Examining the Impact of Inflation on the Economic Security of Disability Program Beneficiaries

Zachary Morris Stony Brook University

Stephanie Rennane RAND

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Abstract

Disability program beneficiaries, including those who receive Social Security Disability Insurance (DI) benefits or Supplemental Security Income (SSI), often incur substantial out-of-pocket (OOP) expenses for disability-related goods and services. The market basket of goods and services purchased by disability program beneficiaries is thus likely to differ from the goods and services purchased by the average urban consumer, thereby creating different actual rates of inflation. Our study explores and documents these kinds of disability-related spending patterns and the potential impact of inflation on these items, providing new evidence to better understand the economic wellbeing of disability program beneficiaries. We present data collected from the Survey of Used and Needed Disability-related Goods and Services (SUNDiGS), a novel survey drawn from the Understanding America Study, a nationally representative panel with a large sample of disability program beneficiaries.

Key Findings:

- 82% of disability program beneficiaries (N = 459) report disability-related OOP costs with an average total reported cost of \$4,412 and a median total cost of \$384 in June of 2023.
- Nearly half (46%) of beneficiaries report that their disability-related costs make it more difficult to make ends meet, while a quarter report going into debt (25%) and cutting the amount their households spend on food (27%) because of these costs.
- 59% of beneficiaries report experiencing higher prices for the disability-related goods and services they need compared to two years ago. 43% report that the 2023 cost-of-living adjustment (COLA) was not enough to help maintain their households' standard of living compared to last year.
- Medical expenses comprise approximately 15% of all expenditures for beneficiaries compared to 7% for the average consumer as measured by the Consumer Price Index-W that is used to determine the COLA for beneficiaries.
- Several possible policy interventions could mitigate the impact of disability-specific costs such as: reducing the cost share of medications; expanding access to energy, transportation, and food assistance; and adjusting the disability benefits COLA to more accurately reflect the prices experienced by disability program beneficiaries.

Introduction

People with disabilities often incur a wide variety of out-of-pocket costs on disability-related goods and services. These costs weigh heavily on household finances and increase the risk of material hardship and poverty (Morris, McGarity, Goodman, and Zaidi, 2021; She and Livermore, 2007). Commonly purchased goods and services include wheelchairs, assistive technologies, hearing and visual aids, out-of-pocket healthcare expenses, and personal care assistant support (Kennedy, Wood, and Frieden, 2017; Mitra, Palmer, Kim, Mont and Groce, 2017; Denny-Brown, O'Day, and McLeod, 2015). Though these extra costs are ever present, recent inflation may be jeopardizing the ability to afford these needed items.

Since 2020, inflation has increased to levels not seen since the 1970s (Ball et al. 2022). Social Security Disability Insurance (DI) beneficiaries and Supplemental Security Income (SSI) recipients (referred to hereafter as "disability program beneficiaries") rely heavily on the fixed income received from these programs with less than 20% reporting earnings from employment (Wittenburg et al., 2018). Beneficiaries are thus vulnerable to financial instability as inflation reduces their purchasing power. To counteract rising costs, all Social Security benefit recipients, including disability program beneficiaries, automatically receive an annual cost of living adjustment (COLA). The COLA adjustment, first introduced in 1975, is based on the percentage increase in the average Consumer Price Index for Urban Wage Earners and Clerical Workers (CPI-W) (SSA, 2023a). The CPI-W provides a monthly measure of prices paid by the average urban consumer who has more than half of their household income coming from clerical or wage occupations and at least one of the household's earners has been employed for at least 37 weeks during the previous 12 months (BLS, 2023a). The CPI-W population represents approximately 30% of the total U.S. population and the index, based on the market prices for over 200 categories

of commodities and services and two housing related indices, is weighted based on the average reported expenditure for these items among the CPI-W population in the Consumer Expenditure Survey (CES) (BLS, 2023a).

The consumption patterns of people with disabilities, including disability program beneficiaries, are likely to differ systematically from the average urban consumer in the CPI-W. Unlike people without disabilities, people with disabilities often need to purchase many kinds of disability-specific items. Some of these items, such as medical goods and services, may be included in the CPI-W but purchased by people with disabilities in greater quantities than the average consumer. For example, in 2021, medical goods and services were weighted as 7.07% of the average annual expenses in the CPI-W but the average person receiving disability benefits may need to expend a larger percentage of their household income on such items because of a health condition related to their disability. This difference could result in an inaccurate weighing of the relative importance of the different components that make up the CPI-W for disability program beneficiaries. Moreover, some disability-related expenses, such as for assistive technologies, specialized software, and home accessibility modifications, may not be fully captured in the CPI-W expenditure categories (see, BLS, 2023b). Differences in the quantity of items purchased and the fact that certain items may not be included in the CPI-W may make the COLA adjustment (which is tied to the CPI-W) less sensitive to the actual price inflation encountered by people with disabilities.

The objective of this paper is twofold. First, we report the results of a novel Survey of Used and Needed Disability-related Goods and Services (SUNDiGS) drawn from a nationally representative online panel, the Understanding America Study (UAS). The survey included a large sample of people with disabilities, including more than 400 DI beneficiaries and/or SSI recipients. We designed and validated the SUNDiGS as part of a collaborative research project with direct input from an expert advisory panel including people with disabilities and other professionals in the disability field. The SUNDiGS provides extensive information on out-of-pocket expenses and unmet needs for more than 70 disability-related goods and services as well as information on additional spending on general items due to a disability. We also included questions on the selfreported impact of disability costs on financial well-being, changes in inflation for disabilityrelated goods and services, and the suitability of the COLA adjustment from the perspective of disability program respondents.

