensive toothbrush that he can easily hold, all to maintain his health and hygiene.

On top of these high direct costs, Edward incurs indirect costs that include forgone salary and time. For example, in order to receive vital nursing care (which he needs for about four hours a night), Edward is part of the Medicaid Choices waiver program. Unfortunately, Edward's income is tied to the amount of services he receives through that waiver. If he earns more income, he qualifies for less services. Therefore, Edward's two jobs are both part-time. His mother also could not juggle helping her son with her full-time teaching and social work job, so she now works for a church Brotherhood Sisterhood program and is a hostess, earning less than she did in the past. Additionally, Edward spends time outside of work to advocate for supports from Vocational Rehabilitation and Social Security.

Due to inefficiencies in these systems, he must research and request services/supports for which he already qualifies, but must fight to receive. In order to do this, Edward balances the risks of taking time off from work with the possibility of losing out on much-needed services. These extra indirect costs are not easily calculated, but Edward recognizes the added financial stress they create. He hopes that sharing his story can paint a realistic view of his extra costs.

This research was supported by a grant from the FINRA Investor Education Foundation. All results, interpretations, and conclusions expressed are those of the research team alone, and do not necessarily represent the views of the FINRA Investor Education Foundation or any of its affiliated companies.

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