



# **Mixed-methods Study on Work-disabled Adults Who Do Not Apply for Social Security Disability Benefits**

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# Mixed-methods Study on Work-Disabled Adults Who Do Not Apply for Social Security Disability Benefits

## Abstract

Take-up gaps in safety net programs, which have been long documented in the United States and elsewhere, are an important policy question as nontake-up compromises the equity objectives and efficacy of programs. The Social Security Disability program is an example of this: More than 20 million adults report a work disability, but only around 11 million currently receive disability benefits through the Social Security Disability Insurance or Supplemental Security Income programs. This comprehensive mixed-methods study examines the characteristics and decision-making around benefits applications among adults with self-reported work disability who have never applied for disability benefits. Analysis of survey data suggests that the availability of personal and socioeconomic resources, including younger age, educational attainment, spousal support, and income may act as buffers to feeling the need to apply for disability benefits. Greater cognitive resources, in particular quantitative and verbal reasoning skills, were associated with a greater likelihood of not applying. Qualitatively, we find that high transaction costs involved in disability applications coupled with the widespread perception of low approval rates may be a critical deterrent for eligible individuals. Uncertain and lengthy medical processes after disability onset were also frequently reported as a central deterrent. Stigma about receiving disability benefits does not emerge as a factor in application behavior, although a change in self-concept involving an adjustment to benefit-receiving, work-disabled status was cited as a deterrent to claiming. These insights could inform targeted interventions to reduce barriers to take-up of benefits among potentially eligible adults.

## Citation

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## Background

Take-up gaps in social assistance and other government transfers have long been a subject of research in the United States, with incomplete take-up documented in welfare programs such as Supplemental Nutrition Assistance Program (SNAP), Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) and Temporary Assistance for Needy Families (TANF), housing and unemployment benefits (Hernanz et al. 2004), and the Earned Income Tax Credit (Bhargava and Manoli 2015). Racial differences have also been reported, with minorities exhibiting lower take-up of certain public safety net programs (e.g., Kuka and Stuart 2021). This is an important policy issue, as nontake-up compromises the equity objectives and efficacy of programs.

A take-up gap is also present with the Social Security Disability program; more than 20 million adults (10% of the working age population) report a work disability, but only around 11 million currently receive disability benefits through the Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) programs (SSA 2023; SSA n/d; Theis et al. 2018). For SSI alone, the take-up gap has been estimated to have been 50% several decades ago (McGarry 1996) and around 32% almost one decade ago (Ribar 2014). The difference is likely at least partially made up of individuals who may be eligible for disability benefits but do not receive them.<sup>1</sup>

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<sup>1</sup> “Take-up” rates are different from “participation” rates; the former is the ratio between the number of individuals eligible for a particular benefit and those who are receiving it. The latter is the total share of the population that receives a particular benefit or participates in a particular program (Hernanz et al. 2004).

While research has investigated the factors associated with the probability and timing of a disability claim (Li and Maestas 2008; Armour 2018; Foote et al. 2018; Deshpande and Li 2019; Maestas et al. 2014), the extent and determinants of nontake-up of disability benefits remains more obscure. One key challenge has been the measurement and identification of the nonparticipant population (Bruckmeier et al. 2021). Another challenge has been understanding *how* individuals make decisions about whether and when to apply for disability benefits. Existing literature has postulated three main reasons for incomplete take-up of public programs: large transaction costs from a complex application process, stigma, and information and awareness limitations (Kleven and Kopczuc 2011).<sup>2,3</sup> Yet there is still a limited understanding of how this manifests on the ground among the individuals involved, i.e., the ways in which these (and other) barriers operate when eligible and potentially eligible individuals weigh whether or not to apply for benefits.

This study aims to contribute to this field through a comprehensive mixed-methods study to understand: (1) the characteristics of nonapplicants among those with self-reported work disabilities, and (2) decision-making around benefits applications among adults with self-reported work disability who have never applied for disability benefits.

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<sup>2</sup> Rejection errors (i.e., when eligible individuals apply for benefits and are rejected) may also have a significant effect in take-up of SSDI and SSI (Benitez et al. 2004).

<sup>3</sup> Previous research about nontake-up of SSI found that financial transfers from family members (in particular, adult children) (McGarry and Schoeni 2015) and the expectation of a modest amount in benefits (McGarry 1996) may reduce applications amongst SSI-eligible older adults.

## *Approach*

This comprehensive mixed-methods study consists of quantitative analyses of existing survey data and qualitative interviews.

For the quantitative analyses, we examined data from respondents in a nationally-representative internet panel, the Understanding America Study (UAS), who participated in UAS survey 322 (n = 8,188). The UAS differs from convenience (opt-in) panels in that its members are recruited through nation-wide, address-based sampling, which counteracts many biases in population parameters that are estimated from panels where members self-select in (Yeager et al. 2011).

To create a pool of respondents potentially eligible for Social Security disability benefits (either SSDI or SSI), we applied the following selection criteria: UAS panelists must have reported (1) one or more chronic health conditions; (2) work limitations because of health condition(s); (3) current income below ~\$1400 per month; and (4) younger than 65.<sup>4</sup> Respondents who fit these criteria (n = 503) were then categorized into one of two groups: those who had never applied for SSDI/SSI benefits (n = 130, 26%) and those who had applied/were applying for SSDI/SSI benefits (n = 373, 74%). The latter group of respondents consisted of those who either had or had not yet received benefits.

