

# The Extra Costs of Disability: New Research Findings and Policy Implications

Hosted by National Disability Institute  
October 14, 2020



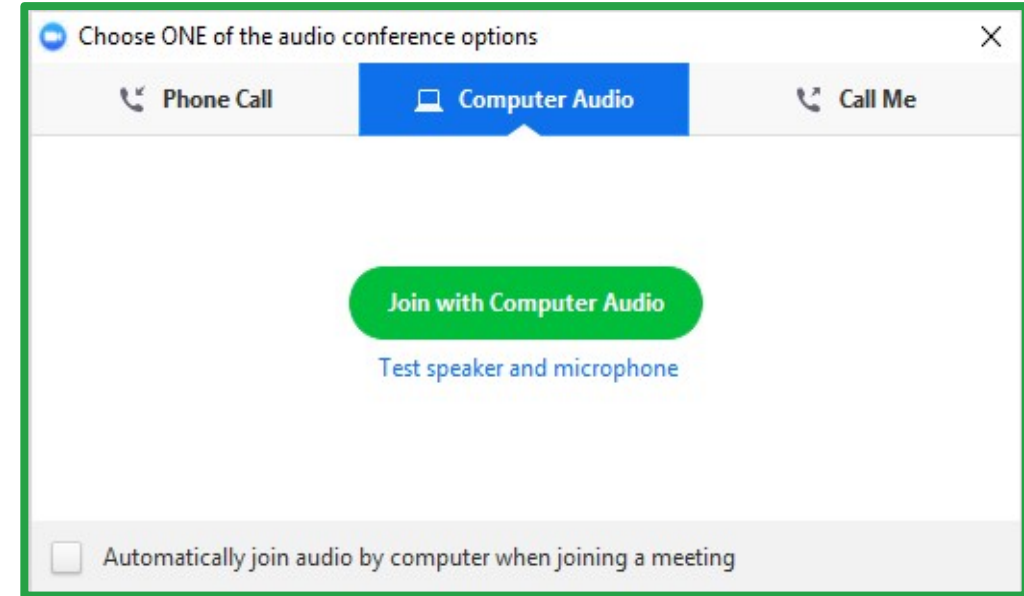
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# Welcome and Overview



**Michael Morris**  
**Senior Strategic Advisor**  
**National Disability Institute**



# Gerri M. Walsh

**President, FINRA Investor Education Foundation**

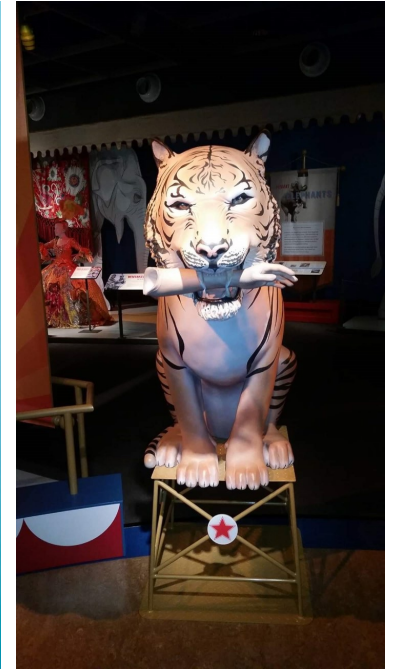
**Senior Vice President, Investor Education, FINRA**