The second objective of this paper is to present an exploratory analysis of how these disabilityrelated goods and services change the overall consumption bundle for disability program beneficiaries and to assess potential impacts on inflation specifically for a disability-related consumption bundle. To do so, we use the survey responses from disability program beneficiaries about the quantity of disability-specific goods and services purchased from the SUNDiGS and the amount spent on these items out-of-pocket (OOP). We assess the relative importance of various items in the overall consumption bundle for disability program beneficiaries. We compare these disability-specific expenditure weights to relative expenditure weights used in various other measures of CPI to understand how the amount spent on disability-specific goods may impact the actual rate of inflation experienced by disability program beneficiaries. Together, these two objectives seek to provide a deeper understanding of the economic well-being of disability program beneficiaries and contribute to policy discussions regarding the best way to design supports and benefits to address their financial needs.

Background

A large body of research seeks to understand consumption patterns in the general population, particularly during times of changing health conditions or economic instability (e.g., Aguiar and Hurst 2005, see Browning, Crossley, and Winter, 2014 for a comprehensive review). Prior work has analyzed trends in consumption for disability program beneficiaries, as well as for all people with disabilities more broadly. Moore and Ziebarth (2014) compared the consumption patterns of disability program beneficiaries with non-beneficiaries from 1986 to 2012 in the CES.¹ They document statistically significant differences in total expenditures among DI and SSI households compared to working households with the differences generally constant over time. While they did not seek to document disability-related expenses specifically, they find that the median DI and SSI household spends more on healthcare spending than the median working household, including on OOP expenditure on medical services, prescription drugs, and medical supplies. This study, however, is nearly ten years old and consumption patterns are likely to differ today. Kennedy, Wood, and Frieden (2017) analyzed the 2014 Medical Expenditure Panel Survey and documented statistically significant higher out-of-pocket medical costs with a mean annual average of \$1,053 for people with disabilities versus \$486 for people without disabilities. However, medical expenditures only represent one aspect of consumption which may differ for people with disabilities. For example, many people with disabilities are likely to encounter other disability-related costs for items such as a home or bathroom accessibility modification or to modify a vehicle for wheelchair accessibility (Home Advisory, 2023; Pynoos and Nishita, 2003). They may need to purchase assistive technologies, require additional services such as

¹ Because the CES does not include a DI indicator (SSI receipt is captured) but includes a general indicator of Social Security receipt, Moore and Ziebarth (2014) approximate DI receipt by identifying those who receive Social Security and whose ages (between 18 to 59 years) could only indicate the receipt of disability benefits.

interpretation or educational assistance, or may require more assistance around the home. Individuals may also incur additional OOP expenses on general items, such as electricity, transportation, or legal fees, as a result of their disability or health condition (Mont and colleagues, 2022).

A related line of research examines the relationships between disability, financial insecurity, and consumption. Meyer and Mok (2019), drawing on the Panel Survey of Income Dynamics, examine changes in food and housing consumption before and after a disability onset and find that both decline significantly following a disability onset, particularly for those with chronic-severe disabilities. They find that the receipt of DI or old-age Social Security benefits did not significantly change the level of consumption. Deshpande, Gross, and Su (2021) examine the effects of DI and SSI receipt on the financial security of applicants. They note that eviction rates are about 50% higher for DI and SSI applicants than the general population, while bankruptcy rates are nearly twice as large, but that the receipt of disability benefits substantially reduces the likelihood of both events. They further conclude that DI and SSI benefits reduce financial insecurity by increasing liquidity and enabling beneficiaries to pay off debts and other expenses.

Even with the protection that comes with the receipt of disability benefits, including cash benefits (average monthly benefits were \$1,486 for DI workers in July 2023 (SSA, 2023b) and maximum SSI benefits were \$914 for eligible individuals in 2023 (SSA, 2023c)) and health insurance (Medicaid for SSI and Medicare for DI recipients after a 24 month waiting period), disability program beneficiaries often struggle financially. Nearly 20% of DI beneficiaries and 43% of SSI recipients had family income below the federal income-based poverty threshold in 2013 (Stegman and Hemmeter, 2015). Both DI beneficiaries and SSI recipients have been found to be more likely to struggle with financial insecurity compared to their peers with similar

characteristics who do not receive disability benefits (Morris, 2023). While many factors are likely to increase this risk of hardship, the need to expend scarce resources on disability-related goods and services is likely an important source of economic strain adding to household budgetary pressures, while creating difficult questions of prioritization of basic needs like food and shelter versus needed disability-related goods and services. This financial predicament may thus result in substantial unmet needs for the disability-related items that are needed while jeopardizing health and the ability to participate in activities such as school and work.

A recent study, using data from four nationally representative surveys of the U.S. workingage population around the year 2018, applies an indirect estimation strategy to calculate the total additional costs of living with a disability. That study estimated that an adult with a work-limiting disability in the U.S. required, on average, 29% more annual income or an additional \$18,322 for a household at the median income level, to obtain an equivalent standard of living as a household without a person with a disability (Morris, McGarity, Goodman, and Zaidi, 2021). While providing an estimate of the overall OOP costs associated with living with a work-limiting disability, including for many disability program beneficiaries, the study does not provide information as to the specific kinds of cost incurred or needs unmet, nor does it consider prices for disability-specific items and how they may be changing over time. Denny-Brown, O'Day, and McLeod (2015) explore the kinds and extent of OOP costs incurred by people with disabilities that are needed to engage in paid work specifically. Upon conducting in-depth interviews with 15 workers with disabilities, they found that most respondents needed some support or accommodations to work and that many incurred OOP costs on these goods and services. Reported costs, which varied based on needs and the type of insurance the person had, ranged from \$0 to

\$14,800 in 2013 for support such as personal care assistants, various medical goods and services, assistive technologies, and service animals.