We acknowledge that it is not possible within the scope of this study to confirm respondents' definite eligibility or to identify individuals who would be awarded disability benefits. First, approximating the population of respondents who have chosen not to

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<sup>4</sup> These are not the exact criteria for the SSI and SSDI programs but an approximation of the broad age (for SSDI), employment status, and income requirements.

apply but who would be eligible for benefits is difficult because the medical and work ability eligibility requirements are complex. Second, like many existing studies, our analyses are unable to leverage actual administrative data and are based on survey data (Bargain et al. 2007). Prior research has found that surveys can be prone to measurement error because of misreporting of variables important to estimating eligibility (e.g., income, wealth, and household composition). In addition, respondent misreporting errors have also been found for the receipt of benefits with some respondents over-reporting and others under-reporting the benefits they received (Bargain et al. 2007; Tasseva 2016). Finally, our analyses do not distinguish between SSDI and SSI benefits applications due to sample size limitations and lack of information regarding insurance eligibility for SSDI applications and asset composition for SSI applications.

Nevertheless, our selection criteria allowed us to create a sample of respondents that is *potentially* eligible for SSDI/SSI benefits based on their characteristics, which enables us to conduct exploratory analyses of the characteristics and behaviors of work-disabled adults who do not apply for disability benefits.

For our analysis strategy, we compared the two groups of respondents on demographic characteristics, cognitive abilities, and disability-related perceptions using binary logistic regressions with nontake-up of disability benefits as the outcome. Analyses were conducted in SPSS version 25. To account for the possibility that disability benefits claiming is associated with respondents' age and education (Marino et al. 2021), analyses were first conducted without and then with the inclusion of these two variables as covariates into the model. Given that the focus of this project was to

understand the population of respondents who have never applied for disability benefits, we contrasted them with those respondents who had applied and had either obtained or not (yet) obtained benefits.

For the qualitative component, we conducted 51 in-depth qualitative interviews with individuals recruited from the UAS sample (described above) of work-disabled adults who have not applied for disability benefits. A sample size of 50 and over was deemed reasonable to provide a sufficiently broad range of experiences, viewpoints, and perceptions to capture a large amount of insights about nontake-up of disability benefits among work-disabled adults. A randomly selected group from the sample of nonapplicant work-disabled adults in the UAS were invited via email to participate in the qualitative interviews, conducted by phone and lasting 25 to 50 minutes.

Interviews proceeded in a systematic way where early questions were open-ended and later questions were more specific, to avoid priming respondents with the researchers' hypotheses. They targeted two core areas that might contribute to respondents' decisions to apply, or not apply, for disability benefits: (1) person-level contributors (e.g., ideas about being a benefits recipient, self-esteem and self-efficacy, type of medical condition, perceptions about the magnitude of benefits, limited knowledge or resources to undertake the claiming process, etc.), and (2) system-level contributors (e.g., complex claiming requirements, stigma attached to being a disability recipient, lack of application resources such as SSA offices, etc.).

All interviews were conducted by phone, tape-recorded, and transcribed for later review, coding, and analysis. We used Dedoose qualitative analysis software to support the organization and coding of the raw qualitative data. Following the analytical



approach developed by Thomas (2006) and Braun and Clarke (2006), a coding scheme for the raw data was developed through an inductive and iterative approach, closely reading and rereading transcripts to identify codes for labeling and organizing of the data. Two team members independently coded five (10%) of the transcripts to establish inter-rater reliability (final Cohen's kappa of 0.91), after which all transcripts were coded line-by-line. The resulting output was analyzed to identify themes, subthemes, and processes within the data, and develop an understanding of how these relate to one another.

The University of Southern California's Institutional Review Board provided ethics approval for this study.

## **Quantitative results**

We first examined differences in demographic characteristics between the two groups. Prior research has found that people claiming SSA disability were more likely to be older, have less education and lower income, and were more likely to be Black/African American compared to the working age and general population (Marino et al. 2021; Thomkins et al. 2014). Much less is known about the demographic characteristics of those individuals who choose not to apply for disability benefits and how they may differ from those who choose to apply. The following analyses aimed to address this question.

### *Demographic characteristics*

Table 1 presents an overview of the demographic characteristics of the quantitative sample.

**Table 1: Demographic characteristics of the quantitative sample**

	<b>Total sample (n = 503)</b>	<b>Never applied (n = 130)</b>	<b>Applied/Applying (n = 373)</b>
<b>Age (mean, SD)</b>	53.0 (9.2)	51.2 (10.6)	53.6 (8.6)
<b>Gender, female (%)</b>	69%	71%	68%
<b>Race, white (%)</b>	79%	85%	77%
<b>Ethnicity, Hispanic/Latino (%)</b>	12%	18%	10%
<b>Education</b>			
-Up to college	83%	73%	86%
-Some college/college grad.	12%	17%	10%
-Advanced degree	6%	10%	4%
<b>Income</b>			
-Up to \$49,999	78%	67%	82%
-\$50,000 to \$99,999	17%	25%	14%
-\$100,000 or greater	5%	9%	4%
<b>Marital Status, married (%)</b>	42%	60%	35%
<b>Location, urban (%)</b>	84%	81%	85%

The results showed that the two groups significantly differed on age ( $p < 0.001$ ). Those who had never applied for disability were significantly younger (mean = 51.2, SD = 10.6) compared to those who had applied/were applying (mean = 53.6, SD = 8.6). Controlling for respondent education, this result remained significant.