**Personal  
experience with  
disability-related  
extra costs**

**Amy Gatlin  
McCoy**



# Research Findings





**Zachary A. Morris, PhD**  
Assistant Professor  
Stony Brook University School of Social Welfare



**Stephen V. McGarity, PhD**  
Assistant Professor  
University of Tennessee College of Social Work

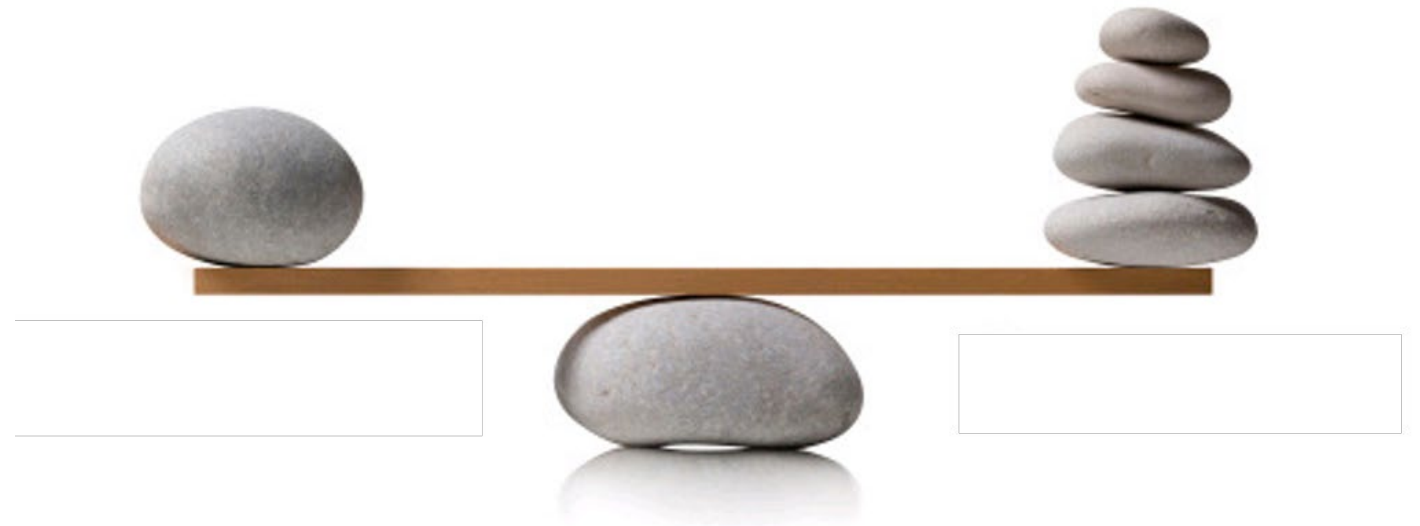


**Nanette Goodman, MS**  
Research Advisor  
National Disability Institute

The working paper was also co-authored by Asghar Zaidi, PhD, Vice Chancellor, Government College University, Lahore, Pakistan.

# Three primary factors influence financial stability

- Income
- Expenses
- Assets



# We already knew a lot about assets and income. But we haven't fully understood expenses and rarely consider them in developing public policy.

- People with disabilities:
  - Are less likely to be employed and thus less likely have *income* from wages.
  - On average, have lower *wages* than those without disabilities.
  - Are more likely to be low or moderate *income* or live in poverty
- Poverty is measured based on *income*. Eligibility for means-tested public programs is predominantly based on *income*.
- These income measures do not consider expenses or the additional **out-of-pocket costs** associated with living with a disability. As a result they understate the true level of economic hardship for households that include a person with a disability.



# Motivation

People with disabilities are:

- 2X as likely to find it “very difficult” to cover expenses
- 2X as likely to have past due medical bills
- 2X as likely to live in poverty

Sources: Goodman, O'Day and Morris (2017); Lauer et al. (2020).

***Disability-related expenses may help explain these inequities.***



# Sen posits (2004) that there are two distinct kinds of financial disadvantage experienced by people with disabilities:

## 1) Earnings disadvantage

Financial difficulties relating to: receiving a suitable education; acquiring human capital.



Professor Amartya Sen  
Nobel Prize winner

## 2) Conversion disadvantage

*\*The focus of our research.\**

The purchasing of disability-related items and services makes it difficult to convert income into a standard of living.

Living standard obtained from \$40,000 for a person w/ disability

≠

Living standard obtained from \$40,000 for a person w/o disability

# What are the extra costs of disability?

## Indirect costs

- Foregone earnings that people with disabilities have because they face barriers to work.
- Family members may reduce their amount of paid work to provide care and support to their family member with a disability.
- These indirect costs are captured when we measure income.

