

WORKING PAPER

The extra costs associated with living with a disability in the United States

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Abstract

People with disabilities encounter many financial expenses that those without disabilities do not incur. In this paper, we provide estimates of the extra costs associated with living with a disability in the United States. Drawing on four nationally representative surveys, we estimate that a household containing an adult with a work-disability requires, on average, 28% 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. Single adults with disabilities are estimated to have higher costs than those with disabilities who are married, and adults with cognitive impairments are estimated to have higher costs compared to those with other kinds of impairments. We further calculate the poverty rate at the federal poverty level for households that include adults with disabilities adjusted for the direct additional costs of disability. The rate rises from 24% to 35% after adjusting for the extra costs of disability, which would result in an estimated 2.2 million more people with disabilities counted as poor. This suggests that the official poverty measure in the U.S. substantially underestimates the level of poverty experienced by people with disabilities.

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Introduction

An estimated 20 million adults between the ages of 18 and 64 (10% of the working-age population) live with a disability in the United States (U.S.) (Lauer, Boege, & Houtenville, 2020). Compared to adults without disabilities, adults with disabilities experience greater difficulty meeting monthly expenses, saving for the future, and making ends meet (Goodman, O'Day, and Morris 2017). Whichever measure of poverty that is used, working age people with disabilities are more likely to be poor than their non-disabled peers (Brucker, Mitra, Chaitoo, & Mauro, 2015). One likely explanation for these financial challenges is the additional disability-related expenses that adults with disabilities incur that those without disabilities do not require. In particular, living costs for items such as medical and pharmaceutical care, mobility equipment or assistive technologies, and caregiving services are often necessary for a person with disabilities to fully function in society. Prior research suggests that these costs of disability are considerable (see, Mitra et al., 2017). Though many studies have been conducted of the extra costs of disability for those living outside the U.S., research has yet to fully quantify the extra costs of disability in the U.S. The purpose of this study is to fill this gap in the literature by drawing on multiple national surveys of the U.S. population to estimate the extra costs of living with a disability. We apply the Standard of Living (SOL) approach, a regression-based estimation method that has been widely adopted in prior studies, to estimate the additional income a household with a person with a disability requires to achieve the same standard of living as a comparable household without a disability. Our paper thus contributes to the literature in the following ways. First, we adopt an established approach to estimating the extra costs of disability that is widely used internationally and provide estimates for the U.S. Second, we draw on multiple nationally representative datasets of the U.S. population and are able to produce an

average estimate of the extra costs of disability that can be used as a baseline estimate for future studies. Third, we draw on data from the U.S. Current Population Survey to calculate an equivalized federal poverty level (FPL) for households that is adjusted for the extra cost of disability in order to demonstrate the applicability of our estimates to the measurement of poverty and how this adjustment might impact eligibility for major safety net programs in the U.S.

Background

Despite the passage of the Americans with Disabilities Act thirty years ago, people with disabilities continue to experience substantial barriers to financial stability. Adults with disabilities are more than twice as likely than people without disabilities to find it “very difficult” to cover expenses and pay bills, twice as likely to have past due medical bills, less likely to have set long-term financial goals, more likely to be unbanked (Goodman, O’Day and Morris, 2017), and twice as likely to use alternative financial services, such as payday lenders (McGarity & Caplan, 2019). Sen (2004) puts forth two distinct disadvantages experienced by disabled people that may explain these financial disparities. The first is what he terms an “earnings handicap.” This indirect cost consists of difficulties that people with disabilities encounter in receiving a suitable education and acquiring the human capital needed to obtain employment, including the experience of discrimination and the lack of accommodation that reduces earnings potential. Yet, Sen argues the earnings handicap alone is insufficient for understanding the financial difficulties that disabled people experience. In addition to the earnings handicap, adults with disabilities also experience what Sen terms a “conversion handicap.” This refers to the challenge of converting income or money into a desired outcome (i.e. a standard of living). This challenge arises when a person must substitute the purchase of items and services in favor of a disability

related expense (i.e. wheelchairs, caregiving services, or out of pocket medical expenses). While both forms of disadvantage are vital to understanding the economic disadvantage of living with a disability, research on the extra costs of disability is specifically focused on estimating the magnitude of the so-called “conversion handicap.”

Approaches to estimating the extra costs of disability

There are at least three different ways one could measure the extra costs of disability. The first, which has been referred to as both the goods and services (Mitra et al., 2017) and the expenditure-based approach (Wilkinson-Meyers et al., 2010), compares household budgets and consumption patterns of adults with disabilities to those without disabilities to directly identify additional disability-related expenses. The limitation with this approach is that identifying a sufficient sample to account for the diversity of impairment types among people with disabilities, and thus the specific needs, is challenging. Additionally, though these studies capture spending patterns, they are limited in that they cannot capture the opportunities available to purchase goods and services in a given context. For example, studies indicate that in low-income countries the costs of disability are lower than in higher-income countries, which may reflect “the unavailability of needed goods and services” (Mitra et al., 2017, 2). Moreover, the direct costs associated with living with a disability may not clearly be discerned as disability-related expenses in consumption surveys (e.g., greater food or electricity costs).