We are unaware of a prior nationally representative survey that seeks to collect comprehensive data on the extent of disability-related goods and services purchased by people with disabilities in the U.S., including disability program beneficiaries. By exploring and documenting these kinds of disability-related costs, we aim to provide new evidence to better understand the economic well-being of disability program beneficiaries. If disability program beneficiaries purchase different market baskets than the general public, they may, in turn, have substantially different experiences with inflation. Since 1987, Congress has mandated the BLS to produce an experimental consumer price index for elderly Americans (CPI-e). The CPI-e uses a subset of the CES urban sample consisting of households with a reference person or spouse aged 62 years of age or older. The rationale behind the CPI-e is that households with older adults have systematically different experimental CPI for Americans with disabilities (CPI-d) may also be warranted to provide a more accurate measure of inflation encountered by people with disabilities, particularly disability program beneficiaries.

Data

Survey of Used and Needed Disability-related Goods and Services (SUNDiGS)

We developed a Survey of Used and Needed Disability-related Goods and Services (SUNDiGS) that was fielded to the full Understanding America Study (UAS) online panel. The UAS is a probability-based nationally representative internet panel administered by the Center for Economic and Social Research at the University of Southern California. The UAS currently

contains about 13,000 potential respondents. Panel members answer researchers' queries once to twice a month via an online interface and are compensated for each completed survey. The survey was developed as part of the current Social Security RDRC grant, as well as a grant from the National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR). Our survey instrument included two main parts: a disability screener administered to all panel members, and a series of questions on the use of and need for various disability-related goods and services.²

The screener included the Washington Group Short Set (WG-SS) enhanced questions, which include a series of questions about respondent functioning, as well as four additional questions about depression and anxiety. The WG-SS enhanced questions have been extensively tested and validated internationally and use the World Health Organization's International Classification of Functioning, Disability, and Health as a conceptual framework for measuring disability (Altman and colleagues, 2010). For each functioning domain, respondents rate their degree of difficulty with the functioning domain on a four-point scale (no difficulty, some difficulty, a lot of difficulty or cannot do at all). For the depression and anxiety questions, respondents are asked how often they feel depressed or anxious (daily, weekly, monthly, a few times a year, or never), and then asked to describe the level of those feelings in the last episode of anxiety or depression (ranging between a lot and a little).

We additionally asked all respondents if they self-identified with a disability, and if yes, we offered eight categories for respondents to select how they would characterize their disability (e.g., physical, learning, mental or psychological, vision, hearing, intellectual, developmental, or other not listed above). Finally, we asked respondents if they received benefits from the Social Security

² See UAS survey 547 at <u>https://uasdata.usc.edu/index.php</u> for the full survey codebook and instrument.

Administration due to their disability and, if yes, we asked whether respondents knew if their benefits were from Social Security Disability Insurance (DI) or Supplemental Security Income (SSI) or both. Respondents were screened as having a disability if they met any of the following criteria: they answered "a lot of difficulty" or "cannot do at all" to any of the WG-SS functioning questions; they answered that they experienced depression or anxiety daily and that the level of feelings was "a lot" (i.e., the WGSS enhanced questions on affect); they self-identified with any disability; or they reported receiving benefits from the Social Security Administration due to a disability.

The respondents who screened in then worked through a series of survey modules about extra expenditures and needs related to their disability or health condition. The survey asked about OOP expenses across ten domains of need for disability-related goods and services, including (1) mobility (e.g. wheelchair, standing or walking supports, vehicle modifications, service animals), (2) assistive goods and technologies (e.g. communication devices, special tools for dressing, cooking, and eating), (3) vision (e.g. vision-related software, long white cane), (4) hearing (e.g. hearing aid or cochlear implant), (5) personal assistive services (e.g. caregivers, personal care assistants, home health aide), (6) interior home modifications (e.g. installing ADA compliant bathroom) and (7) exterior home modifications (e.g. outdoor wheelchair ramps), (8) health services (e.g. medical specialists), (9) health goods (e.g. prescription drugs), as well as (10) additional expenses on general items because of a disability or health condition (e.g. higher food or rent costs).

The domains of need and items specific to each domain were determined through an environmental scan conducted by an eight member NIDILRR research team with a wide array of disability research expertise including individuals with lived experience. First, members of the NIDILRR team identified key domains of need for disability-related goods and services and developed initial lists of disability related goods and services specific to each domain. Then, the domains and items within each domain were presented to an Expert Advisory Panel (EAP) of five individuals all with greater than 10 years of professional work in the disability field and many with lived experience. EAP members provided feedback on items that were missed from each domain, as well as items in the domain which were not important, should be classified elsewhere, or otherwise mis-specified. EAP members scored the items and domains for relevance, clarity, and comprehensiveness. The team members revised items in light of this feedback and presented the new list to EAP members who again scored the domains and items. We assessed the content validity of the survey by creating an item-level content validity index (I-CVI) which is computed as the number of experts giving a rating of "very relevant" for each item divided by the total number of experts. The I-CVI average for relevance of items increased from 60% in round 1 to 92% in round 2 suggesting improved content validity.

