

“It’s Not a Luxury, it’s a Need:” Exploring the Extra Costs of Vision Loss

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Abstract

This study employed qualitative methods to explore the nature of the disability related expenses experienced among adults with vision loss in the United States. Existing quantitative data suggests that adults with disabilities, including vision loss, must earn approximately 45% more than their non-disabled counterparts to achieve the same standard of living. The in-depth interviews and focus groups with fifteen visually impaired adults in the New York metro area were conducted to deepen the current understanding of the costs of disability. A thematic analysis approach was used to analyze the resulting qualitative data.

The research is driven by a social and relational model of disability that seeks to involve disabled people in disability poverty research as well as to identify costs that are intrinsic to impairments as well as brought on by environmental barriers. Semantic and latent coding processes in the data analysis explored themes in visually impaired adults' costs of disability as well as the underlying meaning they make of their economic situations. To date, no prior research study could be identified that has explored the extra expenses experienced by adults with vision loss, as opposed to disability more broadly, in the U.S.

Findings included three primary themes: the areas in which extra costs were incurred; resources for and challenges of meeting the extra costs; and the extra-financial effects of the extra costs with a focus on employment issues. Implications of this research prompt a reconsideration of benefit generosity and consideration of support for health care costs. Barriers to accessing employment, particularly as they relate to adaptive technology, present opportunities for Social Security Administration policy intervention.

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Background

Public policy has long recognized the unique needs of blind people (or people with visual impairments) to have a social safety net in the context of a labor market that typically excludes them. Impacted by the personal testimony of members of the National Federation for the Blind on their ordeals facing discrimination in employment, congressional representatives decided that Blind people were as “needy” as the elderly and included “Aid to the Blind” in the original Social Security Act of 1935 (Berkowitz & DeWitt, 2013). Arguing that blind people required government assistance, Federation president stated that “the handicap of blindness... makes it a practical impossibility for even an employable blind person... to secure employment,” (in Berkowitz & DeWitt, 2013, p. 4) Thus, the Social Security Administration (SSA) created the first disability-based categorical assistance, originally called “Aid to the Blind,” in recognition of the barriers this population faced in participating in the labor market and therefore high incidence of poverty (Kresmer, 2016).

To this day, people with visual impairments, like their otherwise disabled counterparts, are disproportionately represented in poverty and extreme poverty rates, despite the long-standing safety net programs (Batavia & Beaulaurier, 2001; Buettgen et al., 2012; Stapleton et al., 2006; Yeo & Moore, 2003). From an intersectional perspective, the prevalence and degree of poverty increase dramatically taking race and gender into account, with Black women facing the most severe circumstances (Shavers, 2007; Williams et al., 2010). There are multiple aspects to take into consideration in understanding the cause of persistent poverty in this population including sources of income, social services, social inclusion and social welfare support. An additional and understudied factor contributing to poverty and impacting the policies of the aforementioned contributors is the added cost of living with a disability (Mitra et al., 2017; Zaidi & Burchardt, 2005).

Increasing attention to disability and poverty on the global scale has prompted further research on the role of extra costs associated with disability in the persistence of this worldwide problem (Mitra et al., 2017). New Zealand, Australia, and 31 European countries have been studied for national estimates of the cost of disability (Antón et al., 2016; Morris & Zaidi, 2020; Zaidi & Burchardt, 2005). Unsurprisingly, the degree of added cost brought on to individuals by disability differs across countries, in large part because of differing social welfare policies that alter what may be an out-of-pocket expense. Rather than the earnings loss associated with disabled people as a result of un- or under-employment, discrimination in hiring, or discrimination in wages, this economic burden of extra costs of disability has been referred to as the ‘conversion handicap,’ (Sen, 1999). According to Sen’s (1999) concept of distributive justice as a goal of the welfare state, the acquisition of material goods does not in and of itself constitute success of a welfare program. Instead, he argues that the *standard of living*, or conditions and capabilities under which someone lives, is the more important measurement. Thus, in countries examining the role of extra costs for disabled people in poverty, the SOL is increasingly the measure used.

Disabled people, including those with vision loss, experience additional essential costs of living that their non-disabled counterparts do not (Ke, 2010; Mitra et al., 2017; Zaidi & Burchardt, 2005). Prior research suggests that public support programs do not do enough to

account for the extra costs associated with a disability (Braithwaite & Mont, 2009; Ke, 2010; Loyalka et al., 2014; Morciano et al., 2015; Morris & Zaidi, 2020; She & Livermore, 2007; Wilkinson-Meyers et al., 2014). Most previous studies on this topic explore the societal costs of vision loss but typically do not investigate the economic effects borne by the individual with low vision (Köberlein et al., 2013). For example, cost of illness studies usually measure the direct and indirect costs associated with treating a given condition (Hodgson & Meiners, 1982). Direct costs refer to the goods and services used in treatment of the illness, while indirect costs represent the amount of lost economic activity that occurred due to the illness. Smith and Waycaster (2009) estimate, for example, that the total direct and indirect cost of treating patients with bacterial conjunctivitis in the United States was \$589 million in 2005.