## Direct out-of-pocket costs

- Personal assistance services
- Out of pocket health care costs
- Extra costs of housing that is accessible and convenient
- More expensive car to accommodate modifications
- Maintaining service animals
- Extra costs of food for special diet
- Costs associated with going to work
- Etc, etc., etc.
- See #disabilitytax or #criptax



# Research Question and Method

How much additional income does a household containing a working-age person with a disability require to have the same standard of living as a similar household without a member with a disability?

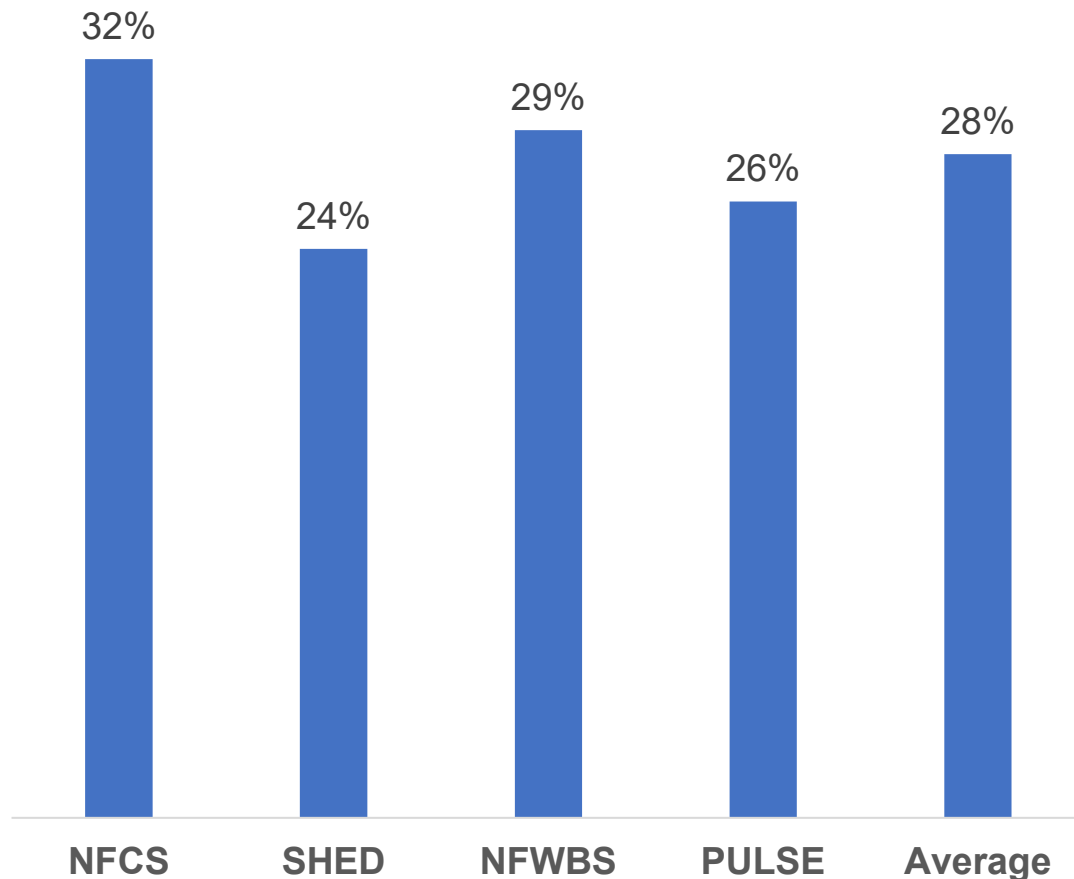
- We apply the “Standard of Living” approach (Zaidi & Burchardt, 2005; Morris & Zaidi, 2020).
- This approach uses multivariate regression to estimate the additional income required to bring the standard of living of a household containing a person with a disability to the same level as a comparable household without a member with a disability.