In each domain, respondents were asked to select whether they purchased any item because of their disability or health-condition from a list specific to each domain. For any selected items, respondents were asked follow-up questions about the quantity purchased in the last 12 months (or frequency of service use in the last 12 months) and the total amount spent the last time the item or service was purchased. Respondents were then asked if any additional items on the list were needed, but not purchased, and if selected, the reason the item was not purchased (e.g., cost too much, not aware of the item). Respondents who did not select any item on the list were also asked if any items on the list were needed but not purchased, and the reason the item was not purchased. Finally, we asked respondents a series of questions about financial well-being related to their disability costs and recent inflation. Members of the NIDILRR research team performed cognitive

testing on the survey instrument in May 2023, and the finalized survey was in the field from June 7, 2023 until July 16, 2023.

In total, 9,088 respondents from the entire UAS panel answered the screener for a response rate of 71%. Among those 9,088 respondents, 2,220 (24%) were identified as having a disability based on our screener. We subsequently conducted data cleaning procedures recommended for online survey panels. These included reviewing survey completion speed, consecutive responses, contradictory responses, as well as assessing the quality of open-ended responses (Arevalo and colleagues, 2022). After data cleaning, we consulted among each other and ultimately dropped 336 respondents for data quality issues with a final sample of 1,884 panelists and 459 disability program beneficiaries.³ We describe the final cleaned survey sample in Table 1. Compared to those screened in with disabilities not receiving DI/SSI, beneficiaries were less likely to be female, married, and White, and more likely to be Black, non-immigrants, and, on average, of older age. 88% of disability program beneficiaries self-identify as people with disabilities and 83% report a work-limiting disability. Moreover, 63% of disability program beneficiaries report a physical disability and 23% a mental disability, significantly higher rates relative to those with disabilities screened in the SUNDiGS survey who do not receive disability benefits.

³ See the Appendix for details on our data cleaning process.

	(1)	(2)	(3)	(4)	(5)	(6)
	Screened in	Screened out	Sig.	DI/SSI	Screened in no DI/SSI	Sig.
Female	0.56	0.49	*	0.53	0.58	*
Married	0.42	0.56	*	0.32	0.46	*
White	0.79	0.78		0.68	0.83	*
Black	0.18	0.14	*	0.28	0.14	*
Spanish/Hispanic/Latino	0.14	0.18	*	0.1	0.15	*
Non-immigrant	0.61	0.54	*	0.68	0.58	*
Age (mean)	51.62	48.34	*	55.1	50.24	*
Household income < \$60K	0.7	0.43	*	0.85	0.64	*
Bachelor's degree	0.21	0.41	*	0.07	0.27	*
Work-limiting disability	0.33	0.01	*	0.83	0.13	*
Health insurance	0.95			0.99	0.93	*
Identifies as PWD	0.66			0.88	0.58	*
Physical disability	0.44			0.62	0.36	*
Learning disability	0.07			0.1	0.06	*
Mental disability	0.18			0.23	0.16	*
Vision disability	0.09			0.11	0.08	*
Hearing disability	0.07			0.08	0.07	
Intellectual disability	0.02			0.04	0.01	*
Developmental disability	0.02			0.03	0.02	
Other disability	0.08			0.11	0.07	*
Depression	0.13			0.1	0.14	*
Anxiety	0.23			0.12	0.28	*
Difficulty seeing	0.08			0.06	0.09	*
Difficulty hearing	0.07			0.05	0.08	*
Difficulty walking	0.19			0.26	0.17	*
Difficulty remembering	0.14			0.1	0.15	*
Self-care difficulty	0.03			0.07	0.02	*
Difficulty communicating	0.02			0.02	0.02	
Observations	1884	6880		459	1425	

Table 1. Summary characteristics of SUNDiGS sample

Notes: Data from the Understanding America Panel 547. Proportions calculated using survey weights. * = p-value <.05. DI/SSI includes all DI beneficiaries and/or SSI recipients. Stars in Column 3 indicate whether the difference between respondents screened as having a disability and those without is statistically significant. Stars in Column 6 assess whether the difference between disability program beneficiaries and other respondents with disabilities is statistically significant.

Disability-related expenditures among disability program beneficiaries

We present self-reported annual OOP expenditures on disability-related goods and services among disability program beneficiaries in Table 2. OOP costs are calculated using the self-reported frequency of items purchased in the past 12 months multiplied by the reported amount spent for each good or service when last purchased.⁴ Among all disability program beneficiaries, 82% reported OOP costs on disability-related goods and services with a mean total of \$4,412 and a median total of \$384. Among the domains of need, health-related goods were the most commonly purchased OOP with 61% of DI/SSI respondents reporting expenses in this category in the past 12 months. The most common health goods purchased OOP included vitamins, supplements, and medical foods (26% paid out of pocket; mean=\$1,180; median=\$240), and prescription drugs (24% paid out of pocket; mean=\$560).

As shown in Table 2, 44% of DI/SSI respondents also reported higher expenditures on general items because of their disability or health condition. The most common general items that disability program beneficiaries reported spending more on were for food (27% reported; mean=\$1,322; median=\$400), transportation (22% reported; mean=\$1,362; median=\$500), and heating or electricity (17% reported; mean=\$1,119; median=\$200). Many disability program beneficiaries also reported OOP costs on mobility related items (21%), health services (19%), and assistive goods and technologies (15%).

⁴See the Appendix for more details on data cleaning and manipulation.