The two groups also differed significantly on education ( $p < 0.001$ ). Those who had never applied for disability benefits had significantly higher educational attainment compared to respondents who had applied/were applying. Controlling for respondent age, this result remained significant.

Both with and without controlling for respondent age and education, results further showed that respondents who had never applied were also more likely to be married, white, of Hispanic ethnicity, and have higher household income compared to

respondents who had applied/were applying. No significant group differences were found for respondent gender or for respondent location (urban versus rural).

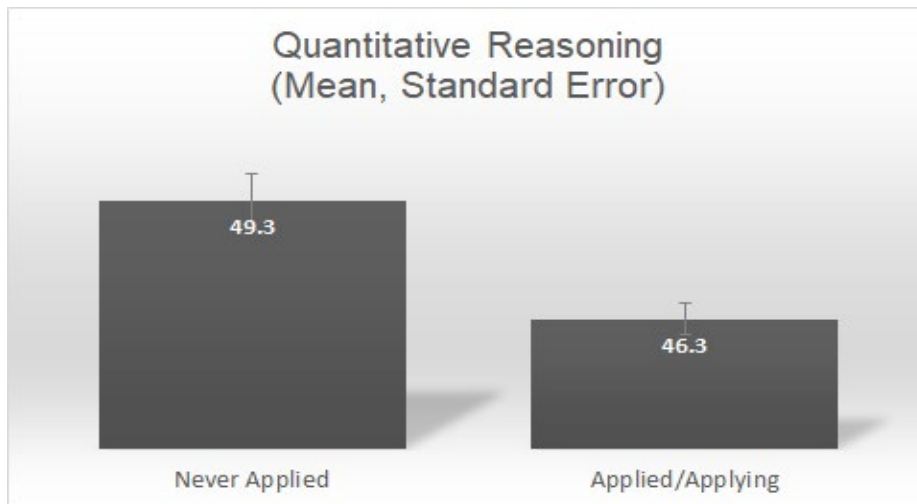
### *Cognitive abilities*

The disability benefits application process is a complex, time-consuming, and cognitively demanding task. It is possible that respondents with lower cognitive abilities may be more likely to shy away from the application process. For instance, prior research on the role of cognition and the take-up of subsidized drug benefits by Medicare beneficiaries has shown that poorer cognition and lower numeracy were associated with lower reported take-up (Kuye et al. 2013; McWilliams et al. 2011). We examined whether respondents' quantitative and verbal reasoning skills and their probability of cognitive impairment were associated with their decision not to apply for SSDI/SSI disability benefits.

The number series task was used to assess quantitative reasoning, a skill that pertains to a respondent's ability to solve mathematical relationships (Mather and Jaffe 2016). Respondents are shown a sequence of numbers with one number missing from the series (e.g., 4, 7, 10, ?).

The results showed that the groups significantly differed on quantitative reasoning skills ( $p < 0.001$ ) (Figure 1). Respondents who had never applied had significantly higher quantitative reasoning skills compared to respondents who had applied/were applying. Controlling for respondent age and education, this result remained significant.

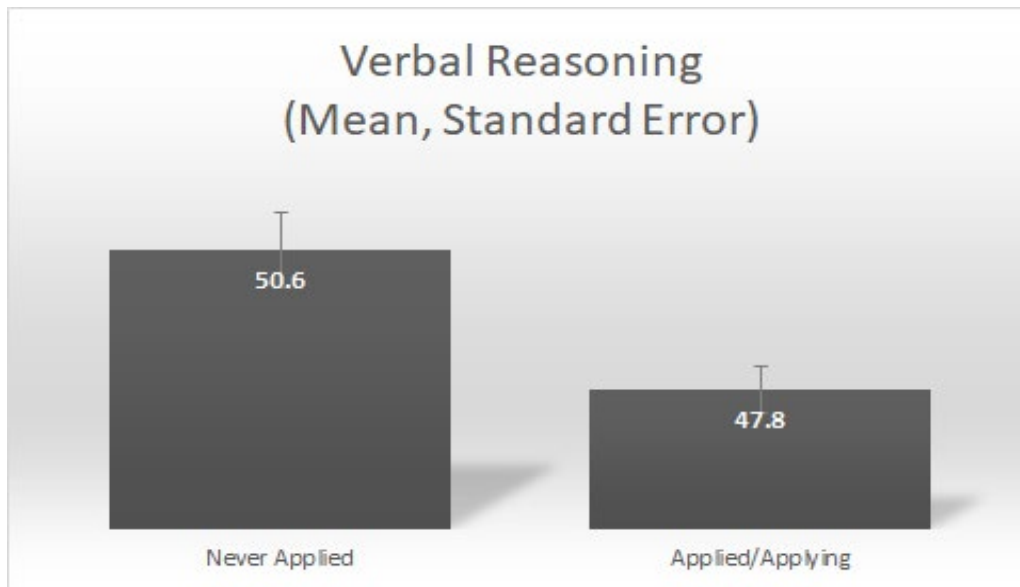
**Figure 1: Quantitative reasoning by respondent disability application status  
(applied versus never applied).**



The verbal analogies task was used to assess verbal reasoning, a skill that pertains to the comprehension of concepts communicated through language (Mather and Jaffe 2016). In this task, respondents were asked to recognize a relationship between two words and translate it to two other words (e.g., “night” is to “dark” as “day” is to ?).

