

# The Disability Squeeze: The Extra Costs of Living with Blindness or Low Vision in the U.S.

## Policy Brief

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### Executive Summary

People who are blind or have low vision (BLV), like other people with disabilities, often must spend money out-of-pocket for needed disability-related goods and services, such as assistive technologies, prescription drugs, or accessible transportation services. These expenses can weigh heavily on finances and force people to choose between paying for these necessary goods and services or other essential items like food and housing. Often BLV people cannot afford needed disability-related goods and services, creating unmet needs that can make it more difficult to work and engage in community life.

In this brief, we call the financial predicament that arises from needing to purchase disability-related goods and services the disability squeeze. We view this squeeze as constraining the full participation of people with disabilities in two primary ways – by reducing disposable income and by creating unmet needs. The squeeze stems from the societal failure to accommodate disabled people and remove the financial barriers that impede their full and equal social participation. We present new data on this problem from a nationally representative survey, the Survey of Disability-Related Goods and Services, fielded in June 2023, which included 288 BLV people.

#### **Key findings include that among BLV people:**

- **80%** reported out-of-pocket costs representing, on average, **27%** of household income.
- **68%** reported at least one disability-related unmet need.
- **75%** of those out of work reported an unmet need versus **57%** of those in paid work.
- **25%** reported cutting back on food costs because of their disability-related costs.
- **26%** reported going into debt because of disability-related costs.
- **39%** reported challenges making ends meet because of disability-related costs.

### Background

People who are blind or have low vision (BLV) in the United States (U.S.) face considerable economic disparity. According to the 2023 Current Population Survey, among working-age adults ages 16-65, 41% of people with vision difficulty were in paid employment compared to 72% without blindness/low-vision (AFB Employment, 2024). Moreover, according to the 2022 American Community Survey (ACS), 22% of people with vision difficulty lived in households

with incomes below the federal poverty limit compared to just 11% of the population without disabilities (AFB Facts, 2024). These poverty statistics, however, do not adjust for the extra costs of living with a disability and thus likely understate the true levels of deprivation in this population. A recent study, for example, estimated that, on average, households with adults with work-limiting disabilities required 29% more income to make ends meet due to disability-related expenses and that if the federal poverty rate adjusted for these extra costs, much like it adjusts for household size, more than 2.2 million more people with disabilities would be counted as poor (Morris, McGarity, Goodman, & Zaidi, 2022).

For BLV people, common disability-related expenses include purchasing assistive technologies, food and medical care for a guide dog, copays and coinsurance for eye care, and costs of rideshare service or grocery delivery. A sizable number of BLV people in the United States, moreover, have additional disabilities. For example, in the 2022 ACS, an estimated 2.5 million people have both vision and hearing disabilities, while 3.6 million people have both vision and ambulatory disabilities (AFB Facts, 2024). People with multiple disabilities are likely to experience both more severe employment barriers and more disability-related expenses (Savin, Morris, Wise, & Marinoff, 2024).

## The inadequacy of existing benefits and services

Legally blind Americans (those with visual acuity less than 20/200 even with prescription eyewear or a visual field less than 20% in the better eye) are eligible for several public benefit programs including Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). But these programs, which also provide eligibility to public health insurance (Medicaid benefits for SSI and Medicare benefits for SSDI beneficiaries after a 12-month waiting period), fall short of ensuring an adequate standard of living (Morris, 2023). Many of the supports and services that BLV people receive do not cover all the goods and services that are needed. For example, Medicaid and Medicare do not pay for assistive technology like screen-reading software or braille displays. Veterinary care for a guide dog is not always covered by guide dog schools, and extra costs of driver services or grocery delivery are typically paid out of pocket.

