

Extra Costs of Living with a Disability

June 16, 2021 11 am CST

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Moderator



Katie Metz

Director, Financial Resilience Center
National Disability Institute

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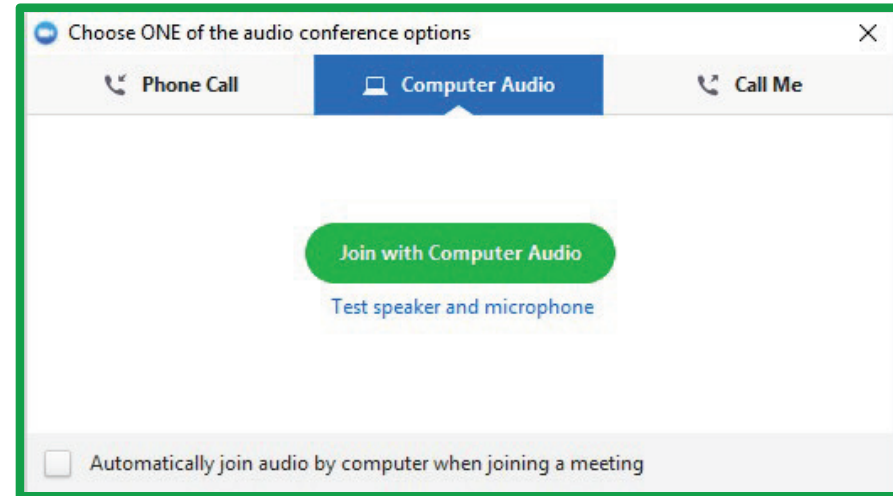
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 - [National Disability Institute ICDD Financial Wellness webinars page](#)
 - [Illinois Council on Developmental Disabilities website](#)

Welcome



Dennis Deany
Program Specialist
Illinois Council on Developmental Disabilities



National Disability Institute

- Our Vision: We envision a society in which people with disabilities have the same opportunities to achieve financial stability and independence as people without disabilities.
- Our Mission: We collaborate and innovate to build a better financial future for people with disabilities and their families.

nationaldisabilityinstitute.org

Financial Wellness for People with Disabilities

In partnership with the Illinois Council on Developmental Disabilities



This project is supported in part by grant number CFDA 1126 from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy.

Agenda

- Welcome
- Overview of Extra Costs of Living with a Disability Research
- Tips on Budgeting and Saving for Extra Costs
- Q&A
- Resources and Announcements

Presenter



Nanette Goodman

Research Director

Burton Blatt Institute, Syracuse University

The Extra Costs of Living with a Disability in the US

Nanette Goodman

Research Director

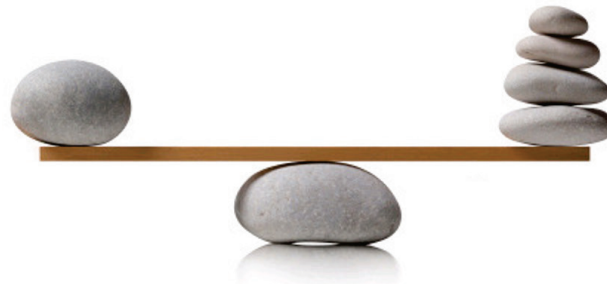
Burton Blatt Institute, Syracuse University

June 16, 2021

Based on research conducted with
Zachary Morris, Stonybrook University;
Stephen McGarity, University of Tennessee,
Knoxville; and Michael Morris, National
Disability Institute

Three primary factors influence financial stability

- Income
- Expenses
- Assets



We already knew a lot about income. But we rarely consider expenses 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.

What extra costs do people with Disabilities Face?

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
- 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?

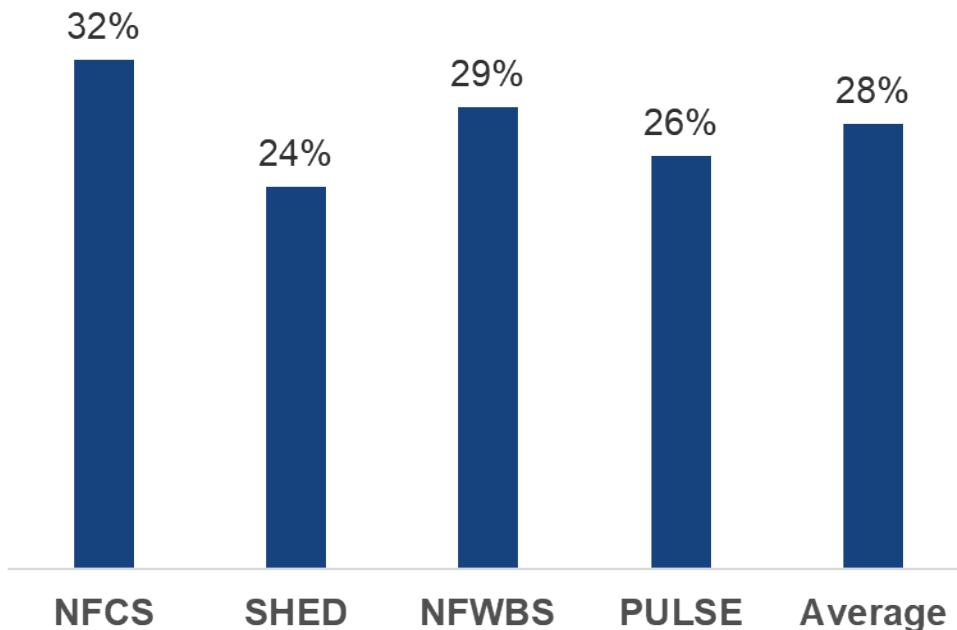
- Work done with Zachary Morris at Stonybrook University, Stephen McGarity at University of Tennessee Knoxville and Ashgar Zaidi Government College University, Lahore.
- We apply the “Standard of Living” approach (Zaidi & Burchardt, 2005; Morris & Zaidi, 2020).
- This approach uses multivariate regression 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).
- 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.