The results showed that the groups significantly differed on verbal reasoning skills ( $p < 0.01$ ) (Figure 2). Respondents who had never applied had significantly higher verbal reasoning skills compared to respondents who had applied/were applying. Controlling for respondent age and education, this result remained significant.

**Figure 2: Verbal reasoning by respondent disability application status  
(applied versus never applied)**



Recently, efforts have been underway by the UAS and Center for Economic and Social Research team to construct a measure to assess a respondent’s probability of cognitive impairment (PCI). This PCI score reflects how probable it is for someone to experience cognitive impairment. It was developed for web administration and corresponds with the Langa–Weir cut point for “CIND or dementia” on telephone scores (Gatz et al. 2023). No significant group differences were found for respondents’ probability of cognitive impairment in our analyses.

Our findings for cognitive abilities suggest that people with greater quantitative and verbal cognitive skills might be less likely to engage in the disability benefits application process because they have more resources to buffer the need to apply.

### *Disability-related perceptions*

Prior research has shown that living with a chronic illness and perceptions of stigmatization often co-occur, and that people can feel they are being viewed as malingering for claiming disability benefits as a result (Whittle et al. 2017; Saffer et al. 2018). In this analysis, we examined whether perceptions of stigma were associated with respondents' decision to apply or not to apply for disability benefits.

The results showed that the groups significantly differed on their perceptions regarding whether there is stigma surrounding disability benefits ( $p < 0.01$ ) (Figure 3). Respondents who had never applied were less likely to perceive stigma surrounding disability benefits compared to respondents who had applied/were applying. This result remained significant once we controlled for respondent age and education.

A possible explanation/implication of this finding is that it is the exposure to the disability benefits application process that evokes perceptions of stigma. Respondents who had this exposure had higher perceptions of stigma compared to those naive to the application process and/or disability benefits more broadly.

**Figure 3: Perceptions of stigma about disability benefits by disability application status (applied versus never applied)**

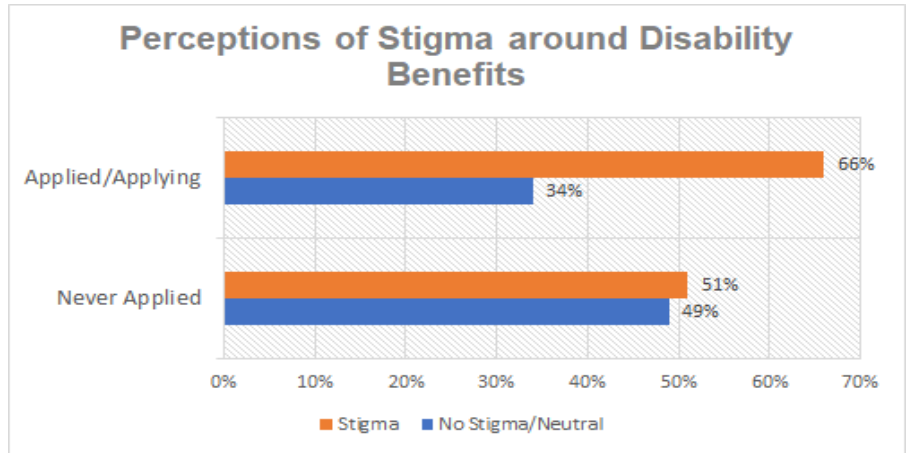


Table 2 presents an overview of the regression results for the demographic, cognitive, and disability-related perceptions analyses.

**Table 2: Logistic regressions predicting nontake-up of disability benefits**

Predictor	Not controlled for age and education		Controlled for age and education	
	b (SE)	OR	b (SE)	OR
<b>Age</b>	0.028 (0.011)**	1.028	0.029 (0.011)**	1.029 <sup>a</sup>
<b>Gender, male</b>	0.114 (0.223)	1.120	0.127 (0.228)	1.135 <sup>c</sup>
<b>Race, white</b>	-0.548 (0.277)*	0.578	-0.581 (.284)*	0.559 <sup>c</sup>
<b>Ethnicity, Hispanic/Latino</b>	-0.699 (0.289)*	0.497	-0.757 (0.297)*	0.469 <sup>c</sup>
<b>Education</b>				
Up to college	--	--	--	--
Some college/ college grad.	-0.698 (0.293)*	0.498	-0.702 (0.296)*	0.496 <sup>b</sup>
Advanced degree	-1.074 (0.397)**	0.341	-1.099 (0.399)**	0.333 <sup>b</sup>
<b>Income</b>				
Up to \$49,999	--	--	--	--
\$50,000-\$99,999	-0.750 (.255)**	0.472	-0.791 (0.265)**	0.454 <sup>c</sup>
\$100,000 or more	-1.013 (0.421)*	0.363	-0.727 (.447)	0.484 <sup>c</sup>
<b>Marital Status, not married</b>	0.871 (0.239)***	2.388	0.886 (0.248)***	2.426 <sup>c</sup>
<b>Location, urban</b>	-0.307 (0.266)	0.736	-0.399 (0.273)	0.671 <sup>c</sup>
<b>Quantitative Reasoning</b>	-0.049 (0.013)***	0.952	-0.039 (0.014)**	0.962 <sup>c</sup>
<b>Verbal Reasoning</b>	-0.039 (0.012)**	0.962	-0.032 (0.013)*	0.969 <sup>c</sup>