The SSA has continued to provide specialized programs and policy adjustments for categorically blind people who receive SSI/SSDI since its initial categorical distinction in 1935. Today, blind beneficiaries of SSI are eligible for blind work expenses (BWE) and blind beneficiaries of SSDI receive a twofold higher substantial gainful activity (SGA) amount (SSA, 2019). BWE refer to expenses that beneficiaries incur in order to earn income. Unlike impairment-related work expenses (IRWE), BWE do not have to be impairment or blindness related and can cover any cost of working, such as transportation costs or Social Security taxes (SSA, 2019). These programs are designed to help people with blindness manage some of the extra costs of disability, particularly as they relate to accessing employment.

People with disabilities are likely to incur additional expenses that people without disabilities will not experience (Cullinan et al., 2011). Thus, in order for an individual with a disability to obtain the same basic standard of living as a person without disabilities they will require additional income to account for their disability related expenses. The Standard of Living approach (SOL) provides an estimation of the differences in the costs that a person with a disability would need to obtain the same standard of living as a person without a disability. Further, we know of no previous study that has applied the Standard of Living (SOL) approach to the study of the extra costs of living with vision loss. Further, most of the research so far is quantitative and few qualitative research studies have explored the economic costs of disability (Mitra et al., 2017). No previous study has applied the SOL approach to adults with vision loss.

While the SOL approach has many advantages as described above, it does not elucidate the specific aspects of living or added material possessions needed by disabled communities. This information is critical to consider for a policy response to extra costs as a driver of poverty in disabled communities, since it has the potential to signal needs for adjustments in health insurance, home care, or any combination of systems of welfare and healthcare. Wilkinson-Meyers et al. (2014) used a community-based, mixed-methods approach to understanding extra costs with her research team in Auckland, New Zealand. She notes an additional important distinction in understanding the extra costs of disability that require a brief detour to disability studies (Dirth & Branscombe, 2017).

During the global disability rights movement of the 1970s, activists and scholars coined the “social model of disability” (Oliver, 2013). In contrast to the “medical model of disability” which locates disability in an individual’s biomedical makeup and perceives it as a flaw that requires fixing or at least managing, the social model of disability uses an ecosystemic perspective that examines the interplay of people and their architectural and attitudinal environments. The social model views disability as a clash between a person and their environment when an environment is not structured to meet their access needs. The classic example used to explicate this model is the idea of someone in a wheelchair confronted with a

set of stairs. The medical model locates the problem in the individual's biology that prevents them from walking up the stairs while the social model locates the problem in the stairs and the lack of ramp that prevents the individual from rolling upwards. In this model, the condition that results in the individual using a wheelchair is referred to as an impairment (Oliver, 2013).

Returning to Wilkenson-Meyer's (2010) study of extra costs of disability in New Zealand, she recognizes the difference between costs that represent impairments as opposed to disability – or, said alternatively, resources needed versus barriers that could be removed or reduced. This idea was appealing to disabled people who often feel that their lives are hyper-medicalized and that they do not have adequate input on issues that directly impact them (Yeo & Moore, 2003). Thus, in order to have maximum participation by the disabled community to truly understand the nature of extra costs, Wilkenson-Meyer et al. (2010) collaborated with a local disability organization to carry out their research, which involved key informant interviews and focus groups. While the study examined one component of a complex problem of poverty amongst the disabled, it was a successful model that called for replication in other countries to ultimately develop a more systematized means for measuring extra costs. To date, no research study was identified that took on this implication and call for future research in the United States. Thus, the following research design seeks to take what was successful about this model in New Zealand and localize it to a specific population in an urban, East Coast, city in the United States. Specifically, this research addresses the following guiding questions:

- 1) What specific costs and categories of costs are identified by disabled adults with vision loss?
- 2) How do costs related to vision loss interact with employment, public assistance and social insurance programs?

Research Design

Data Source Overview

This project analyzed a qualitative data set collected in the context of a mixed-methods, inter-disciplinary and inter-institutional research study that began in August 2018. The study was reviewed by the Institutional Review Board (IRB) at Stonybrook University with reliance agreements from the IRB's at the University of California, Berkley and the State University of New York (SUNY) School of Optometry. The quantitative portion of the study used data from the Health and Retirement Study (HRS) and the U.S. Financial Health Pulse Survey (Pulse) to estimate the percentage of the amount of income adults with low vision require to achieve the living standards of adults without low vision. The HRS is a nationally representative sample of older adults aged 50 and older in the United States that is sponsored by the National Institute on Aging (NIA U01AG009740). The HRS is widely viewed as the gold standard dataset for understanding health, well-being, and economic status of older adults in the US. It is particularly used for this study since it incorporates social transfers, such as Social Security Income and food stamps, into its income measure. The Pulse was also used to estimate extra costs of vision loss because it contains robust indicators of living standards that were made into a composite measure for this analysis. Findings from this analysis are not part of this research proposal and are forthcoming in a manuscript but are briefly summarized here.

In both the Pulse and HRS data, on average households that include someone with vision loss have less household income and a lower standard of living than households without a member with vision loss. In the Pulse survey, the average household income with adults with vision loss is \$51,342 and the average income for households without adults with vision loss is \$80,723. In the HRS data, the average household income with adults with vision loss is \$42,759 and the average income for households without adults with vision loss is \$88,092. Estimates from the HRS survey showed that adults with vision loss needed 23% more income than their peers without vision loss to maintain their standard of living. These findings suggest that having vision loss incurs extra costs that adults without vision loss do not.