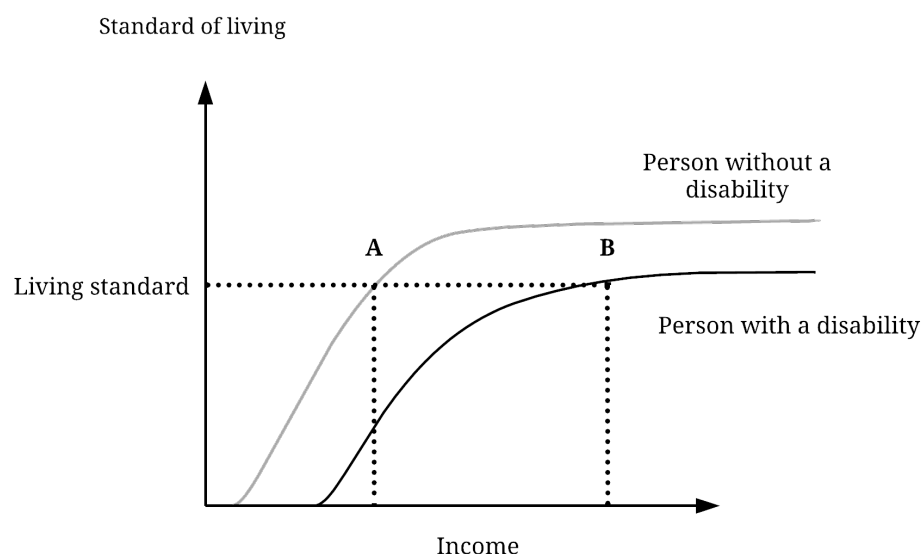
A second method, the “direct subjective approach” (İpek, 2019), directly asks people with a disability about the kinds of goods and services they require to fully participate in society. The strength of this approach is that it incorporates the participation of disabled people as experts in the assessment of their extra costs (Tibble, 2005; Wilkinson-Meyer et al., 2010). A limitation

of the approach is that it may be viewed as subjective or (as is also true for the first approach) suffer from a response bias that can occur when a respondent or interviewee seeks to comply with what the researcher or other participants expect of them (Bogner & Landrock, 2016; Cullinan et al., 2011). For example, an interviewee may inflate the amount of extra costs they encounter when asked directly by an interviewer researching those costs. The respondent may also not have full information of the kinds of goods and services that could improve their living standards, which would downward bias the cost estimates (Mitra et al., 2017).

A third method for estimating the extra costs of disability, referred to as the “standard of living” (SOL) (Zaidi and Burchardt, 2005) or the “expenditure equivalence” (Stapleton et al., 2008) approach, has emerged as the most widely adopted method (most recently applied in the context of 15 Organisation for Economic Co-operation and Development (OECD) countries by Morris and Zaidi, 2020). In their systematic review of the extra costs of disability literature, Mitra et al (2017) found that the majority of quantitative studies adopted the SOL approach, which measures the extra costs of disability indirectly. With the SOL approach, the extra costs of disability are defined as 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 SOL approach uses multivariate regression to analyze the underlying relationship between a standard of living indicator, income, and disability. This relationship is demonstrated in Figure 1, where the ability to obtain a given living standard is expected to increase with income for all households and with diminishing returns as income increases. Yet for a household containing a person with a disability the same income results in a lower living standard. Thus, in Figure 1, income B for a household including a person with a

disability translates into the same living standard as income A for a household not including a person with a disability, and B minus A gives an estimate of the extra costs of disability.

Figure 1. Standard of living, income, and disability



Source: Adapted from Morris and Zaidi (2020) and Zaidi & Burchardt (2005)

The SOL approach can be understood in equation [1], which illustrates the case where the costs associated with living with a disability are independent of the level of income, with a linear relationship between income and the standard of living. The econometric theory is that the latent variable for SOL can be measured by an indicator of material deprivation such as the household's ability to make ends meet. Algebraically, the method can be stated as:

$$[1] \quad \text{SOL} = aY + bD + gX + k$$

where SOL is an indicator of standard of living; Y is household income; D is an indicator variable measuring disability; X is a vector for other characteristics that need to be controlled for, such as age, gender, geographic region, household size, and education status; a, b, and g are the coefficients; and k is the intercept term expressing a constant absolute minimum level of

standard of living. The extra costs of living with a disability are then approximated by the ratio of coefficients associated with disability and income, $-b/a$.

The limitations of the SOL approach include its sensitivity to the measure of disability, standard of living, income, and control variables that are captured differently across surveys. Examining these costs across multiple surveys should, however, bring greater assurance to the validity of the estimate. As an indirect measure, the SOL approach also cannot provide information on the kinds or types of expenses that are driving the cost estimates and only captures the direct expenses for disability, while not accounting for indirect costs such as the provision of unpaid care or foregone earnings (Zaidi & Burchardt, 2005). The SOL approach, moreover, can only account for what disabled people spend on disability-related items and does not provide an estimate of the full extent of need. The strengths of the SOL approach are that it does not require the measurement of expenditures or rely on a subjective evaluation of additional costs. Instead the SOL approach identifies the extra costs by examining whether individuals can translate income into utility as measured by a defined living standard and how disability may hinder the ability to translate income into the living standard. This makes the approach applicable to a wide variety of surveys that collect information on household income, disability, and standards of living.

Prior estimates of the extra costs of disability using the SOL approach

We summarize a sample of the literature on the extra costs of disability using the SOL approach in Table A1.¹ For instance, a recent estimate across fifteen OECD countries found that, on average, adults between 50-65 years old with work-disabilities require 44% more income to make ends meet, while those who received disability benefits require 30% more income (Morris

¹ If you would like to view the appendix, please email Zachary.Morris@stonybrook.edu

& Zaidi, 2020). However, the study further identified wide cross-national differences as well as variation in the extra cost estimates across household types and by severity of the impairment. The table also highlights three relevant prior studies from the U.S. The first by Mitra and colleagues (2009) analyzed data on health care expenditures associated with a disability in the U.S. from 1996 to 2004, and found that persons with disabilities consistently had higher total health expenditures and out of pocket spending relative to those without disabilities. They estimated that the average total health expenditure was \$10,508 for persons with disabilities and \$2,256 for those without disabilities. A second study by Parish, Rose, & Andrews (2009) examined the relationship between income poverty and material hardship for women with disabilities in the United States and found a significantly higher average number of hardships across all income ranges for women with disabilities, including those with substantially greater incomes than the FPL. Though they do not quantify the extra costs using the SOL method, they suggest that disability-related expenses are a likely factor behind the high rates of deprivation experienced. A third study by She and Livermore (2009), while not framed as following the SOL approach, adopted a similar approach. Using panel data from the Survey of Income and Program Participation from 1996 to 1999, the researchers calculated how much additional income a household with an income level at the U.S. FPL and with an adult with a disability would need to reduce the likelihood of material deprivation to the same likelihood as a similar household with no adult with a disability. They estimated that a person under age 65 who had a disability for at least 12 months requires \$23,318 more income annually to avoid material deprivation relative to a poverty threshold of about \$10,000 for an individual with no disability.