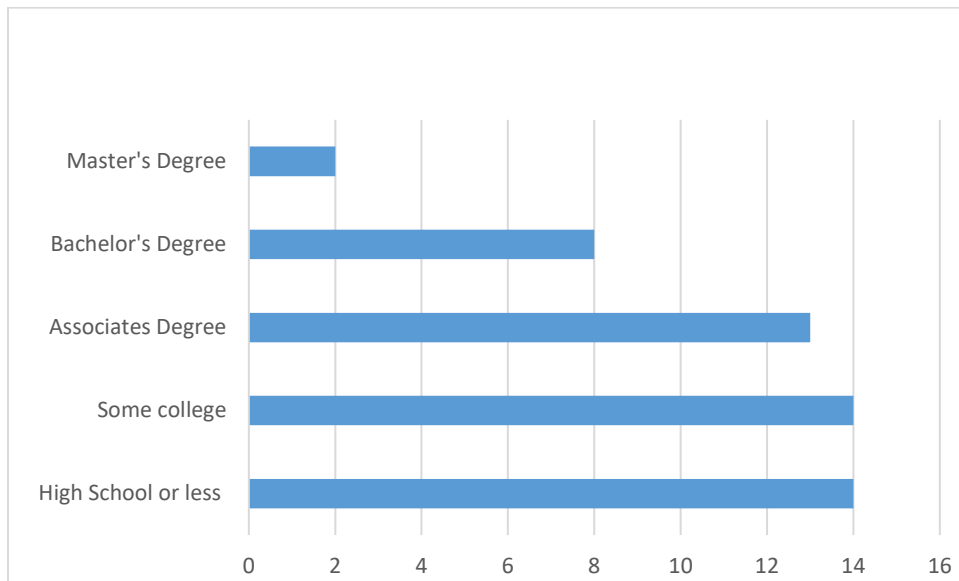
<b>Probability of Cognitive Impairment</b>	1.502 (1.064)	4.490	1.584 (1.072)	4.872 <sup>c</sup>
<b>Stigma Perceptions</b>	0.627 (0.207)**	1.871	0.832 (0.219)***	2.297 <sup>c</sup>

**Notes:** \*  $p < 0.05$ ; \*\*  $p < 0.01$ ; \*\*\*  $p < 0.001$ ; SE = standard error; OR = odds ratio. Logistic regression models were estimated separately for each predictor variable. <sup>a</sup> Controlled for education. <sup>b</sup> Controlled for age. <sup>c</sup> Controlled for age and education.

### Qualitative sample description

Most of our qualitative participants (78%) had associate’s degrees or some college and below (Figure 3).

**Figure 3: Education attainment of qualitative interview sample (n = 51)**



**Source:** UAS data on interview participants.

Fifty-six percent were white, 26% Hispanic, and 10% Black. The gender distribution was uneven, with women accounting for 86% of our interviewees despite efforts to recruit more men.



Importantly, due to errors in self-reporting and recent benefit applications, several participants were screened in that had in fact applied for disability benefits. Ultimately, 78% of our interviewees had never applied for benefits, with the remaining 22% having applied in the past.

## **Qualitative results**

Qualitative research helps us understand the ways in which people think and make decisions about disability benefits when experiencing a work disability, in particular during the time after they leave the labor force or substantially reduce their work due to the disability. As we report below, the weeks, months and, in some cases, years following separation from the labor force due to a disability may be fraught with uncertainty, health struggles, barriers to access to information, and conflicting ideas about personal autonomy and security. We found that participants' behavioral responses to their work disability were typically influenced by a mix of these structural and personal barriers and deterrents to applying for benefits. The following section outlines the themes identified through the qualitative interviews.

### *Theme 1: expectation of denial*

A frequently-cited reason why many interviewees had not applied for disability is the expectation of denial. Although there is limited empirical evidence of whether high claim denial rates in Social Security disability impact applications, evidence in other areas (notably, workers' compensation insurance) suggests this could potentially be the case (Biddle 2001).

Within this overall expectation of denial reported by participants in our study, there were three main narratives. One group of participants believed, or were told by third parties (acquaintances, health care providers), that they would be ineligible, and then they rarely sought further confirmation from Social Security or other sources:

*I guess in my mind I thought that I don't qualify or I don't meet all the criteria for the disability. (Female, 50 to 65, never applied)*

A second group reported that knowing others who had negative application experiences — what one participant called a “long and terrible road” — was a major disincentive:

*My mother applied a while back for disability, and it was a struggle for her, and she's got more problems than I have, so I knew if it was a struggle for her, then I probably would have an even harder struggle, so I haven't applied. (Female, 36 to 50, never applied)*

Finally, some believed the SSA denies the vast majority of applications:

*They're just rubber-stamping denial on it and telling you to do it all again. (Male, 50 to 65, never applied)*

### *Theme 2: onerous nature of the application process*

There is a large body of research on how high enrollment transaction costs affect take-up of benefits. While these “ordeals” were theorized to improve program integrity by screening out undeserving applicants, research has recently shown that onerous enrollment processes result in the exclusion of deserving applicants, especially from minority groups (Bertrand et al. 2004; Currie 2006; Herd and Moynihan 2019; Giannella et al. 2023; Ray et al. 2023; Finklestein and Notowidigdo 2019). In terms of Social

Security specifically, studies have shown that administrative burdens on prospective applicants negatively affect take-up; Social Security office closures, for instance, were found to restrict access to application resources, leading to reductions in applications (Deshpande and Li 2019; Levere et al. 2023).