To complement this quantitative portion, a qualitative study was designed to explore the nature of the extra costs adults with vision loss incur. The remainder of this report refers to this qualitative portion of the study. An interdisciplinary and inter-institutional group of researchers carried out interviews and small focus groups with volunteer participants recruited from a major New York City-based university optometry clinic. A study flyer was posted around the building which housed the clinic and on the clinic's website to carry out a purposive recruitment approach. Participants were given the option of calling, emailing, or visiting in-person to inquire about the study. From this process, fifteen people were screened for eligibility and subsequently consented and enrolled into the study. They participated in four individual interviews and six small focus groups which took place in a conference room at the optometry clinic and ranged from 30-80 minutes in length. When possible, participants were organized into small focus groups, since conversation between participants helped them brainstorm and provided an opportunity for people to engage with their fellow clinic patients. However, many participants faced barriers to transportation and had restrictive schedules, so researchers organized individual interviews to accommodate participants who were not available during the focus groups but still wished to participate. Participants were compensated \$10 to cover any costs of transportation and were offered refreshments during the study meetings.

Sample. Fifteen people with vision loss participated in the study in four individual interviews and six small focus groups. Inclusion criteria required participants to meet either visual acuity or visual field benchmarks for low vision (which was assessed by an optometrist in the study) and to be between the ages of 18-65, working-age adults.

Participants' visual acuity varied from low vision (20/70-20/200) to blindness (worse than 20/400). Of note, vision categories used in this study adhere to World Health Organization guidelines. Participants in categories "low vision 2" and "blindness" meet the definition of blindness per SSA guidelines (SSA, 2019). Participants relied on multiple forms of income including eleven participants receiving SSI or SSDI, two participants employed full-time, and three participants supplementing their benefits with part-time, informal, employment or spousal or familial support. Participants varied in their racial and ethnic identification; degree of educational attainment, and health insurance source. These characteristics and others that may inform participants' broader financial context are reported in Figure 1.

Methods

Analyses relied on audio recordings from the interviews and focus groups described in the previous two sections. Audio-recordings were transcribed through software initially. Due to the automated process, there were many errors in transcription that were cleaned up while

listening to the original recordings. Interviews were imported into the qualitative data analysis software, *Dedoose*, where a thematic approach to qualitative analysis took place.

Data Analysis

I followed Braun & Clarke's (2012) 6-step framework for thematic analysis of qualitative data. The first step, familiarizing oneself with the data, was accomplished in the process of listening to the audio recordings and editing the transcripts to prepare them for analysis. The second step, generating initial codes, took place within *Dedoose*. Both semantic and latent approaches to coding were used in the initial coding. Since the same questions were asked to all participants about different categories of extra costs, some of the data fell neatly into those pre-determined categories, from which a set of semantic, or overt, codes and child (or sub) codes were developed. At the same time, the interpretive lens of the extra costs and disability literature were used for more inductive, covert, coding in order to capture the experiences, subtler meanings, and repercussions that participants expressed as a result of the extra costs. For example, participants often described why they needed a particular vision-related cost even if it might be considered a luxury in a sighted context. Once observed, this concept was discussed among the research team and led to the creation of the code "wants vs needs." Once an initial codebook was created, the third step, searching for themes, commenced. The parent and child code function in *Dedoose* was used to group similar codes together and identify wider organizing concepts for the data.

At this point, the full research team worked together for step four, reviewing potential themes. Other members of the team were not familiar with qualitative analysis but had participated in data collection and thus were well versed in the data. After a brief tutorial on thematic analysis and *Dedoose*, the author presented the initial findings of codes organized by theme to the group for discussion and review. Over a month-long period and multiple meetings, conference calls, and emails, the group process resulted in a revised codebook (see Appendix B) through the identification of new codes, the collapsing of some existing codes, and the renaming and reorganizing of themes. This phase was analogous to the fifth step of Braun & Clarke's framework for thematic analysis, defining and naming. The sixth and final step, producing the report, took place as this report draft was written through reviewing the themes, codes and example quotes alongside relevant literature to present a cogent findings section (Braun & Clarke, 2012).

The full research group's participation in the fourth and fifth steps of analysis served multiple purposes to enhance the rigor of the study's findings. First, it introduced multiple perspectives to the coding process, including a clinical social worker and optometrist who work daily with patients with vision loss. It also served as a peer debriefing for the author, who had to make explicit the initial coding process in order to communicate it to the team. Lastly, it served as analytic triangulation which challenged implicit biases and strengthened the ultimate findings (Barusch et al., 2011).

Findings

Findings from the qualitative data analysis are organized into three overarching themes: (1) the categories of domains in which people incurred extra costs; (2) the environmental resources and challenges that influenced the degree of extra costs; and (3) the extra-financial

effects of extra costs. One of the extra-financial effects relates to employment, which is expounded upon in its own section due to its relevance to SSA's goals. Each theme is presented along with sample quotes from the data.