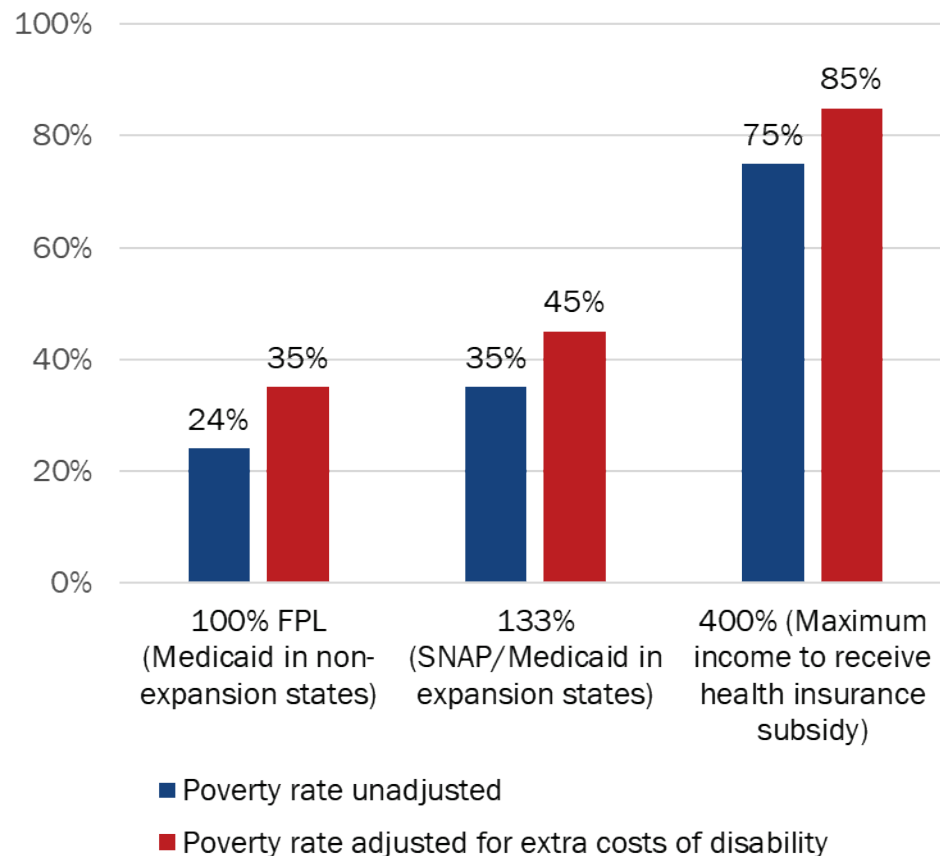
RESULTS: Overall Estimate

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.
- Estimates vary by certain characteristics. For example, married people with disabilities have lower estimated out-of-pocket costs than single people.

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



- If the Federal Poverty Level was adjusted for the extra costs of disability, the rate of poverty among adults with disabilities would increase substantially.
- We estimate that approximately **2.2 million** more people with disabilities would be counted as poor.
- This would expand eligibility for many health and public benefit programs.

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, cont.

➤ 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

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.
- It does not tell us what people “need” to spend to participate fully in society.

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

Policy Brief, Working Paper and Infographic

WORKING PAPER

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

Zachary Morris
Stony Brook University School of Social Welfare

Stephen McGarity
University of Tennessee School of Social Work

Nanette Goodman
National Disability Institute

Asghar Zaidi
Government College University Lahore, and Oxford Institute of Population Ageing

October 14th, 2020

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 extra 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.

Author Note: This research was supported by a grant from the Financial Industry Regulatory Authority (FINRA) Investor Education Foundation.

THE EXTRA COSTS OF DISABILITY

Resetting the Policy Table

Zachary A. Morris (Stony Brook University), Stephen V. McGarity (University of Tennessee), Nanette Goodman, Michael Morris (National Disability Institute), and Asghar Zaidi (Oxford University)

1 **20 million** working-age adults in the United States live with some type of disability.

2 A U.S. household containing an adult with a disability must spend an estimated **28% more income** to obtain the same standard of living as a household with no disability.

