

# Making Sense of Health-Related Labor-Market Exits and Disability: Evidence from the American Voices Project



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*Issues around stigma and deservingness may be particularly salient for people who stop working due to health-related reasons. Although historically those experiencing disability have been viewed as “deserving” of assistance, disability has also been stigmatized. Using the American Voices Project data and narrative and discourse analysis methods, we ask how those with a health-related labor-market exit make sense of their exit. We find that respondents use various words to describe themselves with respect to their exit and that they use legitimization strategies when discussing why they do not work.*

**Keywords:** disability, stigma, deservingness, health, work

Work is a central organizing feature of adult life in the United States (Kalleberg 2009) and for many plays a large role in how individuals construct their identities and make meaning of their place in society. Moreover, work is an expected activity of adults; job loss, then, not only may result in lost income, but also could carry stigma and shame (Brand 2015). Issues around stigma and deservingness may be particularly salient for people who stop working due to health-related reasons. On the one hand, many of these individuals may be considered “disabled,” and historically people who were disabled were considered deserving of support,

particularly public support (Katz 2013). This might result in fewer feelings of shame. Additionally, as former workers, these individuals may be perceived as having contributed to society and, in terms of public benefits, paid into the Social Security system (Beechey 2016). On the other hand, being disabled may carry its own experience of stigmatization, particularly in the context of a nation that values self-sufficiency and individual responsibility (Charmaz 2020).

More recent theoretical work around disability argues that disability is not a matter of individual deviance or inability to function in

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the larger world, including the world of work, but instead the result of social structures that are inflexible and designed to exclude (Grue 2016). This model, the social model of disability, contrasts with the medical model of disability, which, broadly speaking, locates disability within an individual as a pathology or aberration, something to be fixed, treated, or otherwise medically attended to. Although heavily criticized, the medical model informs disability benefits policy; recipients of disability programs are determined eligible based on functional limitations and excused from working instead of being given services to help them work (Smart 2009). From the perspective of stigma, embracing the social model of disability may provide individuals with the language to reject individualized and pathologized notions of disability and focus instead on the barriers placed upon them by the larger society (Shakespeare 2013). The Americans with Disabilities Act tasks employers with providing accommodations for workers who have limitations, demonstrating its rootedness in the social model of disability in that it seeks to remove some of those barriers and allow fuller participation in the labor market.

Disability, therefore, is a status and a term around which there is tension as it relates to stigma and deservingness. How do people who leave the labor market because of their health talk about their identity and their social position (their health, their work, their relationship to the state)? How might these narratives reflect norms and ideas of stigma and deservingness? What do these patterns mean for research and policy? We use interview data from the American Voices Project (AVP) and a narrative analysis approach that draws on a theoretical framework of stigma and deservingness to address these questions, noting relevant limitations in our ability to draw strong conclusions in some cases.

### **THEORETIC FRAMEWORK**

How individuals make sense of their health-related labor-market exit may be shaped by ideas of deservingness, perceptions of stigma, and the ways in which their disability is integrated into their identities. In all these domains, though, there are tensions around how

people experience, understand, and talk about their health and their reasons for not working.

The notion of deservingness has shaped public and private views about who is worthy of assistance and dates back many centuries, having been codified within the English Poor Laws that served as the foundation for U.S. social welfare policy (Katz 2013). People with disabilities have long been viewed as a group who are “worthy,” given that their conditions were due to no fault of their own, whereas someone considered able bodied is assumed to be able to function on their own, including being supported via employment. However, as Celeste Watkins-Hayes and Elyse Kolvasky (2016) note, ideas about deservingness intersect with racism and gender stereotypes to complicate the categorization of various groups. For example, White widows with children were viewed as a group worthy of governmental assistance when the Aid to Dependent Children program was enacted in the 1930s. Yet, as the program grew and was renamed Aid to Families with Dependent Children (AFDC), its recipients increasingly were women of color who had never been married, the view of the program shifted, and policies became more punitive and focused on moving recipients off of the program and into work (Nadasen 2007; Neubeck and Cazenave 2001).