Theme 1: Extra Costs

Extra costs related to vision loss permeated multiple facets of the lives of participants and impacted how they thought about their overall budgets: *"Spending money has gone two ways - not spending money [in order to save] and then finding now that I need to spend more money than before,"* explained one participant. Participants spent money on glasses and other devices that helped accommodate their low vision such as magnifiers, speech to text technology, smart speakers, adaptive computers or tablets. They frequently encountered barriers accessing public transportation and paratransit services which contributed to their extra costs related to traveling. Many participants had specific lighting requirements, such as needing extra light to see, and found that their costs of light bulbs in the home added up quickly. Purchases to make the home accessible also included large print items, such as clock or timer faces, and mechanisms to enhance safety around household items that could be hazardous due to lack of sight, such as knives. Participants also described aspects of their built environment that contributed to higher costs, such as inaccessible information about sale items at the grocery store and being vulnerable as targets of theft.

One frequently emerging narrative of health and visual care costs captured out-of-pocket care costs other than glasses or magnifying devices (which are captured in a separate thematic analysis). This recurring discussion of "out-of-pocket" costs changed in its frequency based on participants' insurance status. Participants discussed their frustration with the frequent and ever-rising costs of care that they are left with either meeting or going without, such as uncovered medications and co-pays for doctor visits. Refractions, or the tests performed by an optometrist to determine visual acuity which determines a contact lens or glasses prescription, are typically not covered by most insurance plans. This is difficult for people with visual impairments, many of whom go through periods of rapidly changing prescriptions. A few participants brought up the challenge of paying for eyedrops, which are over the counter and generally not covered by insurance:

"I have to constantly put drops in my eyes every hour because my eyes get so dry and it gets foggy and those drops cost \$22. . . and could last you for two days."

This participant went on to state that they rationed their own use of eyedrops due to the prohibitive cost.

A thematic analysis of "glasses and low vision devices" examined glasses, contact lenses, magnifying glasses, and other magnifying tools. These tended to be a combination of doctor-prescribed items, such as prescription glasses, and doctor-recommended items that do not go through insurance, such as magnifying glasses. As in the previous theme, here participants described multiple implements that they require to maximize their vision that are outside of insurance infrastructures and therefore must be purchased at full price. Even for prescription glasses, many of the specificities that participants required to fulfill their prescriptions, such as tinted lenses, were not covered by their insurance plans. This left many participants scrambling between spending money they needed for food and rent and simply going without necessary vision correction:

“I need contact lenses, glasses covering them. . . I need all those things so I can function, but they are limiting me on, you know, what it is I can get with the insurance.”

Participants also noted that insurers paid for new glasses once every year or two years, which meant that they could not always get a new pair when their prescription changed or get a back-up pair for the not infrequent occasion of knocking glasses off their surface and breaking them.

Creating a safe and accessible home environment was another source of extra costs for participants, both to protect them from accidents that might occur due to vision loss and to access visual cues in their home. For example, one participant described protective devices they used to store knives and other sharp objects. Another described their efforts to protect themselves from further injury as their vision loss progressed:

“We are changing furniture because the ones we had before, they had edged corners and I was bumping into them a lot of the time.”

Participants also described normal household objects that they bought with attention to certain features to improve access. For example, one participant stated, *“I have to buy things that have color to stand out.”* While the specificities did not necessarily cost more in and of themselves, the need to make choices about everyday items based on qualities other than cost meant that they often ended up spending more, as one participant described in his search for *“a clock radio with a large display, color contrast.”* An additional cost that arose for participants in their homes was non-standard lighting. Some participants required lower wattage due to photophobia, while others required fluorescent lighting to increase visibility. Whatever their particular need was, this type of cost was described as an unavoidable, extra, expense: *“I put those fluorescent lights in . . . they are very light . . . they are expensive, but I have to do it.”*

The costs of getting around was another emerging narrative. Here, participants referred to modes of transportation as well as navigating within large public spaces such as stores or transit hubs. Participants described frequent frustrations with accessing public transportation, from difficulty knowing their whereabouts on a bus or subway to unintelligible aural cues such as conductor announcements. The free or low-cost transit alternative available to most participants was Access-a-ride, the New York metro area paratransit option for disabled adults, which was infamous for long delays, missed pick-up's, and general logistical difficulty. One participant described the difficulty in remaining functional in daily life through Access-a-ride's delays:

“Access-a-ride does not allow you to have a productive day because of all the hours you spend waiting.”

It was not feasible to use Access-a-ride unless one was willing to limit their activities severely, for example, setting aside an entire day for a single errand. Another participant discussed the difficulties that arose from not being able to “just turn on the car and go if I want to go someplace.” He described scenarios in which neighborhood sidewalks were treacherous and bus routes were absent, leaving no option but to take cab rides for small errands:

“Would you pay a cab for three blocks? I know [blind people] that do. . .”

This resulted in paying (and planning) extra for neighborhood outings or what otherwise might be simple errands. Another participant echoed this difficulty in navigating short distances that are unfamiliar:

“When you have vision loss, you cannot walk or you get lost, so you have to take transportation.”

Participants also described difficulty navigating within buildings. For example, grocery stores that frequently rearranged their offerings presented challenges to people with low vision who might know where to find the items on their list from memory rather than sight. This was of

particular concern with regards to items on sale, that may have been misplaced or misidentified, and then incurred a cost when an individual ended up with a purchase larger than they had planned for or expected. Overall, navigating and traveling was evidently a significant financial burden as well as a strain on time and participation in basic daily activities.