3 This translates to a person with a disability needing an additional **\$17,690 a year** at the median household income.

4 Adjusting poverty measures to account for the extra costs of disability could result in the expansion of access to critical programs and services for **2.2 million more people** with disabilities.

Policy Recommendations

Subtract disability-related costs from the income calculations used to determine eligibility for programs like Medicaid and SNAP.

Increase opportunities for people with disabilities to deduct extra costs from their taxes.

Expand upon existing policies to help people with disabilities manage the financial burden of living with a disability.

To read more about the extra costs of disability, including a full research report and a topic, please visit www.nationaldisabilityinstitute.org. For questions about this research, contact Dr. Zachary Morris at zachary.morris@stonybrook.edu.

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

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

October 2020

Nanette Goodman, National Disability Institute
Michael Morris, National Disability Institute

Zachary Morris, Stony Brook University
Stephen McGarity, University of Tennessee, Knoxville

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, **additional \$17,690 a year** to obtain the same standard of living as a similar household without a member with a disability.

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-of-living-with-a-disability/.

Presenter



Bridgett D. Graham, BSW, FSW
Manager, Financial Empowerment
National Disability Institute

Budgeting for the Extra Costs of Living

- Start by creating a spending plan
- Write down all the money you have coming in, your income
- List all your fixed expenses
 - These expenses do not change from month to month.
- List all your variable expenses
 - Examples of these are groceries, gas, electricity, cable, shopping, etc.
- Determine areas to cut back expenses
- Pay off debt, then save money

Financial wellness tools are available on our website to assist you in improving your financial wellness.

Financial Education Tools

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Menu Planning and Shopping List

Weekly Menu

	Breakfast	Lunch	Dinner
Sunday			
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			

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Spending Plan

Monthly Expenses	Cost	Monthly Income Totals	Amount
Rent / Mortgage		Take Home Pay	
Household Repairs		Part Time Job	
Property / School Taxes		Support / Alimony	
Heat / Air Conditioning		Pension / 401(k) / 403(b)	
Electricity		Rental Income	
Water		Self-Employment Net Income	
Groceries (\$327 per adult)		Dividends	
Insurance (auto/home owners/life)		Veteran's Income	
Medical (premium & co-payments)		SSI	
Telephone / Cell		SSDI	
Transportation (gas, parking)		Social Security Retirement	
Auto loan		Worker's Compensation	
Auto Repairs (\$80 per vehicle)		Stipend	
Cable / internet		TANF	
Clothing (\$89 - 100 per person)		SNAP food stamps	
Day Care / babysitter		Child Care Subsidy	
Tuition / after school activities		LIHEAP	
Child Support Paid / Alimony paid		Other	
Personal Care (haircuts, nails, tattoos)		Total Net Income	\$0.00
Entertainment		Total Monthly Expenses	\$0.00
Laundry			
Newspapers / Magazines / Books		Difference	\$0.00
Pets			
Gifts			
Tobacco / Alcohol / Lottery			
Church Charities			
Rent-To-Own			
Banking / Money Order Fees			
Emergency Savings			
Other			
Total Monthly Expenses	\$0.00		

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Ways to Save

- Create a Savings plan
 - Helps you save for unexpected emergencies and expenses
- Brainstorm ways to decrease your spending or increase your income
 - Meal planning, clipping coupons, shopping second hand
 - Look for ways to lower your bills
 - Ask about special programs for assistance
- Utilize tools available to find ways to cut expenses and save
 - NDI's Financial Resilience Center

Options for Saving Money

- **Bank Accounts or Credit Unions**

- Money is protected
- May be charged fees based on the account you have
- Guideline for offering cost effective transactional and savings accounts

- **ABLE Accounts**

- Does not affect eligibility for SSI, Medicaid, or other means-tested benefits
- Can be spent on qualified disability expenses

*Must qualify to open an account

Compare and choose

FDIC MODEL SAFE ACCOUNTS TEMPLATE

- Guideline for offering cost effective transactional and savings account

FINANCIAL WELLNESS TOOLS

- A great banking worksheet to help you find the right bank for your needs

IL ABLE

- Another great option for learning about ABLE accounts to determine if you are eligible
- Can also enroll for an account

ABLE NRC

- Website is a great option to learn more about programs and accounts

Resources

- NDI Financial Wellness tools
- NDI Report: *The Extra Costs of Living with a Disability in the U.S.*
- NDI webinars

Questions and Answers

- Please use the Q&A box to submit your questions now.
- If you are listening by phone and not logged in, you may email: kmetz@ndi-inc.org.

Contact Us

If you have any questions on this project or on financial wellness for people with disabilities, please send an email to ask@ndi-inc.org.

Upcoming Webinar

Housing Opportunities for People with Disabilities **July 21, 2021, 11:00AM Central/Noon Eastern**

Join us as Lore Baker, President & CEO of Association of Individual Development (AID) in Aurora, presents different affordable housing options and how collaboration has created pathways for people with disabilities to obtain supports to secure housing for living independently within the diverse communities of Illinois.

[Register Now](#)

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