	All DI/SSI	DI	SSI	DI or SSI not specified
% with any OOP costs	0.82	0.84	0.83	0.76 *
Mean total OOP cost (June 2023)	\$ 4,412	\$ 5,773 *	\$ 3,470	\$ 1,954 *
Median total OOP cost (June 2023)	\$ 384	\$640	\$ 240	\$73
Any ou	ut of pocket expe	ense by catego	ry	
Mobility	0.21	0.25 *	0.18	0.12 *
Assistive goods and technologies	0.15	0.19 *	0.11	0.12
Vision	0.03	0.03	0.01	0.03
Hearing	0.04	0.05	-	0.07
Personal service	0.03	0.03	0.05	0.03
Int modification	0.11	0.16 *	0.04 *	0.06
Ext modification	0.14	0.14	0.08 *	0.19
Health services	0.19	0.26 *	0.10	0.10 *
Health goods	0.61	0.68 *	0.51 *	0.51 *
General goods	0.44	0.43	0.54	0.38 *
Average	out of pocket ex	pense by categ	gory	
Mobility	77	121	22	20
Assistive goods and technologies	97	81	245	13
Vision	1	0	1	4 *
Hearing	99	104	-	171
Personal service	47	27	155 *	5
Int modification	296	392	72	254
Ext modification	77	101	4	82
Health services	194	221	108	202
Health goods	2,206	3,231 *	1,217	586 *
General goods	1,316	1,495	1,645	616 *
Observations	459	267	87	105

Table 2. Annual out-of-pocket (OOP) expenditures on disability-related items among disability program beneficiaries

Notes: Understanding America Panel 547. Proportions calculated using survey weights. * indicates the difference between the sub-category and All DI/SSI is statistically significant at 5% level. Expenses reported in June 2023.

SSI recipients reported lower average OOP expenditures (\$3,470) compared to DI beneficiaries (\$5,773) likely reflecting the lower financial capacity to spend on disability-related

goods and services among SSI recipients, though the difference was not found to be statistically significant, likely due to our relatively small sample sizes of DI beneficiaries and SSI recipients. Note that 105 respondents reported that they received Social Security benefits due to a disability but did not specify whether it was DI or SSI. As shown in the final column, OOP costs for this group are lower than OOP costs for both the DI and SSI groups across all domains.

We further observe variation in the OOP costs for disability-related goods and services across the DI/SSI population demonstrated by the large differences between the mean (\$4,412) and median (\$384) OOP expenditure figures. In Figures 1 and 2, we present regression-adjusted differences in expenditures relative to the mean to identify characteristics associated with greater OOP disability-related costs. We estimated two versions of regression-adjusted costs: one using the indicators for individuals who self-reported various types of disabilities (Figure 1) and the other using the WG-SS disability indicators (Figure 2). As shown in Figure 1, those who report a physical disability or other disability, or living in a rural setting report significantly greater costs, while beneficiaries who are older than age 50 report lower costs relative to the mean. In Figure 2, individuals with difficulties remembering and concentrating report significantly greater costs and those who identify as Black report lower OOP costs relative to the mean. While future work is left to examine these differences more closely, OOP costs on disability-related goods and services are likely a product of the local knowledge and availability of needed goods and services, the household specific resources available to purchase those items, and the disparate needs for those items across the heterogeneous population of disability program beneficiaries.

Figure 1. Regression-adjusted difference in expenditures relative to the mean, self-reported disability indicators



Notes: Data from the Understanding America Panel 547. Figure reports coefficients from a regression of total out of pocket expenses on all of the characteristics shown along the y-axis. Blue coefficients indicate those which are statistically significantly at the 5% level.

Figure 2. Regression-adjusted difference in expenditures relative to the mean, WG-SS disability indicators



Notes: Data from the Understanding America Panel 547. Figure reports coefficients from a regression of total out of pocket expenses on all of the characteristics shown along the y-axis. Blue coefficients indicate those which are statistically significantly at the 5% level.

Next, we report results from questions on the self-reported impact of disability-related OOP on well-being. Specifically, respondents were asked whether their disability-related costs make it more difficult to make financial ends meet, and if, because of their disability-related costs, they have ever gone into debt, cut household expenditure on food, or been unable to make rent or mortgage payments. We also asked respondents if thinking about their disability-related costs made them feel anxious. In Table 3, we see that nearly half (46%) of disability program beneficiaries report that their disability-related costs make it more difficult to make ends meet, while more than a quarter report going into debt (25%) to pay for disability-related costs and having cut the amount their household spends on food (27%) to help pay for disability-related costs. While 15% report being unable to make rent or mortgage payments due to disability-related costs, 37% report their disability-related costs make them feel anxious. The impact of disabilityrelated costs on well-being, moreover, is more pronounced among SSI recipients. Although our sample sizes are relatively small, there is a statistically significant difference in the rate at which SSI recipients report being unable to make rent payments (24% for SSI compared to 15% among all DI or SSI), and a marginally statistically significant difference (p-value 0.07) in the rate at which they report that their disability-related costs make them feel anxious (47% among SSI compared to 37% among all DI or SSI). While SSI recipients report fewer costs, the costs that they have appear to be more impactful on their well-being.

	All DI/SSI	DI	SSI	DI or SSI not specified
Difficulty making ends				
meet	0.46	0.47	0.56	0.37
Went into debt	0.25	0.26	0.30	0.17
Cut back on food costs	0.27	0.29	0.25	0.23 *
Unable to make rent	0.15	0.13	0.24 *	0.11 *
Feel anxious	0.37	0.37	0.47	0.28 *
Observations	459	267	87	105

Table 3: Self-reported impact of disability-related costs on well-being

Notes: Data from the Understanding America Panel 547. Proportions calculated using survey weights. * indicates that the difference between the sub-category and All DI/SSI is statistically significant at 5% level. DI/SSI includes all DI beneficiaries and/or SSI recipients.