# Data Analyzed

- 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 FINRA Foundation's National Financial Capability Study (NFCS)
  - the 2018 wave of the U.S. Financial Health Pulse Survey (PULSE)
  - the 2016 National Financial Well-Being Survey (NFWBS)
  - the 2018 Survey of Household and Economic Decision-making (SHED).
- Due to data limitations, disability defined as a work-limiting disability with the exception of the 2015 NFCS wave where we analyze extra costs according to six impairment types.
- Standard of living variables consist of composite measures of financial security (i.e. "Because of my financial situation, I feel I will never have the things I want in life"; "I am just getting by financially"; "I am concerned that the money I have or will save won't last.")
- We examine the March 2019 U.S. Current Population Survey (CPS) to produce rates of poverty according to the Federal Poverty Level when adjusting for the extra costs of disability.

# RESULTS: Overall Estimate

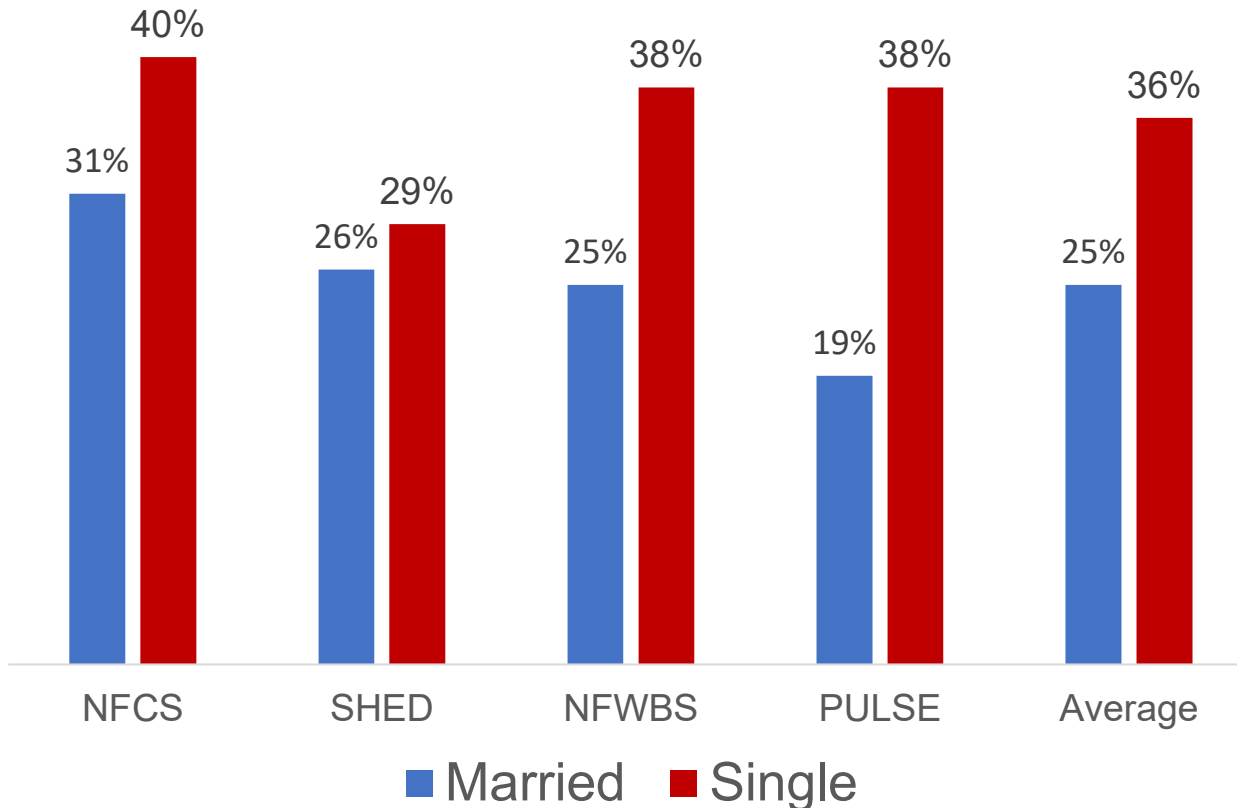
Extra cost of disability estimates,  
all households



- On average across the four surveys, adults with a disability are estimated to require **28% more income** to achieve their living standards compared to similar households without an adult with a disability.
- This translates into an additional **\$17,690 per year** for a household at the national median income level.