Relevance of the conversion handicap for policy analysis and poverty measurement

Estimating the magnitude of the conversion handicap for disabled people can help in evaluating the effectiveness of welfare state programs and their ability to enable disabled adults to achieve a decent standard of living (Morris & Zaidi, 2020). Understanding the extra costs of disability may also assist in establishing eligibility criteria and benefit levels for transfer programs or in-kind services that specifically target disability-related expenses (Tibble, 2005; Stapleton et al., 2008). Our primary focus here concerns the implications of the conversion handicap for the measurement of poverty. The FPL provides a guideline for the measurement of poverty based on pre-tax income and the number of people in the household, and is widely used for benefit eligibility for means-tested health and social welfare programs. The guidelines, which were created in 1963, are based on an estimate of the minimal food budget that is then multiplied by three and adjusted based on household size (Fisher, 1992). Though the FPL is adjusted for inflation, it makes no adjustment for changes in spending patterns, geographic differences in the cost of living, or the extra costs of disability (see, Parish, Rose, & Andrews, 2009). Even the Supplemental Poverty Measure, which was developed as a more robust measure of poverty than the FPL (U.S. Census, 2020), adjusts for family size, composition, tenure, and geography but makes no adjustment for the extra costs of disability. By not adjusting for these extra costs, these poverty measures likely underestimate the rate of poverty for people with disabilities. As the FPL is widely used for eligibility purposes, equivalizing for the extra costs of disability is likely to translate to a material difference in benefit eligibility for major social welfare and health programs.

Surveys Examined

In order to calculate the extra cost estimate for U.S. households containing an adult member with a disability, we examined cross-sectional data from four nationally-representative surveys of the non-institutionalized U.S. adult population: the 2015 and 2018 waves of the National Financial Capability Study (NFCS); the 2018 wave of the U.S. Financial Health Pulse Survey (PULSE); the 2016 Financial Well-Being Survey (NFWBS); and the 2018 Survey of Household and Economic Decision-making (SHED). These surveys were identified and selected for examination as they provided nationally representative samples and included key questions pertaining to income, disability, and the standard of living that are necessary to conduct the SOL analysis. We further analyzed the U.S. Current Population Survey (CPS) to produce equivalized rates of poverty according to the FPL. Table A2 lists each dataset and provides details about the variables used in the analysis below. As our primary disability measure was the presence of a work-limiting disability, we restricted our study to working-age adults (18-69 years old). We further limited the samples to adults ages 18-69 to be consistent with the NFWBS, which provided only age categories in this range. We provide summaries of the surveys and their sampling strategies below.

The National Financial Capability Study (NFCS).

The NFCS is a triennial online cross-sectional survey measuring financial capability in the U.S. that is funded by the Financial Industry Regulatory Authority (FINRA) Investor Education Foundation. Respondents were selected using non-probability quota sampling from online panels of participants who are recruited and compensated for participating in survey research. The NFCS sampled 500 individuals from each state, plus the District of Columbia, and approximates Census distributions for age by gender, ethnicity, education level, and income

based on data from the Census Bureau's American Community Survey (FINRA Investor Education Foundation, 2018). The NFCS focuses on various components of financial knowledge, behavior, and well-being, including the ability to make ends meet (Motola & Kieffer, 2017). Of the four surveys, the NFCS provided the largest sample of the U.S. population with 22,224 respondents, of which 1,284 reported having a work-related disability. The 2018 survey was self-administered by respondents online with fielding conducted from June to October 2018. We also analyzed data from the 2015 wave of the NFCS that included a special module with six disability questions. Fielding for this wave was conducted from June to October 2015.

U.S. Financial Health Pulse Survey (PULSE)

The 2018 PULSE is an online probability-based cross-sectional and longitudinal study funded by the Financial Health Network that collects data on the financial health of Americans. The goal of the PULSE is to provide insight into the financial well-being of U.S. adults. Participants were recruited from the Understanding America Study (UAS), an internet panel including 8,900 individuals maintained by the University of Southern California. Recruiting for the UAS occurs through address-based sampling to create a random nationally representative sample invited to participate in the UAS panel. UAS panelists are invited by email or postcard to participate in specific surveys, including the PULSE. Panelists receive \$20 for every 30 minutes of survey time (UAS, 2020). The data analyzed was collected from April to July 2018 (Financial Health Network, 2018) and included 4,186, of which 393 reported having a work-related disability.

The National Financial Well-Being Survey (NFWBS)

The NFWBS is a cross-sectional, online survey that measures the financial capability and financial health of U.S. non-institutionalized adults, and is funded by the Consumer Financial Protection Bureau. The goal of the NFWBS is to document the state of the financial well-being of U.S. adults and important subpopulations (Consumer Financial Protection Bureau, 2017). The NFWBS survey was designed to represent the adult population of the 50 U.S. states and the District of Columbia. The survey was fielded on the KnowledgePanel, a large probability based online panel, from October to December of 2016 (Consumer Financial Protection Bureau, 2017). Using address-based sampling and dual-frame (i.e., landline and cell phone) random digit dialing, a random sample were selected to complete the 2016 online survey. Oversampling was implemented for older adult adults (i.e., 65 and older). Our analytic sample consisted of 5,150 adults between the ages of 18-69, of which 275 reported having a work-related disability.