Inflation analysis

We have thus far established that a substantial share of disability program beneficiaries incurs OOP costs on disability-related goods and services; that the magnitude of these costs varies across the disability program population; and that for many disability program beneficiaries these costs weigh heavily on household financial security. In this next section, we will consider the impact of recent economic inflation on the price of disability-related goods and services and its impact on disability program beneficiaries. Table 4 indicates that 59% of disability program beneficiaries in our sample report that they are experiencing higher prices on the disability-related goods and services that they need relative to two years ago. Moreover, among those reporting higher prices, 60% report that these higher prices have made it more difficult to afford needed items and 59% report that these higher prices have impacted their ability to make ends meet. In 2023, DI and SSI benefits increased by 8.7% as a result of an automatic COLA. Disability program

beneficiaries were asked if the adjustment was enough to help maintain their household's standard of living compared to last year. 43% of the DI/SSI program beneficiaries surveyed in June of 2023 felt that the COLA was not enough, while 36% thought it was somewhat enough, 12% enough, and the remaining 9% reporting that they didn't know.

	All DI/SSI	DI	SSI	DI or SSI not specified
Prices <u>higher</u> than 2 years ago for disability-related goods and services needed	0.59	0.63	0.51	0.56
Prices lower than 2 years ago for disability-related goods and services needed	0.05	0.03	0.12	0.05
Prices the <u>same</u> as 2 years ago for disability-related goods and services needed	0.21	0.20	0.18	0.24
[If report higher prices] Higher prices on disability- related goods and services impacted ability to afford needed items	0.60	0.59	0.67	0.55
[If report higher prices] Higher prices on disability- related goods and services impacted ability to make ends meet	0.59	0.59	0.61	0.57
Cost of living adjustment <u>enough</u> to help maintain household's standard of living compared to last year	0.12	0.13	0.05	0.16
Cost of living adjustment <u>somewhat enough</u> to help maintain household's standard of living compared to last year	0.36	0.32	0.45	0.38
Cost of living adjustment not enough to help maintain household's standard of living compared to last year	0.43	0.47	0.38	0.38
Observations	459	267	87	105

Tab	le 4	. Self	f-reported	impact	of infl	ation a	and a	dequacy	of COLA	adjustment
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Notes: Data from the Understanding America Panel 547. Proportions calculated using survey weights. No differences between the sub-categories and All DI/SSI are statistically significant at the 5% level. DI/SSI includes all DI beneficiaries and/or SSI recipients.

Next, we examined how the disability-related goods and services reported in the prior section may affect the overall consumption bundle of disability program beneficiaries. Recall that the COLA is based on the CPI-W, which tracks price changes for an average bundle of goods purchased among all urban wage earners and clerical workers in the U.S. To aggregate the prices of all items in the bundle into one price index, the Bureau of Labor Statistics generates relative importance weights for each item. These weights reflect the relative share of all expenditures that consumers spent on each item in a prior period (BLS, 2023c).

Disability program beneficiaries may have different bundles of goods purchased for two main reasons: first, their disability may require them to purchase either disability specific items and/or general goods and services in different quantities than people without disabilities; secondly, they are likely to spend their time differently. Meyer and Mok (2019) find, for example, that men with disabilities spend more time watching television, relaxing, sleeping and using medical services compared to men without disabilities. As a result, the relative importance of various items in their bundle may be different from the relative importance in the CPI-W if the prices of this disability-weighted bundle evolve differently from the prices of goods included in the CPI-W, then disability program beneficiaries may have different experiences with inflation, and a COLA tied to CPI-W may not always match this experience.

Using the information collected in SUNDiGS, we conduct an exploratory exercise to generate a new set of weights specific to the items purchased by disability program beneficiaries. Recall that our survey only asked respondents about additional expenses specific to their disability. Even though the survey asked respondents about expenditures on general goods, the question only asked about *additional* spending on these general goods due to their disability. Therefore, the first step in our process of generating these exploratory weights is to estimate respondents' expenditures

on items that are not specific to disability. We identified five common expenditure categories where we needed to estimate non-disability specific expenditures: food, housing, transportation, standard preventive medical care not specific to disability, and other general spending (including spending on apparel, entertainment, and education). We estimated these amounts by first deriving the share of total income spent on each of these categories by the average consumer, using data reported by BLS (BLS 2022; see Table A). We multiplied these shares by respondents' reported household income in the survey to estimate the base expenditure amount on these common items for each respondent.⁵ We then added to these base amounts any additional amount spent because of a disability in the relevant general goods category by respondents in the survey. For example, if a DI/SSI respondent reported they spent \$500 more on housing or rent the last 12 months than if they did not have a disability, we added the additional \$500 to the base amount for housing. Next, we added the estimated expenditures on the five common categories of general goods to the total OOP expenses reported across the nine other disability-specific domains in our survey to obtain an estimate of the respondents' total expenditure. We divided each category-specific total by the overall expenditure total to obtain the relative importance weight spent on each category of goods and/or services.⁶ Table 5 compares the relative importance weights derived for disability program beneficiaries to the 2021 relative importance weights in the CPI-W and the CPI-e (BLS 2023c). For this comparison, we combined several of our disability specific domains into broader categories. We combined interior and exterior home modifications with the estimate of expenditures on housing; we added disability-specific expenses on health goods, health services,

⁵ Because household income is reported in binned categories in the UAS, we used the median of each bin as the measure of household income when multiplying by the share.