# RESULTS: By Marital Status

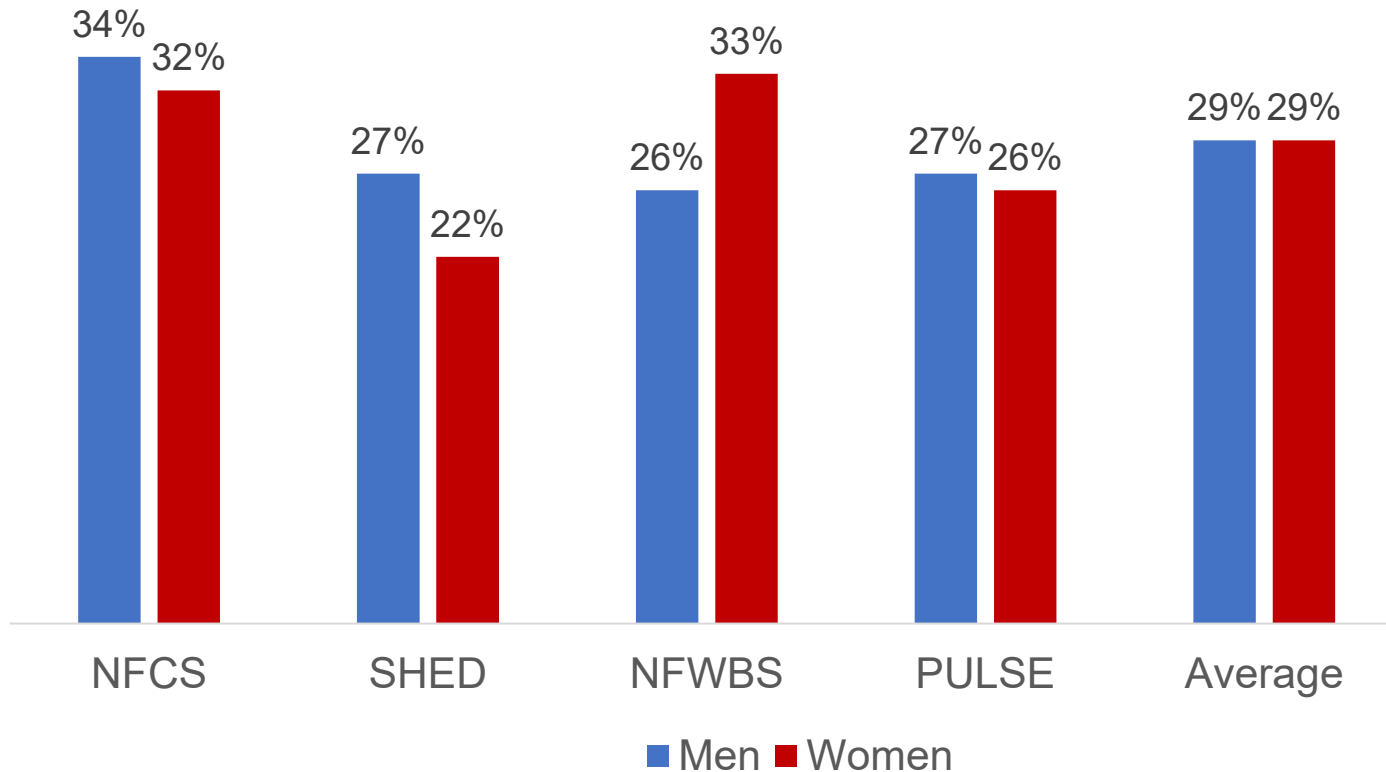
Extra cost estimates,  
married and single households



- On average across the four surveys, single adults with disabilities experience greater disability-related costs compared to married adults with disabilities (**36% vs. 25%**, respectively).