Survey of Household and Economic Decision-making (SHED)

The SHED is an annual online cross-sectional survey measuring the economic health and financial choices of U.S. households that is funded by the Federal Reserve Board. The goal of the SHED is to share the range of financial challenges and opportunities facing individuals and households in the U.S. (Board of Governors, 2019). Like the NFWBS, the SHED also drew from the KnowledgePanel. The analytic sample taken from the SHED consisted of 9,373 respondents between the ages of 18-69, of which 453 reported a work-related disability. Nominal monetary incentives were offered to some targeted, hard-to-reach populations (e.g., adults between the ages of 18-29, those without high school degrees, and minorities) to increase response rates. Additionally, lower-income households were oversampled to account for survey attrition within that demographic. The 2018 SHED was fielded from October to November 2018.

Current Population Survey (CPS)

To generate disability-adjusted poverty estimates under the federal poverty level, we also analyzed the CPS Annual Social and Economic Supplement (ASEC) downloaded from IPUMS (Flood et al., 2020). The CPS is a nationally representative household survey conducted by the Census Bureau that uses a probability selected sample of approximately 60,000 households (CPS, 2020). The ASEC is administered once a year in March and provides additional data to CPS on work, income, and poverty. The analytic sample analyzed consisted of 114,800 respondents between the ages of 18-69, including 9,544 working-age adults who reported activity limitations.

Measures

Disability

To identify disability in all four surveys, we apply a binary measure of work-disability as determined by the respondent indicating that their labor force status was disabled and that they were unable to work. For example, respondents were coded as work-disabled if they listed that they were “permanently sick, disabled, or unable to work” in response to a question about their current work status. The strength of this measure is its consistency across surveys, as well as its likeness to the criteria used to determine eligibility for disability benefits. Though we lacked data on disability benefit receipt in all four surveys, we assume that a large percentage of those whose labor force status is listed as disabled receive Social Security Disability benefits. In the PULSE, for example, which included questions on benefit receipt, 47% of those identified as work-disabled reported receiving either Disability Insurance (DI), Supplemental Security Income (SSI), or both. The weakness of the measure is that it does not include large segments of the population with disabilities who are able to work. There is also the possibility that some may

justify their nonworking by reporting a work-disability (Hyde & Stapleton, 2017). This single labor force status measure has nevertheless been used in prior studies examining the financial well-being of people with disabilities in the U.S. (Conroy, McDonald, Morris, & Jennings, 2014) and is similar to common survey questions that ask about health limitations that limit the ability to work which are commonly employed in disability policy research (Morris & Zaidi, 2020; Choi, 2003; Heiss, Börsch-Supan, Hurd, & Wise, 2009; Schimmel & Stapleton, 2012).

In addition to the work-disability measure, we also estimate the extra costs according to a six-question activity limitation measure that was available in an earlier wave of the NFCS from 2015. The six questions were developed to be in line with the International Classification of Functioning, Disability, and Health (WHO, 2001) and have become the data standard in which the U.S. government measures disability (U.S. Census, 2017). The six limitations include: hearing difficulty, vision difficulty, cognitive difficulty, ambulatory difficulty, self-care difficulty, and independent living difficulty. One of the advantages of this measure of disability concerns its ability to capture working-age adults with disabilities who are in work and its ability to discern differences between people with various types of disabilities. Following the established criteria, we constructed binary disability measures in the 2015 NCFS with those who reported any one of the six disability types. We also explore the extra costs estimates by each impairment type, as in Van Minh et al., (2014.) Among the 4,917 respondents who reported having at least one impairment, 3.3% (163) answered “yes” to all six disability questions. While it is possible for a person to have all six impairments, it is more likely that these cases are anomalies in the data. Given these considerations, we followed the approach of Goodman and colleagues (2017) to remove these cases from the analysis. We conducted a sensitivity analysis

where we included those who reported all six impairment types, which did not change our estimates. Results are available upon request.

Standard of Living

In selecting the SOL measures, there are two primary criteria that are important (see, Zaidi & Burchardt, 2005). First, as assumed in the model, the indicator should be highly elastic to income to ensure that it is sensitive to changes in available resources. Second, the indicator should consist of goods and services that are desired by all people independent of disability status. As preferences are likely to differ in terms of taste, a composite indicator of SOL that uses a range of items is preferable as these differences should be “averaged out” (Zaidi & Burchardt, 2005, 97). With these considerations in mind, the purpose of the empirical work is not to specify a model that could explain variation in standards of living overall but to quantitatively demonstrate the relationship between income and standards of living and how that relationship varies by disability status.

We empirically selected SOL indicators in each of our four core surveys that were shown to be highly sensitive to income and that consisted of index measures of material deprivation desired by all independent of disability status. The SOL indices from the SHED, the NFWBS, and the PULSE were constructed using three core questions. The questions asked respondents how strongly they agreed with a series of three statements: “Because of my financial situation, I feel I will never have the things I want in life”; “I am just getting by financially”; and “I am concerned that the money I have or will save won't last.” For all three statements, respondents could choose from a five-panel response set that ranged from “completely” to “not at all.” The responses to these questions were reverse coded so that a higher score indicated better financial security and then aggregated into an SOL index with a maximum score of 15 and a minimum

score of 3. The indices demonstrated adequate internal consistency and were highly correlated with income.

Since only the 2018 NFCS wave included the three core questions used in the other surveys, we created a separate SOL index in the NFCS to allow for comparability across waves. The SOL index for the NFCS consisted of three alternative questions. The first question asked how confident the respondent could come up with \$2,000 for an unexpected expense. Responses ranged from “I am certain I could”, “I probably could”, “I probably could not”, or “I am certain I could not come up with \$2,000.” The second question asked how difficult is it to cover monthly expenses. Responses included “very difficult”, “somewhat difficult”, or “not difficult at all.” The third question asked the respondent if they had an emergency rainy-day fund that could cover expenses for three months. Responses were either yes or no. Answers for each item were aggregated into an index with a maximum score of seven and coded so that a higher score indicated a better financial situation. As a sensitivity test, we also provide the 2018 NFCS estimates using the three core deprivation questions used in the other surveys. The results did not deviate from the alternative SOL index (see Table A7.)