⁶ Relative weights across each disability program beneficiary in the survey were averaged together using survey weights to obtain an estimate of relative weights for disability program beneficiaries in the survey

mobility, hearing, and personal care services to expenditures on medical goods; and we combined expenditures on assistive technologies and vision services with other general spending.⁷

	CPI-W	CPI-E	Disability program beneficiaries
Food and beverages	15.78	12.85	12.56
Housing	42.67	49.40	42.07
Transportation	18.16	12.96	17.45
General medical care	7.07	11.29	15.73
Other general spend	16.88	13.50	12.20

Table 5. Relative importance weights derived from SUNDGiS, compared with CPI

Notes: Relative importance weights for disability program beneficiaries derived from data from the Understanding America Panel 547. Data on relative importance weights for CPI-W and CPI-e obtained from BLS 2023c.

The relative importance weights on food and other general spending are lower among disability program beneficiaries compared to the CPI-W weights (12.5% vs. 15.7% for food and 12.2% vs. 16.88% for general items). The weight on transportation is also slightly lower among disability program beneficiaries (17.45% vs. 18.16%). The weight on housing is quite similar to the CPI-W (42.07% vs. 42.67%). However, the relative weight on medical spending is much higher among disability program beneficiaries (15.73% vs. 7.07%). These findings are consistent with prior work cited above which find evidence of slightly lower consumption on food among people with disabilities, and significantly higher medical expenses (e.g., Meyer and Mok 2019, Kennedy, Wood and Frieden 2017, Moore and Ziebarth 2014).

⁷ Our choice in this allocation was driven by the specific items asked about in each domain (see the survey instrument for details). For example, the main items asked in the hearing section are hearing aids and cochlear implants, which we view as a specific type of medical expense, whereas vision items include items like screen-reading software, which we do not view as a medical expense.

There are also some interesting comparisons between the relative weights for disability program beneficiaries and the relative weights in the CPI-e. Although the relative weight on medical care is higher in the CPI-e (11.29%), it is still lower than the estimated weight among DI and SSI beneficiaries. The CPI-e also places a lower weight on transportation (12.96%), and a higher weight on housing (49.40%). The weight on general spending is lower than the weight in the CPI-W, but slightly higher than the weight among disability program beneficiaries (13.5%), and the weight on food is similar to that among disability program beneficiaries (12.85%).

Discussion

This paper demonstrates that disability program beneficiaries incur significant financial costs as a result of their disabilities: 82% of disability program beneficiaries reported extra OOP due to their disability, with a mean annual amount of \$4,412 and median amount of \$384. Although costs do vary with some characteristics, we found evidence that the costs are widely held across disability program beneficiaries of many impairment types, gender, and race and ethnicity. Nearly half of beneficiaries report that their costs make it more difficult to make ends meet, while a quarter report going into debt and cutting the amount their households spend on food because of their costs. The results do show evidence that SSI recipients incur lower OOP expenses; however, they also report greater financial burden and anxiety associated with these costs. These findings likely are more indicative of the fact that SSI recipients' lower incomes leave them with less financial capacity, rather than the fact that they have less need for disability-specific items. Future work will use data from SUNDGiS to explore the extent of unmet need for disability-specific goods and services among disability program beneficiaries.

Survey respondents also report feeling the pressures of recent inflation on their disabilityrelated purchases. 59% of DI and SSI respondents report experiencing higher prices for the disability-related goods and services they need compared to two years ago, and 43% report that the 2023 COLA was not enough to help maintain their households' standard of living compared to the prior year. As a result, it is important to understand whether inflation affects disability program beneficiaries differently from other individuals.

The reported expenses in the survey enable us to estimate an overall expenditure bundle for disability program beneficiaries and to compare this bundle with bundles typically used in the CPI-W. The estimated weights demonstrate that a disability-specific bundle is likely to be weighted much more heavily towards medical expenses, a point raised in prior work. However, these weights raise some other interesting questions to be investigated: first, even though some people with disabilities need to make home modifications to live in homes accessible to their needs, in the aggregate, these costs do not increase the relative weight on housing significantly, and in fact the CPI-e places a higher weight on housing. This lower weight on housing for disability program beneficiaries may indicate the need to prioritize limited resources towards one's health related needs over their housing related needs or wants. The need to prioritize resources towards other items could be an explanation for the lower weight on food expenses as well. On the other hand, the relative weight on transportation among disability program beneficiaries is higher than the CPI-e and quite similar to the CPI-W, even though the population of disability program beneficiaries likely use very little transportation to get to work, and may have transportation patterns that look more similar to individuals included in the CPI-e. This difference could be influenced by the fact that although transportation patterns are different, there are higher overall

costs of transport when living with a disability, due to vehicle modifications, or increased use of taxis and other ride services.

These findings point to several possible policy interventions which could assuage some of the financial strain due to disability specific costs. First, understanding the types of additional expenses being made by disability program beneficiaries could elucidate areas where additional financial support could be warranted. For example, expanding access to energy, transportation, and food assistance programs for disability program beneficiaries could reduce costs. Second, even though most disability program beneficiaries have health insurance coverage (as shown in Table 1, in our sample, 99% of beneficiaries report having health insurance coverage), they continue to spend significant additional costs on medical care. Identifying and covering items not currently covered by programs like Medicare or Medicaid, or reducing the cost share on key items such as prescription and over the counter medications, could provide additional financial relief. Finally, the fact that the relative weight of items purchased by disability beneficiaries could support an argument for deriving a disability-specific CPI to be used when adjusting disability benefits for cost of living expenses.