Theme 2: Resources and Challenges Impacting Extra Costs

This theme represented factors that impact or mitigate the costs of vision loss. It included factors that may increase extra costs, such as issues with insurance coverage; factors that may cover extra costs so they are not born solely by the individual, such as family and organizational support; and other factors that may influence the degree of extra costs in either direction such as related health conditions and gaps in social services. Moreover, this theme demonstrated the numerous systems that people with vision loss must interact with to manage their vision-related costs.

Challenges experienced by participants that increased their extra costs of vision loss were primarily in three categories: 1) related to health insurance coverage; 2) related to vision loss and related health conditions; and 3) due to gaps in social services. Health insurance was a frequent topic of discussion for participants who seemed to be well versed in the nuances of their insurance policies and described numerous frustrations with insurer interactions. People who were not dually eligible (i.e. enrolled in both Medicare and Medicaid) experienced the most insurance difficulties. Costs went up for participants whose insurance did not cover refractions, glasses and medical transportation. Participants who were not on Medicaid and faced copays for doctor visits and prescriptions struggled to afford them, particularly when faced with multiple visits for a variety of specialists. Health insurance-related costs such as deductibles and caps increased extra costs for participants. Participants described a lifetime of interactions with health insurers that suggested plans were not prepared to cover the degree of visual health care that they required:

“I remember being five, six years old and my mom happened to shell out two, three, four, five hundred dollars for my glasses. Back in the early 80’s that was pretty significant you know and they were very, very, thick at the time. They had not started with high index lasers or anything yet like they have now. Still ... the biggest thing for me is still paying for glasses because I have to have two pairs. I have my contact lens; I have my glasses over my contact lens ... which I am about to spend another well \$280 on because my insurance is covering my distance glasses without my contact glasses and I think that is like 400 and something dollars.”

Given the high burden of health care costs, it is perhaps not surprising that participants with multiple health conditions experienced additional extra costs. One participant described extra costs as a result of their difficulty in holding a pen in order to write legibly as a result of their neuropathy and arthritis:

“If I want to fill out an application or something like that, I’m like, go ahead and do it for me. . . I pay people to help me do my paperwork if I need paperwork done and all that.”

Another participant described paying extra for a glucose meter with an extra-large face. Moreover, several participants referenced time periods in which their own visual impairments were progressing quickly which required more frequent doctor visits and prescriptions, again leading to additional extra costs. One participant described this process:

“I think the older that you get, the more unexpected progress your vision goes through, so the more things that you need such as more technology or more different medications. . . just the progress of it, like I said, it’s a daily thing.”

Some participants were so impacted by the changes in their vision and the unexpected expenses that resulted that they ended up budgeting for emergency or unexpected health costs. While this is a prudent adaptation to the situation, it also speaks to the significance of the impact of costs of vision loss on people’s budgets and standards of living.

Participants’ discussion of their extra costs frequently broached the social services that they engage with, whether or not they were actually able to receive the services. They evidenced a broad knowledge base of available resources and described what they perceived as helpful as well as gaps in available services that might address extra costs. The most common service organizations referenced in this context were The New York State Commission for the Blind (“The Commission”) and Lighthouse for the Blind and Visually Impaired (“Lighthouse”). One participant described their experience at The Commission:

“I went through The Commission and I was doing, like, a work program. So, they provided all of that [accessible technology]. But once I stopped doing that program, they had to take it back . . . those technologies, for other people needed it. . . in order for, to help on a daily basis, you actually need these things at hand, you know. But they cost a lot, right? I mean, the computer is necessary in order to progress.”

Multiple participants discussed similar experiences with The Commission. They recounted that while the organization had many useful programs, they were only able to access resources under specific conditions which did not always line up with the idiosyncrasies of their lives. Some resources required people to be in school, while others in a job or in an active job search. This requirement left participants frustrated that the same technology that could help them with “every day regular needs where we could be reading books, magazines, and mail” was not available to them to simply manage their lives on disability benefits. For all participants in this study, accessible technology such as screen readers and CCTV (Closed Circuit Television) were prohibitively expensive without a third-party payer such as a non-profit organization or an employer.

Resources that participants employed to meet their costs of daily living and the extra costs associated with vision loss included section 8 vouchers for housing; paratransit services; reduced-fee MetroCard’s, and various work and training programs provided by local organizations. Some services required careful life planning in order to access at the right time, such as the technology example above. Others, such as Access-A-Ride, left participants feeling socially ostracized and at a disadvantage in the workforce:

“The reliability of cheaper transportation is not that great. Access-A-Ride does not allow you to have a productive day, either because of all the hours you spend waiting on your ride and all the hours they take to get you to where you have to go. So, at that point, you do a lot less.”

Thus, while many services people reported using helped mitigate their extra costs, using public services often came with social costs.