In our study, the onerous nature of the application process was the most frequently cited reason for not applying for Social Security disability, and it interacted closely with the concern about high chance of denial. Even when other issues were less prominently mentioned as barriers to applying for benefits, the participants' narratives about the value proposition of applying almost always included these two variables: how much effort it takes to apply and how (un)likely they are to be approved.

Broadly, there were two subthemes within this perception of the onerous application process. First, many participants were concerned with the time, effort, and cost involved with obtaining all the necessary documentation, correctly filling out all paperwork, and responding to all application requirements in a timely manner:

*...I [know about] all the paperwork and all the red tape... I don't have time because I'm always trying to make money and thinking about how to get money. (Female, 50 to 65, never applied)*

*...[W]hen you go and you try to collect information from all your different care providers [...] it was a lot of, 'Hold on. Just a moment. We'll get right back to you.' I had someone answering the question, and then only to have them say, 'Well, there's a fee attached.' So, I did not go that route with them. (Female, 36 to 50, currently applying)*

Second, some interviewees felt that the application process is also emotionally taxing; a few were especially discouraged by the idea that they would have their disability scrutinized and questioned:

*“I don’t feel like I should have to explain the fact that at one point in time I was very productive [...] it’s a long and emotional process and I don’t feel like I’m up to that.” (Female, 50 to 65, never applied)*

### *Theme 3: diagnosis, treatment, and medical care*

Related to the issue of application burden, a central barrier participants raised was around their diagnosis, treatment, and medical care. Specifically, participants noted the various ways in which access to and interactions with health care providers impeded disability claiming. We observed three main ways in which health care-related barriers operated. First, some participants reported long delays in receiving a diagnosis for their symptoms:

*My liver is malfunctioning... If they can figure out what's wrong... then maybe we can reverse the process. But it's been a year and they still can't figure out what the heck is going on with my dang body. (Female, 36 to 50, never applied)*

A lack of formal diagnosis was cited not only as a barrier in itself; it also meant that participants in this situation often considered recovery and a return to the workforce as a possible outcome, which negated the need or desirability of applying for disability benefits. Similarly, uncertainty about a diagnosis affected the search for appropriate and effective treatment for several participants, also raising questions about whether a return to work was possible.

*With my endometriosis, there's not really been a diagnosis of it because they say that they would have to go in and do some kind of surgery to see if that's what it was, and the doctor wasn't willing to do it...I want to get it taken care of because I wanna get back out there, and work, and get back to my life, and that's the only thing holding me back...I can't really do that if I'm in pain all day, and there is nothing to stop the pain so that I can get through it. (Female, 36 to 50, never applied)*

Within this theme, participants also reported that their acute health care needs could have overwhelmed considerations about disability benefits:

*I think we may have thought about [applying for benefits], but then we didn't do anything. I spent so much time at the hospital and I had a lot of problems where I kept being hospitalized for different things. It was not at the top of my thinking. (Female, 50 to 65, never applied)*

Finally, there were cases in which participants were experiencing disabilities but not receiving the care they needed, which was also a barrier to disability application since they could not obtain the documentation and support needed for an application. Reasons for not receiving medical care included not having a primary care doctor, closures during the COVID-19 pandemic, inability to afford medical care, and lack of transportation to medical appointments:

*I don't know [why I haven't applied for disability], maybe because I don't have those doctors' notes. I haven't had a primary doctor in a long time. (Female, 36 to 50, never applied)*

*I always thought that I had to go through my private practice as far as going to the doctor, having the doctor determine whether I can work or not work. And I haven't done that because I reached out for help during COVID and nothing — everybody was closed down. So I just pretty much have not picked it up since then. (Female, 50 to 65, never applied)*

*Financial and transportation both would be the biggest thing. You know, you just can't — without money upfront you can't make appointments to see doctors to you know, even try to get the fact of disability. (Male, 50 to 65, never applied)*

#### *Theme 4: negative self-concept*

While we initially expected stigma to be an important factor in application decision-making, we found that interviewees were significantly more swayed by how applying for disability would affect their own self-concept.