Income and controls

The income variables across all four surveys were measured at the household level. All but one of the surveys included questions that were designed to identify a post-transfer measure of income, meaning that they include both market income and income from any cash assistance programs. The SHED was the only income variable that was not explicitly post-transfer. However, the household income question comes after a series of questions asking about a large number of cash income sources, which may prompt respondents to think more broadly about the income measure (J. Larrimore, personal communication, March 9, 2020). None of the surveys

explicitly asked for a post-tax measure of income and we thus assume that most were responding on a pre-tax basis.

The income variables used in the SHED, the NFWBS, and the NFCS were bracketed categorical values, while only the income variable in the PULSE was continuous. This posed a methodological challenge as treating the income categories as continuous would assume the categories were equidistant. To account for this limitation, random numerical incomes were generated according to a normal distribution around the means and standard deviations of each income bracket, which were retrieved from the income data in the March 2019 CPS supplement. Before imputing the income data, we rescaled the standard deviations derived from the CPS using a linear transformation (i.e., divided each value by ten). This ensured that the generated numerical income values were within the range of each income bracket without changing the shape of the distribution. For example, we randomly imputed income values along a normal distribution ranging from \$1 to \$14,999 around the CPS mean of \$8,392 with a rescaled standard deviation of \$431 for each of the 2,874 individuals in the NFCS who indicated that their income was less than \$15,000. We did the same imputation process for each income category in the SHED, NFWBS, and the NFCS. As a test of the validity of this method, we created a bracketed income variable from the continuous income measure in the PULSE dataset and then randomly imputed incomes between the income categories following the same approach described above using the CPS mean income data. We then compared the extra cost estimates using the randomly imputed and actual income measures and found them to be generally consistent with a variation of 1 percentage point in the model with the best fit. We provide the results of this sensitivity test in tables A3 and A4.

A limitation of the SOL approach identified in prior literature concerns the sensitivity of the extra cost results to the functional form applied to the household income variable and its relationship to the standard of living measure (Palmer, Williams, & McPake, 2019; Hancock, Morciano, & Pudney, 2013; Zaidi & Burchardt, 2005). As in previous literature, we address this issue by conducting an analysis of the correct specifications of income with differing functional forms (e.g., linear, logarithmic, and square root) and then using the Akaike information criterion (AIC) to compare the parametric models with the best fit. We did this for each survey and reported the income specification that had the best fit in our results provided below. We did not adjust the income measures for household size as we included measures of household size in the regression models as suggested by Zaidi & Burchardt (2005). In all regression models we further controlled for age, gender, race, marital status, and the education level of the respondent. Geographic data based on state (PULSE, SHED, NFCS) and census region (NFWB) was also used to provide some control for the geographical differences in the costs of living. Robust standard errors are reported in all models to account for the problem of heteroscedasticity. The final analytic samples contained no missing values on the selected variables. The statistical analysis was conducted using Stata Version 15 (Stata Corp., Texas, USA).

Results

We begin by presenting descriptive information in Table 1 from the four surveys. Consistent with prior estimates of the working-age population with a work-disability in the U.S. (Lauer, Boege., & Houtenville, 2020; Theis, Roblin, Helmick, and Luo, 2017), the surveys estimate the prevalence of work-disability among adults ages 18-69 in the U.S. from a low 5% in the SHED to a high of 10% in the PULSE. Those with a work-disability had substantially lower household incomes and were less likely to be married. In three of the four surveys, respondents

with work-disabilities were also more likely to be of an older age and more likely to be female.

We further observe that respondents with work-disabilities reported significantly lower living standards on the SOL indices in each of the respective surveys.

Table 1. Characteristics of the analytic samples across four surveys, by work-disability status

| NFCS (2018) | No work-disability | Work-disability | Significance |
|--------------------|--------------------|-----------------|-----------------|
| Income (mean) | \$73,354 | \$27,687 | $p < .001$ |
| Average age | 44 | 49 | $p < .001$ |
| Female | 55% | 64% | $p < .001$ |
| Married | 54% | 34% | $p < .001$ |
| SOL Index (1-7) | 4.93 | 2.97 | $p < .001$ |
| Observations | 20,940 | 1,284 | |
| PULSE | No work-disability | Work-disability | Significance |
| Income (mean) | \$81,741 | \$23,887 | $p < .001$ |
| Average age | 47 | 54 | $p < .001$ |
| Female | 57% | 66% | $p < .01$ |
| Married | 60% | 36% | $p < .001$ |
| SOL Index (3-15) | 9.57 | 7.56 | $p < .001$ |
| Observations | 3,793 | 393 | |
| NFWBS | No work-disability | Work-disability | Significance |
| Income (mean) | \$95,410 | \$38,625 | $p < .001$ |
| Average age group | 35-44 | 45-54 | $p < .001$ |
| Female | 47% | 47% | not significant |
| Married | 59% | 40% | $p < .001$ |
| SOL Index (3-15) | 9.48 | 7.45 | $p < .001$ |
| Observations | 4,875 | 275 | |
| SHED | No work-disability | Work-disability | Significance |
| Income (mean) | \$81,651 | \$27,781 | $p < .001$ |
| Average age | 49 | 49 | not significant |
| Female | 52% | 60% | $p < .001$ |
| Married | 58% | 40% | $p < .001$ |
| SOL Index (3-15) | 9.60 | 7.11 | $p < .001$ |
| Observations | 8,920 | 453 | |

Note: On the previous table, Bivariate significance determined by t-test for continuous variables and chi-square for categorical variables. Average age categories provided for the NFWBS