Theme 3: Effects of Extra Costs

This theme depicted the impacts of the extra cost of vision loss that extend beyond the purely financial into psychological, social, and occupational realms. These narratives emerged

latently from the interviews, as they were not topics interviewers asked about explicitly. Study participants described how the burdens of tight budgets coupled with the extra costs of vision loss required them to change their daily lives in ways that they otherwise would not. For example, participants thought seriously about the necessity of purchases before making them. The narrative “wants vs needs” emerged from multiple participants describing a constant mental process of analysis, in order to determine if they truly did need an item prior to buying it. This question of wants versus needs took on particular salience as it related to emerging assistive technology which is more and more frequently integrated with technology for the general population:

“The most accurate and blind-friendly phone is an iPhone. . . you can dictate a text and hear the one they are sending you. . . So that is why it does not matter how much they cost. I have one because as I said, you know, it is not a luxury, it is a need.”

Phones were a frequent topic of discussion as it related to negotiating wants versus needs. Many participants used their phones as magnifying glasses, navigation assistants, transcribers, and readers.

This theme also emerged in the focus group context, when participants disagreed over whether a cost related to vision loss was a “luxury” or a “true need.” While the purpose of most assistive technology is to provide equivalent access to sighted people’s environment, participants had different conceptions of the degree to which they might be able to emulate the sighted environment. For those who sought access to the labor market and rapidly accessible information, the newest computer software and CCTV devices were necessary accommodations. For others, that degree of social integration was beyond the reach of practical imagination. One participant, notably, did not describe any extra costs related to assistive devices and had never heard of the examples, such as CCTV, suggested by interviewers. When asked if she ever paid for software or technology to help her see, she simply responded, *“No. I need people to program my phone for me . . . if I want apps or something . . . I don’t, because I do not see them.”* While this participant described serious financial need and recent experiences with homelessness, she reported the fewest extra costs out of all of the participants. Yet, this did not represent a lack of need, exactly, as much as it reflected a lack of access to information and resources as well as very different expectations for her life as a blind person.

At the same time, participants described spending money on services they wished they did not need to, particularly related to assistance from other people or expensive services for help with tasks of daily living. Participants described the limitations they experienced on their spending capacity and therefore standard of living in making ends meet while meeting the demands of their extra costs:

“See, all the new movies are coming out. You want to see them but you pick one movie and it will be the one you really, really want to see and all the rest you will see it when you see it . . . you cannot splurge that much because you have to worry about eyeglasses or medicine or whatever else. Okay, so, it’s kind of hard.”

Here, this participant is aware that they have costs related to vision loss that impacts their spending in other domains. In some cases, “splurges” were restricted, while in others, assistive devices or healthier food were deprioritized in order to make ends meet.

Employment Access Issues. One of the primary non-financial effects of extra costs on participants was access to employment. In particular, perceptions and experiences of ableism with the extra costs associated with accommodations for vision loss, created a number of issues

that fell between the cracks of current disability rights law. Participants who were employed or had previously been employed discussed extra costs related to maintaining employment given their vision loss.

Several participants suggested that getting assistive and adaptive technology at the time of employment was too late. One participant expressed his need for time dedicated to practicing and sharpening his computer skills before he felt ready to enter the job market. Yet, he could not afford the hundreds – thousands of dollars necessary for an accessible computer with the requisite adaptive software. Existing programs that might provide this access required him to be actively applying for jobs or already holding a job. Similarly, participants described fears that they would not be employed or would struggle to stay employed if they asked their employer for expensive assistive technology:

“ . . . I know that if I am seeking a job, I know it is going to be hard for someone to hire me and then to invest money on me right away. One of my keys is to get those devices even if I can work from home or take it to the place that I’m going to work. I have it in mind because I know it’s going to be hard - it’s a huge amount of money for someone to hire.”

Another participant vocalized understanding of their rights under the Americans with Disabilities Act (ADA) as well as their understanding that there were ways for employers to get around the law:

“Of course, they can’t legally say, well we are going to let you go because you require us to do too much . . . there are other ways they could get rid of you or make your life a living hell.”

Fears about employer discrimination came up from participants throughout the employment process:

“When I go in on job interviews, it’s kinda hard because not everyone knows you’re visually impaired and you cannot see the application to fill it out.”

One participant referenced their weariness from years of overworking in an attempt to combat what they perceived as their employer’s distrust of their competence:

“I am working longer and harder to get projects done to prove myself. . . We are limited as to . . . what people think we can do . . . once you disclose your visual impairment, they’re not going to give you another opportunity.”

As a result of all of these employment-related fears, participants expressed a perception of job scarcity. They described feeling the need to stay in jobs that “make them miserable” because of fear that they are generally undesirable hires and they might lose, or had lost, their only opportunity at employment. There were a few ways in which accommodations enshrined under the ADA were not adequate to cover these costs. One participant who worked as an accommodation’s consultant for other working people with disabilities, described the issues and financial repercussions of a blind social worker. As a social worker who conducts home visits, she requires frequent, reliable *and* accessible transportation.

“She ends up paying a tremendous amount of money to be able to do her job effectively, by taking a car service. . . and so although she is making good money, when you break her travel expenses down, I think she is probably coming home with minimum wage. . . They do have Access-A-Ride for those people that do not travel well but Access-A-Ride is a system that really needs to be fixed. You know, people . . . spend more of their hard-earned money to take a cab versus Access-A-Ride because jobs are not always very understanding.”

While many participants discussed their previous work life with nostalgia and others expressed their desire for work, only two participants were fully employed. The experiences that the two employed participants recounted suggested that their work lives were filled with fights for access and fears of employer discrimination, both of which indirectly incurred extra costs.