The higher weight on medical expenses is of particular note, as the price of medical expenses has trended quite differently than the overall CPI recently. The years around the COVID-19 pandemic were unique in the fact that medical inflation was actually lower than overall inflation measured by the CPI; however, this was likely driven in part by the unprecedented inflation in other items in the bundle which were uniquely affected by supply chain and workforce shortages during the pandemic. In the aggregate, however, medical inflation has outpaced the CPI in 13 out of the last 20 years (<u>BLS 2023</u>d). This differential leads to a significant cumulative impact on individuals who face high medical expenses year after year: since 2000, the price of medical

services has increased 114%, compared to 80.3% for the CPI-U (Rakshit et al., 2023). As a result, adjusting benefits with a price index that is closer to the rate of inflation for medical goods, rather than the CPI-W, could offer financial relief to disability program beneficiaries (see Dunn, Grosse and Zuvekas 2018 for further discussion of medical price deflators). More generally, a separate price index for people with disabilities could be developed to capture the price changes relevant more accurately to disability program beneficiaries.

Finally, there are some limitations of this work. As noted above, the SUNDGiS survey did not ask about general spending on everyday items purchased by all individuals; it focused solely on additional items purchased due to disability. As a result, our estimates of general spending used in the weighting exercise are approximations derived from BLS relative expenditure shares in the general population. If the estimates of total spending were to change with a more accurate measure of general spending, the relative importance weights may change as well. Second, SUNDGiS asked respondents to self-report estimated out of pocket costs on items over the last 12 months, and like any self-reported data, these estimates are likely measured with error and subject to recall bias. Prior evidence suggests that respondents may be likely to under-report OOP costs on expenditure surveys (e.g., Eckman 2022). Any possible under-reporting in our survey would lead to our estimates presenting a lower-bound on total OOP costs. Any differential under-reporting across expenditure domains could also affect the relative weights. Furthermore, because costs are self-reported, we rely on respondents to determine what costs are disability related and what are not; there is a degree of subjectivity in determining this and different respondents may have different views on what constitutes a disability-related cost. Finally, despite the richness of our survey, the relatively small number of respondents who specified whether they received DI or SSI limit our ability to make robust comparisons between these two groups. Nevertheless, we do find statistically significant differences in several measures of financial well-being between these groups, confirming the suggestive trend that SSI beneficiaries experience more financial distress.

Conclusion

We collected novel data on disability-specific goods from a nationally representative panel of individuals in the Understanding America Study. While other work has measured overall consumption patterns of people with disabilities, little is known about the specific goods and services purchased because of a disability or health condition, and how these goods impact overall financial well-being of disability program beneficiaries. We found that a majority (82%) of disability program beneficiaries do have out of pocket costs specifically due to their disability, at a mean (median) annual amount of \$4,412 (\$384). Survey respondents report that these costs do impact their overall financial well-being: 46% of beneficiaries report that their costs make it more difficult to make ends meet; 25% report going into debt; and 27% report cutting the amount their households spend on food because of their costs. We also find suggestive evidence that this burden is larger among SSI recipients. Finally, in an exploratory analysis of the relative importance of various types of expenditures, we find that the overall expenditure bundle of disability program beneficiaries is more heavily skewed towards medical expenses when compared to the average consumer. Medical expenses comprise approximately 15% of all expenditures for disability program beneficiaries, compared to 7% as measured by the CPI-W. These findings point to several possible policy interventions to alleviate some of the financial strain associated with disabilityrelated expenses for disability program beneficiaries: expanding access to energy, transportation, housing, or food programs; increasing the items covered by health insurance or reducing cost

shares on items currently covered by insurance and adjusting the disability benefits COLA to more accurately reflect the prices experienced by beneficiaries.

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APPENDIX: Data cleaning notes

Our data cleaning process proceeded in several steps. First, we excluded anyone who was identified as having a disability based on our disability screener questions, but who completed the full survey, including the inclusion questions, in less than 5 minutes. We set the threshold for exclusion at 5 minutes as it took respondents on average 6 minutes to answer the screener. Therefore, we determined that if a respondent completed the full disability survey in less than 5 minutes, it was likely incomplete or an error. This criterion identified 145 respondents for exclusion. Next, we reviewed data responses in each question domain. In each domain, we identified respondents who entered the same number for the quantity of an item purchased, and the cost of the item - which we believed to be an error. We also reviewed the distribution of costs for each item and flagged cases which were extreme outliers. Because the cost distributions varied widely for each item, this was done on an item-by-item basis, through an assessment of the reported distribution and our review of current prices for the item. Any respondent reporting such an outlier was flagged for exclusion. After reviewing the distribution of item costs, we then reviewed the distribution of quantity purchased in the last 12 months and similarly identified outliers to be flagged for exclusion. This second round of data cleaning identified an additional 191 respondents for exclusion. Thus, out of our initial sample of 2,220 respondents who were screened as having a disability, we have an analysis sample of 1,884, approximately 86% of the original sample.

We did some additional cleaning steps on the data. As described in the paper, we obtained an estimate of out of pocket costs by multiplying the quantity of items purchased or frequency of service use by the per-unit out of pocket cost reported by the respondent. Respondents were flagged as having any out of pocket cost if the estimate was greater than zero. For questions related to services, respondents were asked if they used the service on a daily, weekly, or monthly basis. There was also an option for respondents to enter a different frequency in a free-text field. We coded respondents who used the service daily as having 365 uses in the year; those who used the service weekly as having 52 uses in the year, and those using the service monthly as having 12 uses in the year. We used the actual frequency reported by respondents who chose the free-text entry option.