While BLV people receiving SSDI or SSI benefits can deduct disability-related work expenses, the strict asset and earnings limits required to maintain benefits eligibility still restrict income and earning potential (Bell & Silverman, 2018; McDonnall et al., 2022). The need to “self-accommodate” (Savin et al., 2024) by purchasing needed assistive technologies out-of-pocket to avoid the risk of employment discrimination represents a further employment-related barrier. And for BLV people who are unable to afford their needed disability-related goods and services, they are likely to rely on unpaid sources of support and care from friends and family members (for transportation and print-reading tasks, for instance), which itself imposes indirect financial costs in the form of foregone household earnings.

## Financial pressures from the disability squeeze

The disability squeeze consists of two core financial pressures, both of which relate to the need for disability-related goods and services. The first is the pressure to purchase one’s needed

disability-related goods and services out-of-pocket. These extra costs of living reduce the amount of disposable income that is available to afford other basic needs and makes it more difficult for BLV people to make financial ends meet.

The second financial pressure stems from the needs left unmet when BLV people cannot afford to purchase their needed goods and services. Going without assistive technologies, for example, can make all forms of participation in daily life more difficult, particularly to engage in paid work. This creates opportunity costs both in terms of foregone earnings for the BLV person and potentially also for a family member providing unpaid care to them. In combination, the pressures of living with out-of-pocket costs and unmet needs create the disability squeeze — a challenging financial environment for disabled people that yields inequitable financial outcomes.

## Methods

In this brief, we present novel estimates of the disability squeeze for BLV people in the U.S. from the Survey of Disability-Related Goods and Services. The survey was developed and validated in collaboration with an expert panel of disabled people to estimate the use of and need for various disability-related goods and services. The survey included 81 specific disability-related goods and services within 10 domains of need. The full survey codebook with all questions can be found in [the full survey codebook](#). The survey was fielded in June of 2023 to panelists with disabilities in the Understanding America Study, a nationally representative online survey with ~13,000 respondents. The final cleaned data set consists of detailed information from 1,731 people with disabilities including 288 BLV panelists. BLV panelists are identified based on whether they (a) self-identify as someone with a vision-disability and/or (b) responded that they have a lot of difficulty seeing or cannot see at all, even if wearing glasses.

## Findings

### Characteristics of survey respondents

Among the 288 BLV people included in the survey:

- The average age was 53 years old (ages range from 18-88).
- 52% identified as female.
- 41% reported being married.
- 15% identified as Latino/a/x, 22% identified as Black, 74% identified as White.
- 37% reported employment in paid work.
- 22% reported receiving SSDI and/or SSI benefits.
- 48% reported household income less than \$30,000 annually.
- 24% reported living in urban areas, 31% suburban areas, and 30% rural areas.
- 43% reported multiple impairments in addition to blindness and low vision.

## Out-of-pocket costs

Survey respondents were asked about the disability-related goods and services that they use and how much they spend out-of-pocket on these goods and services annually. The key findings include that:

- **More than 2/3 of BLV people reported out-of-pocket costs.** 80% of BLV people reported out-of-pocket disability-related expenses. The average annual out-of-pocket expenses in June of 2023 were \$6,743 but the median amount was \$240 suggesting wide variation in costs.
- **Disability-related expenses jeopardize household finances.** BLV people reported spending, on average, 27% of their household income on disability-related costs. 39% of BLV people reported that their disability-related costs make it difficult to make ends meet, 33% reported that their costs make them feel anxious, 25% reported going into debt due to their costs, and 25% reported cutting the amount spent on food due to disability-related expenses.
- **Poorer BLV people pay a larger financial toll.** Those earning less than \$25,000 per year reported spending, on average, 40% of their income on disability-related costs compared to 16% among those who earn more.
- **Healthcare related goods were the most reported out-of-pocket expense.** 64% of BLV people reported out-of-pocket spending on health-related goods, including for prescription drugs, vitamins and supplements, and over the counter medications. Other commonly reported costs were for additional general goods and services because of a disability (38% reported), and for mobility-related goods and services (17% reported).
- **Many BLV people spend more on general goods and services because of their disability.** 23% reported spending more on transportation costs, such as a taxi or ride share because of their disability; 22% reported spending more on food costs, such as prepared foods and delivery services; and 12% reported spending more on housing or rent costs than they would have spent if they had no disability.