Significance: * $p < .05$, ** $p < .01$, *** $p < .001$, ns = not significant

We provide our baseline estimates of the costs of disability for all adults between the ages of 18-69 across the four core surveys in Table 2. As mentioned in the description of our methods, these results are generated from Ordinary Least Squares regression with the SOL indices serving as the dependent variable. The extra cost estimate is obtained by calculating the ratio of the disability coefficient over the income coefficient. For example, in the NFCS the extra costs of disability are estimated to be 32% $(-.123/.385)$. Though there was some difference in the estimates calculated across the different surveys, the results were generally consistent. Across all four surveys, on average, households containing a working-age adult with a work-limitation are estimated to require 28% more income to obtain their standard of living as similar households without a member with a disability. At the median national household income of \$63,179 in 2018 (U.S. Census Bureau, 2020), this translates into an additional \$17,690 per year required for households containing a member with a disability to achieve their SOL relative to comparable households without a member with a disability. We further examined differences for each gender and found no consistent differences across the four surveys, though, on average, men (30%) had slightly higher costs than women (27%). When looking at household types, we do observe noticeable differences. Averaging across the four surveys, single adults with disabilities are estimated to require 36% more income to achieve their living standards relative to non-disabled single adults, whereas households containing adults with disabilities who are married are estimated to require 27% more income relative to non-disabled married adults. This lower estimate for married adults, consistent with prior research (Morris & Zaidi, 2020), may be due to greater household economies of scale as well as the ability to obtain informal care in a partnership that decreases the need to purchase caregiving services.

Table 2. Extra costs of disability estimates from four nationally-representative surveys

Table 2-1) Survey of All households

| Dependent variable = SOL indices | <u>NFCS</u> | <u>SHED</u> | <u>NFWBS</u> | <u>PULSE</u> | <u>Average</u> | <u>Cost \$</u> |
|----------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|----------------|----------------|
| Extra cost estimate | -32% | -24% | -28% | -27% | -28% | \$17,690 |
| Work-limitation | -0.123 <i>p</i> <.001 | -0.087 <i>p</i> <.001 | -0.078 <i>p</i> <.001 | -0.086 <i>p</i> <.001 | | |
| Income | 0.385 <i>p</i> <.001 | 0.356 <i>p</i> <.001 | 0.279 <i>p</i> <.001 | 0.314 <i>p</i> <.001 | | |
| R-squared | 0.332 | 0.2 | 0.164 | 0.195 | | |
| Observations | 22,224 | 9,373 | 5,150 | 4,186 | | |

Table 2-2) Survey of Married

| Dependent variable = SOL indices | <u>NFCS</u> | <u>SHED</u> | <u>NFWBS</u> | <u>PULSE</u> | <u>Average</u> | <u>Cost \$</u> |
|----------------------------------|--------------------------|--------------------------|--------------------------|-------------------------|----------------|----------------|
| Extra cost estimate | -30% | -27% | -31% | -20% | -27% | \$17,058 |
| Work-limitation | -0.110 <i>p</i> <.001 | -0.093 <i>p</i> <.001 | -0.088 <i>p</i> <.001 | -0.064 <i>p</i> <.01 | | |
| Income | 0.368 <i>p</i> <.001 | 0.350 <i>p</i> <.001 | 0.288 <i>p</i> <.001 | 0.319 <i>p</i> <.001 | | |
| R-squared | 0.304 | 0.201 | 0.158 | 0.173 | | |
| Observations | 11806 | 5,371 | 3,008 | 2,430 | | |

Table 2-3) Survey of Single

| Dependent variable = SOL indices | <u>NFCS</u> | <u>SHED</u> | <u>NFWBS</u> | <u>PULSE</u> | <u>Average</u> | <u>Cost \$</u> |
|----------------------------------|--------------------------|--------------------------|--------------------------|--------------|----------------|----------------|
| Extra cost estimate | -0.084 <i>p</i> <.001 | -0.075 <i>p</i> <.001 | -0.115 <i>p</i> <.001 | | | \$22,744 |
| Work-limitation | 0.279 <i>p</i> <.001 | 0.242 <i>p</i> <.001 | 0.276 <i>p</i> <.001 | | | |
| Income | 0.122 | 0.109 | 0.142 | | | |
| R-squared | 4,002 | 2,142 | 1,756 | | | |
| Observations | 10,418 | | | | | |

Table 2-4) Survey of Men

| Dependent variable = SOL indices | <u>NFCS</u> | <u>SHED</u> | <u>NFWBS</u> | <u>PULSE</u> | <u>Average</u> | <u>Cost \$</u> |
|-------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|----------------|----------------|
| Extra cost estimate | -33% | -28% | -25% | -32% | -30% | \$18,954 |
| Work-limitation | -0.128 <i>p</i> <.001 | -0.095 <i>p</i> <.001 | -0.069 <i>p</i> <.001 | -0.102 <i>p</i> <.001 | | |
| Income | 0.391 <i>p</i> <.001 | 0.342 <i>p</i> <.001 | 0.270 <i>p</i> <.001 | 0.320 <i>p</i> <.001 | | |
| R-squared | 0.300 | 0.175 | 0.157 | 0.200 | | |
| Observations | 9,788 | 4,505 | 2,735 | 1,746 | | |

Table 2-5) Survey of Women

| Dependent variable = SOL indices | <u>NFCS</u> | <u>SHED</u> | <u>NFWBS</u> | <u>PULSE</u> | <u>Average</u> | <u>Cost \$</u> |
|-------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|----------------|----------------|
| Extra cost estimate | -32% | -23% | -28% | -25% | -27% | \$17,058 |
| Work-limitation | -0.122 <i>p</i> <.001 | -0.083 <i>p</i> <.001 | -0.081 <i>p</i> <.001 | -0.078 <i>p</i> <.001 | | |
| Income | 0.379 <i>p</i> <.001 | 0.368 <i>p</i> <.001 | 0.290 <i>p</i> <.001 | 0.308 <i>p</i> <.001 | | |
| R-squared | 0.322 | 0.21 | 0.175 | 0.176 | | |
| Observations | 12,436 | 4,868 | 2,415 | 2,440 | | |