Government assistance for those with serious health problems also reflects the deservingness framework. For those with work histories in the formal labor market, the Social Security Disability Insurance (SSDI) program may be available. Benefits for this program tend to be more generous than those of the public assistance disability program, Supplemental Security Income (SSI), in part because of differences in their funding structure. SSDI benefits are funded via employer and employee payroll tax contributions, whereas SSI is funded out of general government revenue streams with receipt limited to individuals meeting income and related eligibility criteria. Thus recipients may view SSDI payments as “theirs,” given that they have paid into the system before drawing these benefits, and the general public may have a positive view of this group due to their history as workers. SSI, on the other hand, may be viewed as welfare, a form of assistance

that in the United States has historically had negative connotations (Gilens 1999). That said, SSI benefits are typically more generous than other forms of cash assistance, in particular the Temporary Assistance for Needy Families program that replaced AFDC, reflecting the view that those with disabilities are more deserving of assistance than the so-called able bodied are. However, growth in both the SSDI and SSI rolls has been accompanied by an increase in public discourse about people who are supposedly cheating the system with fraudulent disability claims (Whittle et al. 2017). Are people who receive disability benefits, regardless of program type, still considered deserving?<sup>1</sup>

Research on public perceptions of disability programs and the extent to which recipients perceive stigma from receiving them is fairly limited. Experimental studies have found that how SSDI is perceived is predicated upon whether survey respondents are primed to consider the important social insurance role the program plays or to consider its potential for abuse (Fang and Huber 2020). A smaller study found strong negative perceptions of disability programs, grounded in ideas about recipients committing fraud and a belief that one should work hard instead of receiving handouts (Rabinovich 2020). From the perspective of program beneficiaries, Henry Whittle and his colleagues (2017) argue that the arduous disability application process can doubly stigmatize people; individuals may already be experiencing stigma because of their health conditions, and this negative sense of self may be made worse by a bureaucratic system that assumes applicants are seeking to commit fraud or are shirking responsibility by not working (see also Lopez et al. 2018). Other research has found that Black women perceive that their disability applications will be subject to higher levels of scrutiny, in part because of stigmatizing, racialized perceptions about welfare recipients, including racist tropes about so-called welfare queens who abuse the system (Pryma 2017). Among those experiencing mental health problems, though, receipt

of a monthly income through a disability program was a source of status and importance in their community and helped offset the stigma these individuals perceived from having been diagnosed with a mental disorder (Hansen, Bourgois, and Drucker 2014).

The broader literature on stigma is relevant to discussing feelings of worthiness related to receipt of government benefits and having a disabling condition. Erving Goffman's (1963, 3) seminal work on the topic posits that stigma arises from having a characteristic that is socially constructed as "deeply discrediting," resulting in a "spoiled identity." Bruce Link and Jo Phelan (2001) theorize that stigma is the result of processes of labeling (such as calling a person "disabled"), separating (distinguishing those with disabilities from the able bodied), stereotyping (believing that SSI recipients are really just lazy), and status loss (being viewed as lower status because of an inability to work). They also note that stigma involves power, in that these processes can only occur to groups with lower levels of power within a particular domain. In the context of benefit receipt, to the extent that programs such as SSDI and SSI may be perceived negatively or as welfare, the stigma associated with the program itself may be transferred onto the beneficiaries.

Having a disability in itself may result in experiences of stigmatization. It may mark difference or even social deviance, although not all types of disability may be stigmatized in the same way, or at all (Grue 2016). The extent to which a disability is concealable, perceived as controllable, or part of a larger collective community may all play a role (Major et al. 2017). For example, some individuals with mental health diagnoses may have no outward appearance of disability, whereas someone who uses a wheelchair is seen as being unable to walk. A person who was injured from a falling object may be viewed more favorably than a person whose accident occurred while they were under the influence of a substance. And those whose disability links them with others in the same group (such as people with limited hearing)

1. The Centers for Disease Control and Prevention (2023) estimates that one in four Americans have some sort of disability. Yet the proportion of working-age adults who receive some sort of disability is around 4 percent (Social Security Administration 2021).

may be able to deflect stigmatization through advocacy and other efforts.