Discussion

Study Limitations

The study sample was recruited from the New York City metro area through a university-affiliated optometry clinic. Thus, participants live in a region of the U.S. with a relatively large and wide access to social services, public transportation, cutting-edge optometry care and technology. This may have provided more access to information about assistive and adaptive devices that result in extra costs. In addition, they likely had access to more public resources than counterparts in more rural areas with fewer social services serving them.

Additionally, the study sample size was fifteen participants. While this sample allowed for the development of several strong themes related to the extra costs of low vision, a larger sample size would add rigor to these findings and allow for a more nuanced understanding of how extra costs may vary among subpopulations. Moreover, no one in the sample was on an SSA work-incentive program at the time of their interview, which would be beneficial in future studies to explore how BWE and higher SGA levels might mitigate extra costs.

Study Implications

The findings from this study depicted a scenario in which visually impaired people must continually adapt to their sighted and often inaccessible environment. Each additional aspect of life, whether an extra appointment to fit in the day or an added health complication, incurred an extra cost in order to be managed while self-accommodating. The extra costs appeared to be most pronounced and profound in the area of health and disability accommodations. There are a number of policy implications related to the effects of these costs on overall well-being, standard of living, and access to employment.

Consistent with Wilkenson-Meyer's (2010) study of extra costs of disability in New Zealand, study findings showed that extra costs reflected needs due to physical impairments as well as environmental barriers. Some costs, such as medical care, magnifiers, and glasses, were necessary due to participants' visual impairments. Other costs were necessary to work around environmental barriers, such as inaccessible signage at grocery stores or on public transit. Employment costs, too, reflected environmental and attitudinal barriers to work for visually impaired adults. This distinction is important since impairment-based costs versus disability-based costs may require different financial and policy responses (here, impairment and disability are defined as in the social model of disability (Oliver, 2013).) While not all barriers can be removed with money, such as employment discrimination, other barriers, such as inaccessible transit options, may be mitigated with additional resources.

One policy implication of this study is the reconsideration of income guidelines that inform SSA benefit amounts as well as eligibility for means-tested services more broadly. Quantitative research that precedes this study suggests that people with disabilities must spend more money to the same standard of living (e.g. Mitra et al., 2017; Morris & Zaidi, 2020). As

this study explores the nature of these expenses, particularly how many of them are necessary for basic health maintenance, it is reasonable to consider whether cost of living estimates encoded in social policy and programs ought to be higher for the disabled population. The participant in the study who was an outlier and did not spend money on assistive devices or technology described in the findings section prompts philosophical inquiry into the concept of necessity and how it might differ for those who do not have access to large swaths of society. If accommodations were more widespread, and braille, text-to-speech, and transcription were widely available, people would not require personal and costly devices to access public spaces and resources. Yet, given that they do, providing additional funding through another form of public funds to gain this access might increase equity in access to everything from knowing which food is on sale at the grocery store to being able to navigate the streets of one's neighborhood. This implication implicitly questions whether the goal of income replacement is to meet basic survival needs or to meet a certain social standard that might permit equity in education, occupation, and social opportunity.

Visual impairments are a useful example of the type of disabling impairment that Stapleton & Livermore (2011) reference in their issue brief on government expenditures on working-age people with disabilities. In the six years they analyzed, 2002-2008, the combined federal and state government expenditures on working-age people with disabilities increased by \$149 million. In those six years, health care costs grew by 34% and were responsible for 55% of the total government expenditures on the same group of working-age people with disabilities. Moreover, the brief highlights the fact that "advances in technology and medicine make it possible for many individuals with significant impairments to work" and that many of these individuals, particularly younger adults, prefer employment to disability benefits (Stapleton & Livermore, 2011, p. 3). Yet, these advances in medicine and health-related technology often fall into the categories of extra costs related to healthcare that participants noted as being unlikely to be covered by health insurance and prohibitively expensive. Thus, more extensive health coverage that is available to disability beneficiaries whether or not they are working is likely to improve overall health and therefore return to work capacity.

The technology for assistive visual devices is rapidly progressing and could theoretically allow for easier integration into the labor market and other aspects of society. Findings suggest that home access to visual devices before the job application period might be beneficial to begin incorporating their use into daily life and to sharpen skills in preparation for the job market, even if one cannot access an in-person job preparation program. One participant suggested that a no-interest technology loan or grant might benefit people with low vision who find themselves seeking job placement in the future. Funds would need to allot upwards of two thousand dollars per capita to account for the expensive software and hardware that adapts to people with low vision. This type of access could help people acculturate to a fast-moving world with quickly accessible information that otherwise may feel out of reach.

Participants described two different spheres of existence in their worlds and in the sighted world that holds access to the labor market. Most saliently, the sighted world operates more quickly than most participants are able to without significant expense. In discussing luxuries and necessities, participants would often pause over what they considered technical luxuries that provided them access into mainstream society. Access-A-Ride was too slow to use for work or a day with more than one appointment, thus paying for a cab or car service might be necessary to hold down a job or even search for an apartment. Food preparation without assistance was challenging for many participants, thus ordering takeout was often more feasible and less

disruptive in participants' lives. There are social services that could provide a volunteer who might read one's mail aloud, yet if urgent reply was required and the service was not available for a couple of weeks, participants often paid people to do the work for them. In this way, the cost of conveniences straddled a complex line between necessity and luxury. Some people, such as the outlier in this study, could exist outside of the mainstream economy through the use of homeless shelters and section 8, Access-A-Ride, and free magnifiers from the optometry clinic. Yet, in this sphere of existence, survival remained the primary focus and this participant did not consider returning to work an option even worth considering.