# RESULTS: By Gender

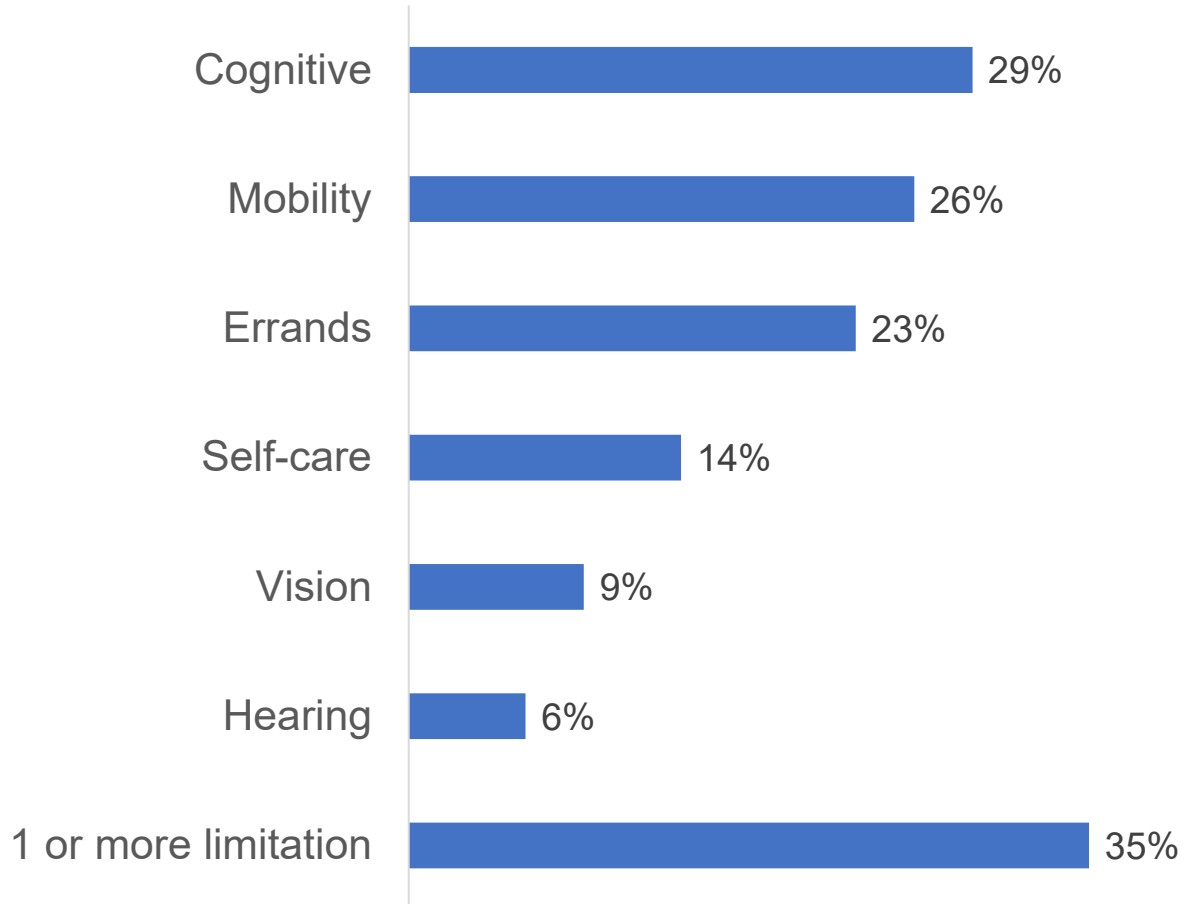
Extra cost estimates,  
men and women



- We do not observe consistent differences in the extra costs estimates between men and women with disabilities.