## Unmet needs for disability-related goods and services

Survey respondents were also asked if there were any disability-related goods and services that they needed but could not afford or access. The questions were designed to identify the extent of unmet needs for disability-related goods and services and their likely costs. The key findings concerning BLV people include that:

- **A majority of BLV people reported at least one unmet need (68%).** Unmet needs for healthcare-related services were the most reported unmet need. 35% of BLV people reported an unmet need for health-related services, 30% for health-related goods, and 26% for additional general goods and services.
- **BLV people with multiple disabilities reported more unmet needs.** 84% of BLV people with multiple disabilities reported unmet needs versus 55% for those without multiple disabilities.

- **Those with lower incomes reported fewer expenses but more unmet needs.** Among those with less than \$25,000 in income, 78% reported unmet needs with average disability expenses of \$4,195. Among those with >\$25,000 in income, 59% reported unmet needs with average disability expenses of \$8,750.
- **BLV people out of work reported more unmet needs.** Among the 63% of BLV respondents not in paid work, 75% reported an unmet need versus 57% for BLV people in paid work.
- **Medicare and Medicaid beneficiaries reported more unmet needs.** 73% of BLV people with Medicaid and 77% with Medicare reported unmet needs, while 52% of BLV people with private health insurance reported unmet needs.
- **Disability benefits recipients reported more unmet needs.** People receiving SSI (84% reported unmet needs) and/or SSDI (73% reported unmet needs) reported higher unmet needs compared to those not receiving SSI and/or SSDI (66% reported unmet needs).

## Discussion

This research found that a wide majority of BLV people in the United States incur out-of-pocket expenses on needed disability-related goods and services. These costs weigh heavily on household financial security making it more difficult for BLV people to make ends meet and afford their other basic needs like food and housing. The research further points to a relationship between income, out-of-pocket costs, and unmet needs for disability-related goods and services. Those with lower household income reported fewer out-of-pocket costs but greater unmet needs. Those receiving public health insurance and disability benefits also reported higher rates of unmet needs. These findings point to the inadequacy of public supports to ensure that people with disabilities can access all that they need to fully participate and thrive in their communities. BLV people who were not in work, which includes those receiving disability benefits and others, also reported higher rates of unmet needs. These unmet needs are likely a major barrier to work.

Prior to examining the policy implications of these findings, it is important to note some limitations. A first limitation concerns the relatively small sample size of BLV people. A second concerns the self-reported nature of their expenses and unmet needs. A third concerns the lack of information on the nature of insurance coverage and the extent to which it helped BLV people afford needed goods and services. In future work, we hope to survey a larger sample of BLV people about their costs and unmet needs and investigate pertinent insurance coverage gaps. We also hope to conduct a follow-up wave of the survey to examine how costs and unmet needs change over time and examine how these changes impact employment and health outcomes.

## Policy Implications of the Disability Squeeze

1. **The federal poverty rate is likely underestimated:** The fact that more than two-thirds of respondents, including 57% of those employed in paid work, reported having unmet needs strongly suggests that BLV people (and people with disabilities generally) need additional income to maintain the same standard of living compared to people without

disabilities. This data suggests that additional poverty measures that distinguish between people with and without disabilities would more appropriately account for the extent to which people with disabilities live in poverty.