Stigma is typically understood as a set of negative characteristics that a society or group of people attach to a group of individuals labeled “different” or “other,” with concomitant status loss and discrimination experienced by the labeled group (Link and Phelan 2001); stigmatizing experiences have been reported among adults with long-term work disabilities in the U.S. (e.g., Whittle et al. 2017). Our interview participants did not report feelings or perceptions of stigma attached to being a disability benefits recipient; that is, they did not report the perception that others would view them negatively if they were disability beneficiaries. Instead, they more commonly reported feeling that applying for disability benefits would affect their own self-image and self-

concept, broadly understood as the references, feelings, and ideas that a person has about him/herself, which are expected to influence the way they act (Mercer 2012):

*For me to apply for disability is pretty much admitting that I'm weak and I can't do it on my own, and I don't want that... I tell myself that I've put into that system for so long... Financially, it would lift so much off of me. [But] pride is a big part of it for me. (Female, 51 to 65, never applied)*

Existing literature has described *internalized* or *personal* stigma as a process whereby individuals with a stigmatized attribute or attributes (such as having a disability that prevents them from working) come to accept the negative characterizations as valid, leading to the development of negative self-perception, a devalued self-identity, and low self-esteem (Whittle et al. 2017; David 2017; Baumberg 2016). This type of stigma has been documented in the literature on participation in public assistance programs such as food pantries, food stamps (e.g., Kindle et al. 2019), rental assistance (Lasky-Fink and Linos 2022), and Medicaid (e.g., Allen et al. 2014).

Internalized stigma may be a possible interpretation of what our participants reported, especially those who argued that applying for disability is akin to becoming dependent on “assistance,” in line with a common stereotype of public assistance recipients that holds that they do not in fact *need* benefits but choose not to work and to take advantage of the system (Henry et al. 2004). Yet it also seems likely that disability benefits status is tied to negative ideas of the self *independent* from internalized negative stereotypes. The shift in self-concept involves a difficult process of acclimatizing to a new reality of being disabled and unable to work (O'Donnell and Habenicht 2022). We observe this with respondents who highlighted how work, health,

and independence were tied to their self-worth, and how a disability application would be a fundamental departure from this sense of self:

*It kind of became a reality in the last couple of years that I am disabled. To be able to really say that and try to understand it, and live with it has been a real struggle in itself... And I think a lot of times I was in denial of it. I probably should have applied [for disability benefits] a long time ago. But I feel like dealing with government supplements is going to be really a challenge to get through. (Female, 51 to 65, never applied)*

*The way I was raised, you do your part and you don't take from other people, and you don't take from the government unless you really, really need it, because there are people that really, really need it. Maybe one of them won't get it if you take it. (Female, 50 to 65, never applied)*

*I was the main breadwinner of our family. And to go [from that] to not being that and not being able to support my family, it's very difficult. And I think that's where pride steps in. (Female, 50 to 65, never applied)*

#### *Theme 5: information barriers*

Exploring the ways in which informational barriers operate with individuals likely eligible for benefits is important. Information can make a difference in program take-up, as empirically demonstrated in the U.S. with take-up of SNAP among the elderly (Finkelstein and Notowidigdo 2019), SSDI (Armour 2018), and EITC (e.g., Barghava and Manoli 2015).

In our study, our qualitative sample reported high levels of awareness of Social Security disability benefits (even when the distinction between SSI and SSDI was not



clear). Although hypothesized to be a barrier to program take-up (Linos et al. 2022), the cost associated with *learning about* Social Security disability appeared to be lower than other information barriers. Specifically, we identified two other overall information barriers. The first one refers to the difficulty in gaining the momentum necessary for taking the initial steps to look for information on benefits and eligibility. A sense that this may be an overwhelming process was mentioned, as was a lack of knowledge of the existence of benefits or where to look for that information:

*I wouldn't even know where to start, where to go. 'Cause there's so many websites online that could be like, "Yes," and then another one could be like, "No," [...] I wouldn't even know what's true or not. (Female, 18 to 35, never applied)*

*I don't know how to contact, maybe a lawyer or whatever I would need and I don't know where to apply, how to do the paperwork. It's kind of an overwhelming process. (Female, 18 to 35, never applied).*

Even when individuals were aware of the existence of benefits, participants reported barriers to information-seeking about eligibility and application requirements:

*I guess I didn't really have anybody kind of tell me about it. You know? I didn't even know I could apply for it. (Female, 18 to 35, never applied)*

A possible interpretation of this information barrier relates to procrastination, limited self-control, and “status quo bias” — that is, that even when potential participants know a program (or switching programs) might be beneficial for them, they delay taking the actions necessary to apply (Ribar 2014; Janssens and Van Mechelen 2022), which includes searching for information about eligibility and application. This phenomenon

has been empirically documented in the area of financial decision-making, including take-up of health insurance (Sinaiko et al. 2013; Krieger and Felder 2013) and employer-based saving programs (Thaler and Benartzi 2004). However, we still know little about how this operates in safety net program enrollment and take-up.

A second barrier identified in our study is around accessibility of information for those who considered taking steps to learn about the disability programs.

*[The] financial and transportation both would be the biggest thing. If I can fix, you know, my primary vehicle then that [...] probably would be enough to get me started going in that direction again. (Male, 50 to 65, never applied)*

As noted, other studies have already shown that availability of resources such as local Social Security offices or online registration can affect program enrollment. Qualitatively, we observe this as well. These barriers may be more pronounced for some groups; for instance, a Hispanic participant cited concerns about language and transportation as reasons why she had not gone to a Social Security office to get more information about benefits.