# RESULTS: By Disability Type

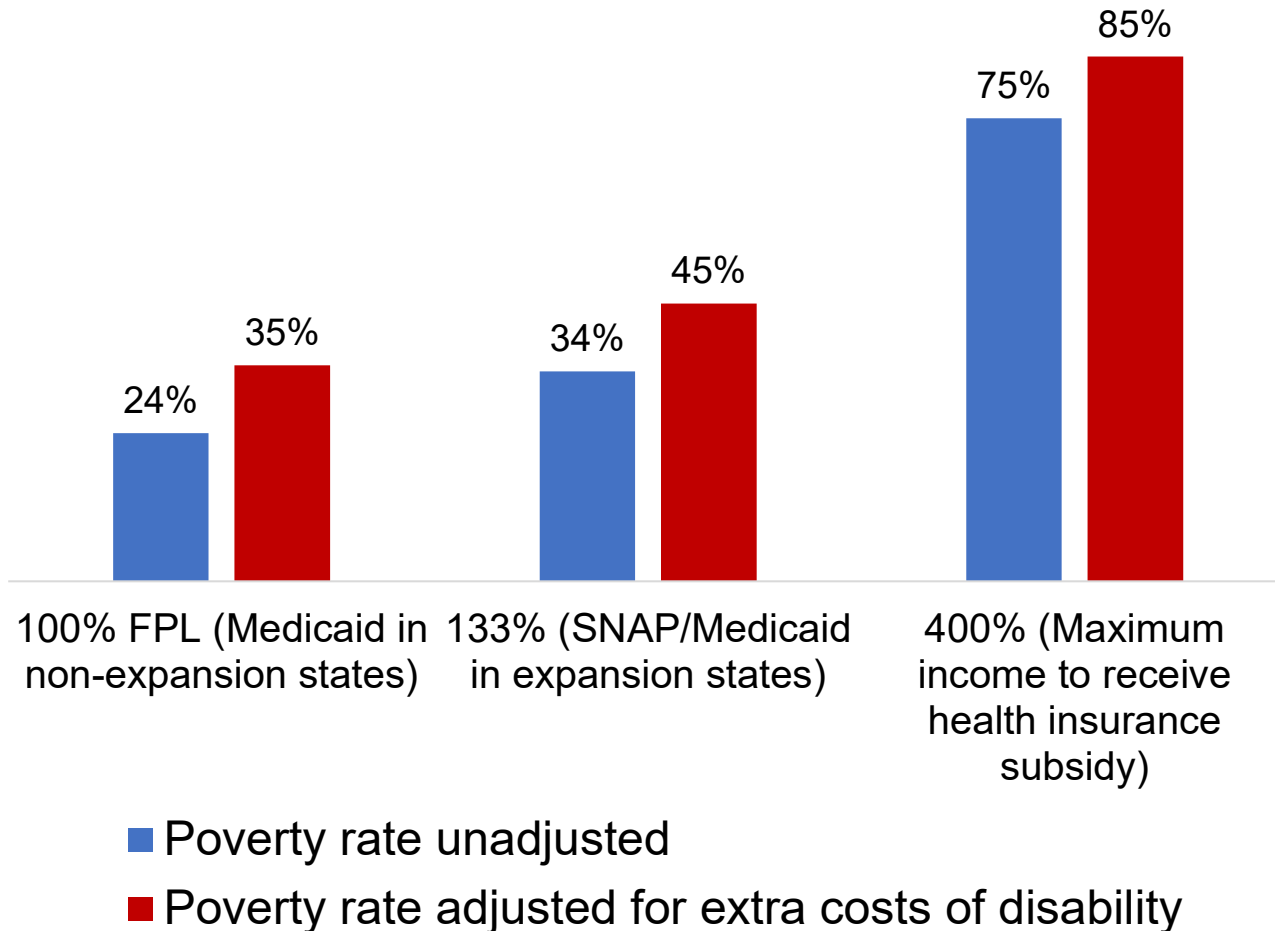
Extra costs of disability estimates,  
by impairment types (NFCS 2015)



- Adults with one or more impairment require an estimated **35% more income** to meet their living standards.
- Adults with cognitive impairments are estimated to have the highest extra costs of living (**29%**), whereas those with hearing impairments are estimated to have the lowest (**6%**).

# RESULTS: Poverty Rate Adjusted for Extra Costs

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



- If the measures of income used to determine the Federal Poverty Level adjusted for the extra costs of disability, the rate of poverty among adults with disabilities would increase from **24% to 35%**.
- Approximately **2.2 million** more people with disabilities would be counted as poor.
- This would expand eligibility for many health and social welfare programs.