2. **The disability squeeze contributes to financial insecurity:** Existing federal income benefits like the SSI, SSDI, and Social Security Retirement programs are modest. When considering that on average, BLV people reported spending 27% of their income on disability-related costs, these programs are not sufficient to offer reliable financial security to people with disabilities. Social security is highly effective at raising people out of poverty, but the United States lags behind other wealthy countries in ensuring that all people have access to sufficient income to meet basic needs across their lifespan. Given that the median out-of-pocket cost for BLV respondents (not counting other unmet needs) is about \$240, even moderate annual increases in social security benefits would make federal financial security programs more equitable for people with disabilities. Moreover, although certain federal rules do recognize the disability squeeze for BLV people, these work incentive rules and higher standard tax deductions generally apply to people who already have some earned income from employment. Thus, their impact is positive but limited.
3. **Directly providing disability-related goods and services would reduce the disability squeeze:** In addition to increasing cash benefits that provide individuals with the flexibility to meet their own individualized needs, there are numerous proposals that would directly provide certain disability-related goods and services to people who are blind, have low-vision, or are deafblind.
  - a. Fully fund programs at the state and federal levels (including the Assistive Technology Act Programs) that allow people with disabilities to obtain and maintain possession of assistive technologies.
  - b. Pass the Access Technology Affordability Act to establish a refundable tax credit for blind Americans to offset the cost of access technology. Access technology includes computer-based solutions like braille note takers, screen reading software, and screen magnification software.
  - c. Pass the Communications, Video, and Technology Accessibility Act that would, among other provisions, increase the number of DeafBlind people with access to the National Deafblind Equipment Distribution Program, which provides accessible communications technologies to DeafBlind people who face some of the most significant communication barriers.
  - d. Add comprehensive vision, dental, and hearing insurance coverage to original Medicare and Medicaid. Many people with disabilities, especially those living in poverty, do not have access to comprehensive preventative care or medical treatment for vision, dental, and hearing issues. Instead, they must pay out of pocket or receive a patchwork of treatments that tend to result in poorer health outcomes.

- e. Invest in Older Individuals who are Blind Independent Living Programs and fully fund the Individuals with Disabilities Education Act (IDEA) to ensure that people who are blind or have low vision receive the services needed to complete their education, begin a career, and live independently as older adults. These services may include learning braille, using assistive technology efficiently, and receiving orientation and mobility training.
  - f. Equalize the cost of paratransit and transit services. Paratransit services provide ADA complementary services to people with disabilities who do not have the same degree of access to fixed route transit as people without disabilities. However, the ADA regulations allow transit providers to charge up to twice the comparable fixed-route fare to paratransit riders. This practice of passing the costs of providing accessible service on to people with disabilities places additional financial burdens on people who are already facing the disability squeeze.
  - g. Invest in reliable and affordable public transit, paratransit, and true on-demand transit. People who are blind or have low vision are disproportionately nondrivers. Yet, most communities in the United States require people to be able to drive a private vehicle to travel throughout communities safely, easily, comfortably, and on their own schedule. Greater investments in transit services, accessible public rights of way (e.g. sidewalks and street crossings), and other nondriver services and infrastructure are necessary to increase opportunities and lower costs for nondrivers – who by some estimates make up nearly one-third of the US population when accounting for people with disabilities, children younger than 16, and people who cannot afford to own a car.
  - h. Invest in developing more transit connected, affordable housing in communities throughout the United States in large urban cities as well as smaller rural communities. In addition, particular attention should be paid to developing fully accessible units with built-in accessibility features that remove the burden of making accessibility alterations from the resident.
4. **Barriers to employment are both created by and contribute to unmet disability needs:** BLV people who were not employed in paid work reported greater unmet needs than people in paid work. Some unmet needs, such as reliable transportation access, may prevent individuals from maintaining consistent employment while not having access to reliable employment income reduces their ability to meet these needs on their own. Increasing support for unemployed individuals would help a greater number of people meet basic disability-related needs. However, the Social Security Disability Insurance rules also discourage some individuals from seeking employment advancement. SSDI forces many people who are blind or have low vision to contend with a “cash cliff” that discourages seeking promotions or greater pay. This “cash cliff” occurs when recipients reach a certain income threshold in their paid employment. Passing that threshold results in an immediate end to their social security benefits, leaving many people with less money even though they receive more employment income. Ending the “cash cliff”

would help people confidently work towards better paying employment while retaining the social security benefits that help them cover disability-related goods and services that other workers at the same pay level do not face.

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## Additional Resources

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