Note: In previous table all models control for household size, geographic region or state, and the age, gender, race, marital status, and education level of the respondent. We apply the functional form for income that provided the best model fit as displayed in Tables A3, A5, A6, and A7: NFCS = log income; SHED = square root income; NFWBS = square root income; and PULSE = square root income. Standardized beta coefficients. Robust standard errors. Cost estimates are based on the median national income in 2018.

p*<.05, *p*<.01, ****p*<.001

Work-limitations represent just one kind of disability and many U.S. surveys capture disability more broadly across six-disability types, which has become the data standard for the U.S. government. In Table 3 below, we draw on the 2015 NFCS wave that contained the six functional limitation questions and report the estimate of the extra cost of disability according to whether the respondent reports one of the six disability types. The estimates for all respondents with one or more impairments at 35% is close to the estimates for the work-disability measures used in Table 2. Though we are unable to determine with certainty, we hypothesize that the

higher estimate may have to do with a lower rate of disability benefit receipt than those with work-disabilities. We further observe some differences across the various activity limitations with adults experiencing cognitive difficulties (28%) estimated to have the highest extra costs of living and those with vision (9%) and hearing limitation (7%) estimated to have the lowest cost estimates. This may be attributable to a number of factors, including the severity of the disability, the presence of comorbidities, the need for caregiving services, as well as differences in the generosity, accessibility, and availability of public support for adults with different kinds of limitations.

Table 3. Extra costs of disability, for those with 1 or more limitation and by type of limitation

| Costs | 1+ limitations | Hearing | Vision | Self-care | Errands | Mobility | Cognitive |
|---------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Extra cost estimate | -35% | -7% | -9% | -13% | -22% | -26% | -28% |
| Cost \$ | \$22,112 | \$3,791 | \$5,686 | \$8,845 | \$14,531 | \$16,427 | \$18,322 |
| Limitation | -0.143 <i>p</i> <.001 | -0.033 <i>p</i> <.001 | -0.038 <i>p</i> <.001 | -0.056 <i>p</i> <.001 | -0.096 <i>p</i> <.001 | -0.111 <i>p</i> <.001 | -0.121 <i>p</i> <.001 |
| Income (log) | 0.414 <i>p</i> <.001 | 0.445 <i>p</i> <.001 | 0.445 <i>p</i> <.001 | 0.441 <i>p</i> <.001 | 0.431 <i>p</i> <.001 | 0.426 <i>p</i> <.001 | 0.426 <i>p</i> <.001 |
| Controls | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| R-squared | 0.338 | 0.319 | 0.320 | 0.321 | 0.327 | 0.330 | 0.332 |
| N | 23,185 | 23,185 | 23,185 | 23,185 | 23,185 | 23,185 | 23,185 |

Note. In previous table extra cost percentages are based on data from the 2015 NFCS. Income is transformed to log based on functional form comparison in Table A6. Controls for household size, number of children, state, and the age, gender, race, marital status, and education level of the respondent. Standardized beta coefficients. Cost-in-dollars estimates were calculated using median income from the March 2019 supplement of the Current Population Survey.

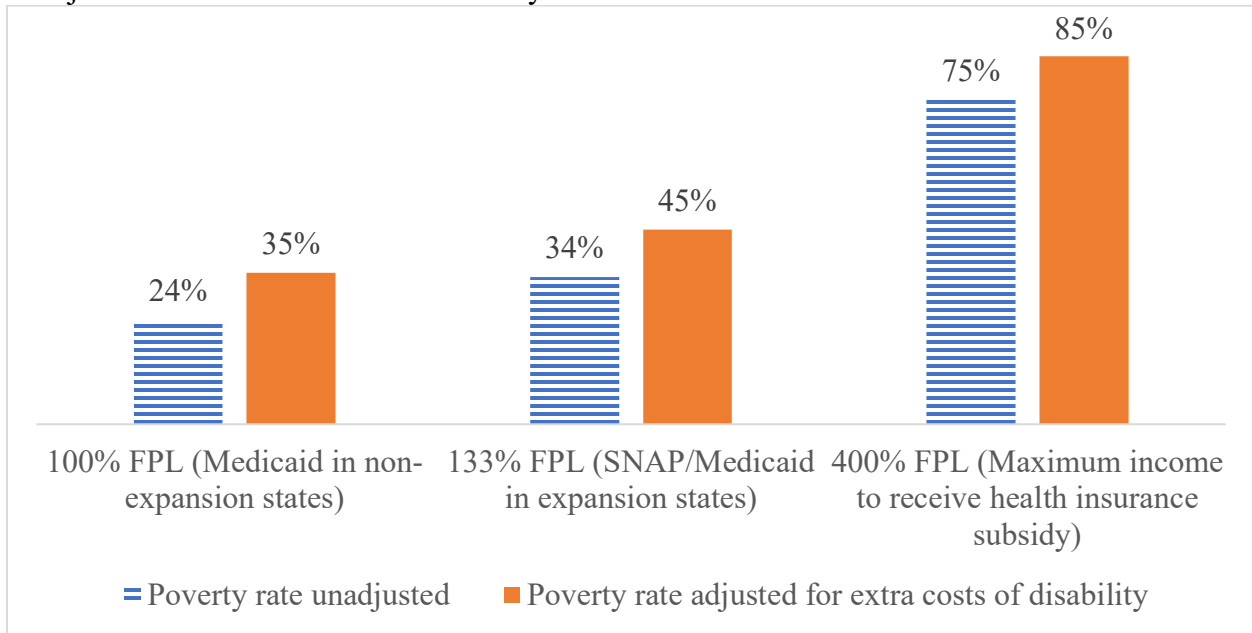
p*<.05, *p*<.01, ****p*<.001

Poverty Estimates

We now turn to estimate how the risk of poverty is affected for households containing adult members with a disability when we adjust for the extra costs of disability. As stated above, insofar as the income measures do not equalize to the additional costs associated with living with a disability, they understate the true level of poverty experienced. To compare unadjusted to adjusted poverty measures, we first find an unadjusted rate of poverty for households with an adult with one or more limitations using the official poverty rate cutoff scores provide in the CPS. We then generate a measure of the disposable income devoted towards disability-related expenses using the 28% estimate of the extra costs. We then subtract the measure of disposable income devoted to disability-related expenses from the total household income score for