# Limitations

- 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.
- 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 their work hours to provide care, the lost income is not captured.
- As the research draws on cross-sectional data, it cannot identify differences between people living with long-term versus short-term disabilities or how the extra costs vary over the course of an individual's lifetime.



# Policy Implications



# The U.S. recognizes these extra costs ...sometimes

## ➤ In legislation:

- When passing SSI for Children in 1972, Congress said, “Poor children with disabilities should be eligible for SSI benefits because their needs are often greater than non-disabled children.”
- ABLE recognizes 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.

## ➤ In administrative rules:

- SNAP exempts people with disabilities (who are receiving benefits) from the gross income threshold and allows certain deductions from net income. Plus, they have a higher asset threshold.

# The U.S. recognizes these extra costs ...sometimes

## ➤ In tax code

- Larger standard deduction for people who are blind
- Deduction for impairment-related work expenses for workers with disabilities
- Deduction for medical care expenses that exceed 10 percent of adjusted gross income.

## ➤ Personal budgets in Medicaid

- Self-directed participants are allotted a customized budget developed through a person-centered planning process.

## ➤ Other in-kind benefits (generally disjointed and idiosyncratic, means-tested)

- Medicaid long-term care and home and community services, such as personal assistance services
- Housing assistance/energy assistance

# Approaches to addressing the extra costs of disability in other countries

## ➤ **United Kingdom: Personal Independence Payment**

Cash payment that is non-means-tested, non-contributory and tax-free; it is not linked to a person's ability to work and it is available equally to people in or out of work. Assessment by health professional determines level payment. Regular reviews.

## ➤ **Australia: National Disability Insurance Scheme**

Entitles people with a "permanent and significant" disability (under the age of 65) to full funding for any "reasonable and necessary" support related to their disability (subject to certain restrictions). Funding is allocated to the individual, and the individual or their guardian chooses which providers supply the funded goods and services (subject to certain restrictions).

## ➤ **Thailand: Disability Allowance**

Small monthly payment intended to cover extra costs. Not means tested. Not based on ability to work. Operated by the National Office for Empowerment of Persons with Disabilities (NEP)

# Policy Implications

## ➤ Changes to the social safety net

- different eligibility standards for food and housing assistance
- change in eligibility for Medicaid

## ➤ Changes to the tax code

- changes to who is eligible to open ABLE accounts
- changes to how much funding annually can be contributed to an ABLE account

## ➤ Changes to financial planning

- recalculation of financial needs short and long term
- examining financial savings and investment choices

# Additional Research Needed

## Goals

- Develop strong research foundation
- Identify promising interventions
- Inform policy makers
- Motivate policy change

## Possible Next Steps

- Identify the specific supports, services and items that account for these extra costs in order to better understand the problem.
- Conduct mixed-methods research to understand hard to measure costs and the lived experience.
- Further develop and evaluate disability-specific financial planning tools for people with disabilities and financial professionals.

# Participate in the research!

Take our survey and tell us more about your extra costs.

[https://utk.co1.qualtrics.com/jfe/form/SV\\_2gliuT9YijfSLsh](https://utk.co1.qualtrics.com/jfe/form/SV_2gliuT9YijfSLsh)

We will put this link in the chat box.





**Personal  
experience with  
disability-related  
extra costs  
Edward  
Mitchell**

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# Questions and Answers



# Link to Policy Brief and Working Paper

[nationaldisabilityinstitute.org/reports/extra-costs-living-with-disability](https://nationaldisabilityinstitute.org/reports/extra-costs-living-with-disability)

## Policy Brief

- *Extra Costs of Living with a Disability in the US—Resetting the Policy Table*
- Provides overview of research and policy implications.

## Working Paper

- *The extra costs associated with living with a disability in the United States*
- Provides details of the research approach and findings.



## Link to Survey

[https://utk.co1.qualtrics.com/jfe/form/SV\\_2gliuT9YijfSLsh](https://utk.co1.qualtrics.com/jfe/form/SV_2gliuT9YijfSLsh)

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