#### *Theme 6: financial barriers*

Finally, financial barriers were also cited by participants. Some noted their knowledge or perception that the benefit amount would not be sufficient to survive on, which echoes research finding that expected benefit amounts affect take-up rates (Janssens and Van Mechelen 2022):

*Just from asking around, asking people about what they got for their disabilities. And it's like, 'Wow. I couldn't live off that.' So, I just gotta figure it out. (Female, 36 to 50, never applied)*

Others were concerned that disability benefits would negatively interact with other benefits they were receiving:

*[A]t least as far as my understanding goes, you can't be on all that stuff at the same time — Section Eight, food stamps, and disability — because you start getting checks for one, then they'll count it as income, and you get cut off of something else. So, I'm not trying to be greedy. (Female, 50 to 65, never applied)*

A final set of individuals had a different narrative: that their financial situation was not urgent and therefore benefits were not needed:

*My husband retired and it was like, "Oh, never mind now." I'm 63 so, yeah, I don't have to now. My husband's retired and really, we're fine. So, you know, it was like, "Well, if I don't need it." I would have liked it but I'm okay. (Female, 50 to 65, never applied)*

## **Implications**

This study contributes to the literature by providing new insights into the characteristics and decision-making of work-disabled adults who do not apply for Social Security disability benefits. These insights are important for targeting interventions that aim to reduce barriers to take-up of benefits among potentially eligible adults.

The results of our quantitative analyses suggest that the availability of personal and socioeconomic resources, including younger age, educational attainment, spousal support, and income may act as a buffer to feeling the need to apply for disability benefits. We further found that greater cognitive resources, such as quantitative and verbal reasoning skills, were associated with a greater likelihood of not applying for

disability benefits. People with greater cognitive abilities are likely to have access to a greater amount of diverse employment opportunities to maintain their standard of living and might be less pressed to rely on government assistance. With the availability of sufficient resources, people may be less inclined to engage in the process of seeking disability benefits.

Finally, we found that stigma surrounding disability benefits likely emerges from exposure to the system and experiences with the application and claiming process. This result is in line with prior research documenting the experience of stigma by those who have engaged with the process of obtaining disability benefits (Whittle et al. 2017).

The themes that emerge from the qualitative inquiry broadly align with those of other research that has examined the information, transaction, and social costs of applying for benefits. Nevertheless, the qualitative data afford a more in-depth understanding of what may be the primary factors affecting application decisions, and how those interact.

Notably, high transaction costs involved in disability applications *coupled* with the widespread perception of low approval rates may be a critical deterrent for eligible individuals. While critical, these were by no means the main or only reasons cited by participants for not applying for disability benefits. Uncertain and lengthy medical processes after onset of disability were also frequently reported as a central deterrent to applications. The often-complex dynamics of obtaining a diagnosis, appropriate treatment, and the required documentation for a disability claim contributed to the direct costs of application, as well as to uncertainty about eligibility and the likelihood of award. Previous literature recognized the high direct cost of obtaining the requisite

medical records for a claim. However, other complexities of the health care interaction come clearly to light through the qualitative interviews, including, for certain individuals, the difficulty of obtaining diagnoses and prognosis on the extent to which the impairment limits work in the long term. These complexities, as our participants revealed, have a direct bearing on application decisions.

External or societal stigma about receiving disability benefits does not appear to be a factor in application behavior among our qualitative sample, although a change in self-concept involving an adjustment to benefit-receiving, work-disabled status was cited as a deterrent to claiming. This adjustment to the new status is made especially difficult because, in the eyes of many of our interviewees, it is permanent.

The present study provides an important preliminary evidence for understanding the personal and structural characteristics of people who decide not to apply for disability benefits. However, this research has several limitations. First, our selection criteria for the quantitative analyses yielded a fairly small sample of respondents who were potentially eligible, but had never applied for disability benefits. Second, we were not able to leverage actual administrative data but relied on survey data, which can be prone to measurement error and misreporting of benefit receipt (Bargain et al. 2007; Tasseva 2016). Sample size limitations further precluded us from examining differences in specific chronic health conditions and how they may relate to nontake-up. Finally, our analyses did not distinguish between SSDI and SSI benefits applications. For the qualitative portion, there was an under-representation of men who wanted to participate in the interview, and some respondents had already applied for benefits by the time of the qualitative interview.

Nevertheless, this study has several strengths. Our quantitative sample was drawn from a nationally representative sample of the general population. In contrast to other panels, which are often convenience (opt-in) samples, UAS members are recruited through nation-wide address-based sampling, which counteracts many biases in population parameters relating to opt-in panels (Yeager et al. 2011). The rich information collected in the UAS further allowed us to examine the role of respondents' cognitive abilities and disability-related perceptions. The qualitative interviews enabled a fine-grained and comprehensive examination of the personal and structural factors associated with disability benefits decisions from the respondent perspective.

Qualitatively, this study shows that various factors may play a part in disability application decisions, but on its own, it does not shed light on the external validity of these findings, nor does it enable us to disentangle the relative power of these various barriers to application. This study thus suggests several possible avenues for further research. More research about the psychological factors contributing to individuals' decision not to apply for disability benefits would be useful. Our results suggest that barriers surrounding a negative self-concept may play a central role in a person's hesitation to seek out these benefits. A better understanding of these and other factors, such as coping styles, self-efficacy, and resilience in the face of complex and demanding tasks may aid in the development of communication and information interventions that more precisely address this issue (rather than, for instance, using de-stigmatizing language that may be less resonant). Future research would benefit from including these types of psychological measures in new UAS data collection efforts. Also, field experiments on these barriers would provide better evidence on both their

relative effect on application decisions and on opportunities for programmatic intervention (Janssens and Van Machelen 2022).

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