SSA Policy Implications

Implications for SSA policy relate to benefit amounts, healthcare costs, and return to work strategies. While SSA provides higher benefit amounts for its blind beneficiaries, findings from this study suggest that many people still struggle to pay for necessities. This suggests that benefit amounts may not be adequately addressing the costs of vision loss, or disability more broadly. Further studies among other groups of people with particular types of disability would help determine whether these extra costs are unique to vision loss and what other types of disabilities incur extra costs. Extra costs were particularly striking in the realm of health care. SSA policy might address this issue either through advocacy within the Centers for Medicare and Medicaid Services (CMS) by encouraging coverage of common medical necessities such as refractions and prescription eye drops. Alternatively, SSA might provide beneficiaries with an annual fund, akin to a Flexible Spending Account (FSA) on an employer-sponsored health plan, that can be used on allowable medical expenses. Beneficiaries would not be entitled to any remaining funds at the end of each fiscal year. These would mitigate the impact of healthcare costs on poverty, particularly as the inflation rate for healthcare is higher than the rest of the US economy, and therefore is not addressed through the SSA annual cost of living adjustment.

Lastly, which access to adaptive technology in order to access the labor market was a significant concern among the study's findings. In particular, having access to technology prior to interviewing or obtaining a job is a need not addressed by current ADA laws and BWE policy. The SSA should consider facilitating access to this technology either through government-industry partnerships that could lower costs for beneficiaries or through the provision of technology grants.

Conclusion

The cost of fitting in to expectations of expediency is a component of labor market entry that emerged in the context of discussion with blind and visually impaired people, both disability beneficiaries and formal workers. This study reinforces the importance of talking to the people who are closest to the (social) problem in order to identify possible solutions. Qualitative research among people with a variety of disabilities is an important contribution to the disability, rehabilitation, and work literature. Further research with individuals who are actively participating in work-incentive programs is implicated in order to gain further understanding on their gaps, particularly regarding assistive devices. In addition, intervention studies that can provide assistive devices and technology to people before they attempt to re-enter the labor market and follow their progress and challenges in the reentry may provide further insight into this process.

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Appendix A: Figure 1: Participant Characteristics

FIGURE 1: TABLE OF PARTICIPANT CHARACTERISTICS		
PARTICIPANT CHARACTERISTICS		# PARTICIPANTS (N=15)
AGE		
	18-26	0
	27-36	3
	37-46	4
	47-56	5
	57-65	3
GENDER		
	F	5
	M	10
RACE / ETHNICITY		
	Black	7
	Hispanic/Latinx	3
	Multi-racial	1
	White	1
	Did not state	3
INCOME SOURCE		
	SSI or SSDI	11
	Full-time employment	2
	Part-time & informal employment	2
	Family support	3
EDUCATIONAL ATTAINMENT		
	Some High School	2
	High School / Equivalent	5
	Associates Degree	3
	Bachelor's Degree	4
	Graduate Degree	1
# CHILDREN		
	Zero	6
	One	5
	Two	2
	Three	1
HOUSING		
	Rents	12
	Owns	2
	Rents via Section 8	1
HEALTH INSURANCE		
	Medi-Medi	5
	HHC (NYC city plan)	0
	ACA Marketplace (subsidized)	1
	Medicaid	5
	Private Insurance	2
VISUAL ACUITY		

	Blindness/ worse than 20/400	2
	Low Vision 1 / 20/70-20/200	3
	Low Vision 2 / 20/200-20/400	9

Appendix B: Figure 2: Final Codebook

Final Codebook		
Theme	Code	Child Code
(1) Extra costs		
A.	Glasses and low vision devices	
		Magnifying devices
		Phone
		Smart speaker devices / Alexa's
		Tablets/Laptops/Computers + software
		Technology fails
		text to voice / voice to text tech
		Glasses
B.	Travel costs	
		Navigating
		Public transportation
C.	Health Care Costs	
		Effects on/of related conditions
		Medications
D.	Food-related costs	
		Kitchen/cooking
E.	Emergencies / unplanned costs	
F.	Home-related costs	
		Items with large faces and/or color contrast
		Lighting
		Safety
G.	Access Issues	
(2) Resources and challenges impacting extra costs		
A.	Insurance challenges	

		Insurance challenges
		Insurance coverage
B.	Resources	
		Kindness of others
		Family Support
		Social services/orgs
		The Commission
		Lighthouse
C.	Strategies for extra costs	
		Going without / cost-prohibitive
		Prioritizing costs
		Programs
D.	Factors influencing extra costs	
		Effects on/of related conditions
		Vision lost trajectory impacts extra costs
		Gaps in services / insufficient services
(3) Effects of extra costs		
A.	Employment Issues	
B.	Impact of costs on standard of living/well-being	
C.	wants vs needs	
D.	Vision lost trajectory impacts extra costs	
E.	Ideas on in-/inter-/de-pendency	