households including a member with a disability to create an adjusted household income variable. Finally, we again apply the official poverty rate cutoff scores but to the new adjusted household income variable to generate an extra cost adjusted poverty rate for households including people with disabilities. These results are provided in Figure 2. The official poverty rate at 100% FPL for a person with a disability increases from 24% to 35% after we adjust for the extra costs of disability. Assuming a working-age population of adults with work-disabilities at 20 million, this translates into an additional 2.2 million adults with disabilities counted as poor. We also examine changes in the poverty rate at different income thresholds commonly used for eligibility criteria and observe that many more would meet these income thresholds after the adjustment.

Figure 2. Poverty rates for households with adult members with disabilities: adjusted and unadjusted for the extra costs of disability



Source: Author’s analysis of March 2019 CPS data

Discussion

This paper provides national estimates of the extra costs experienced by households containing an adult living with a disability in the U.S. using the SOL approach of Zaidi and Burchardt (2005). The underlying idea behind this approach is that households with disabled members require greater resources to achieve their living standards due to the extra costs of living associated with living with a disability. The measurement of these extra costs of living associated with disability is necessary not only for a more realistic measure of poverty among persons with disability, but it also bears on the adequacy of current disability-related social welfare programs and services.

Though there is robust international research literature adopting this approach, prior studies of the extra costs of disability relating to the U.S. population are sparse. Drawing on four nationally representative surveys of the U.S. population, we aim to fill this gap. We find that, on average, U.S. households between the ages of 18-69 that include an adult with a work-disability require 28% more income to achieve a comparable standard of living to those households without disabled members. We also find a slightly higher estimate of the costs of disability (35%) when defining disability as the reporting of one or more of six daily living limitations. These total cost estimates can serve as a benchmark for future studies, particularly those exploring the impacts of policy changes or major exogenous shocks. We further identify variation in the cost estimates across household and impairment types. Single adults, which represent a disproportionate share of the population with disabilities, were estimated to have higher costs than those who were married with disabilities. Adults with cognitive impairments were also estimated to have higher costs compared to people with other kinds of impairments.

After identifying these quantitative estimates, we calculate disability-adjusted federal poverty levels both to demonstrate the applicability of the estimates to the measurement of poverty and to show how this adjustment would impact eligibility for major safety net programs in the U.S. Here we demonstrated that the share of the adult population with disabilities counted as living at or under the FPL would increase by nine percentage points or by an estimated 2.2 million people with disabilities if the poverty measure adjusted for disability. We further observe similar increases in the poverty rate when calculating poverty at alternative levels that are used as eligibility cutoff points for major health and social welfare programs. This suggests that, if the poverty measures were adjusted for the extra costs of disability, many more individuals with disabilities would be eligible for these programs and services.

Study Limitations and Avenues for Future Research

We present our findings as robust initial estimates of the extra costs associated with living with a disability in the U.S. However, due to a number of limitations, further research is needed to strengthen public understanding of the extra costs of living associated with disability. A first limitation concerns the cross-sectional research design, which limits the ability to examine the dynamics of disability costs, such as differences between a person with a long-term versus a short-term disability (Mitra et al., 2012). Prior international research has found that those with longer term disabilities have greater costs than those with shorter times since onset (Vu et al., 2020; Cullinan et al., 2011). Our estimates capture only the direct costs of disability and do not include foregone earnings by people with disabilities and their caregivers and may therefore understate the financial burden of living with a disability. We thus present this study as descriptive and do not draw causal inferences based on the cross-sectional analysis alone. Future research using longitudinal data is needed to investigate these issues further.

A second limitation includes the measurement of disability at the individual level while income was measured at the household level. We are thus unable to account for the possibility of having more than one individual with disability in the household, which may impact the cost estimates. A third limitation may arise due to imprecise measurement of household income in the majority of surveys used. This paper relied on an imputed continuous income variable that was transformed from categorical income measures. While we think this method provides an adequate proxy for post-transfer numerical income, a robust continuous income variable would clearly be preferable if available. Future research should thus specifically seek to draw on surveys with more robust post-tax, post-transfer numerical income measures, including measures that allow analysts to disentangle market income from disability benefits such as in Morciano and Hancock (2015) and Morris and Zaidi (2020).

At an average extra cost estimate of 28%, households that include adults with work-disabilities in the U.S. had similar costs as Germany, which was also estimated at 28%, and may be on the lower end in terms of disability costs cross-nationally (Morris & Zaidi, 2020). Yet, given the degree of differences between the population samples analyzed and the various income, disability, and standard of living measures adopted, we caution against drawing cross-national inferences from our results. Additional research should also consider alternative estimation approaches, such as the “direct subjective approach” and the “goods and services approach,” which could both validate and complement this study. Indeed, this paper is limited as it is unable to identify what the expense items are that drive the extra costs of living with a disability. This information could guide policy makers in identifying specific programs and services that reduce the extra costs of disability. Lastly, this study only looked at the extra costs experienced by the working age population. Children and older people, who form a significant

portion of the population living with disabilities, should be included in future research and compared to this study of working-age adults. Despite these limitations and the multiple avenues available for future research, this study has a singular message: the extra costs of living with a disability in the U.S. are substantial and current measures of poverty, which fail to adjust for these necessary expenses, likely understate the true level of deprivation experienced among adults with disabilities in the U.S.

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