Many studies on disability make the distinction between congenital versus acquired conditions, including a number of studies on stigma and disability. A review of this work has found mixed results, with some studies finding greater stigmatization for those with congenital disabilities and others that those with acquired disabilities are sometimes blamed for having become disabled (Bogart, Rosa, and Slepian 2019).

Ideas about deservingness and experiences of stigmatization may or may not play a role in how people with health-related work exits talk about this transition. One strategy in which former workers may engage is to draw on some type of disability identity as a way to understand and make meaning of their situation. The term “disability identity” has no one agreed-upon definition in the literature (Forber-Pratt et al. 2017) but may be thought of as orientation toward a disability (Darling 2003), which in turn may be shaped by individual experience and social structures (Adler et al. 2021). This disability identity may be grounded in one of the different models of disability, most notably the medical and social models of disability. The medical model, which has been dominant in much policy formation around disability, locates disability as an impairment that deviates from normal functioning but that can be managed through medical intervention. This process of medicalization may be driven by individuals with a given health status or institutional actors, such as doctors (Conrad 1992). The social model, by contrast, views disability as the interaction between a health condition and the social environment. Access and opportunity, in this model, are not the result of impairment but rather of socially constructed barriers (for an overview, see Colorafi et al. 2021). The social model promotes a positive view of disability and has been used by many in the disability

rights movement to push for policy development and change in societal attitudes (Oliver 2013). The medical model, on the other hand, may reinforce stigma if people with a disabling condition believe themselves to be deviant (Grue 2016).

For adults, onset of a disabling condition may require a renegotiation of how they understand themselves, both from the perspective of having an impairment but also placing the individual in a social minority group—people with disabilities (Adler et al. 2021). However, adults may have had other identities on which to draw, including worker, parent, and others, and may not need to develop a disability-rooted identity nor even consider themselves disabled (Heller and van Heuman 2013).

Our review highlights a number of tensions and challenges individuals with health-related work exits may face when trying to explain their reasons for not working and receiving benefits and how the frameworks of stigma and deservingness are reflected in their accounts. In what ways might people’s narratives around their health-related work exit reflect notions about deservingness or stigma? How might the ambiguity of deservingness as it relates to disability shape the words and the structuring of the accounts people use to talk about themselves, their identities, and the circumstances under which they left the labor market? These are the questions this study will address.

## METHODS AND SAMPLE

To analyze discourse around health-related labor-market exits, we used transcripts from the American Voices Project, as described in the introduction to this issue (Edin et al. 2024). After exploratory research reviewing the transcripts of both workers and nonworkers as they related to the decision to work, we constructed a sample of individuals with health-related labor-market exits, as this emerged as a distinct phenomenon.<sup>2</sup> We first selected all cases in which the primary respondent reported not

2. Our exploratory analysis occurred iteratively throughout the research process. Ultimately, this exploratory analysis included reading and categorizing the transcripts of labor force nonparticipants ( $n = 388$ ), workers over sixty ( $n = 121$ ), all workers who received SSI or SSDI benefits ( $n = 31$ ). We also read a sample of the transcripts where other adult members of the household beyond the primary respondent may have been labor-market nonparticipants ( $n = 149$ ). We initially read the transcripts of workers over sixty-five and nonworkers over sixty,

working in the week before the interview. We excluded cases when the respondent was looking for work or was a full-time student. This left a total of 388 transcripts. We read through these transcripts to determine whether the reason for not working was related to health problems that were not temporary. We eliminated from consideration respondents who reported retiring (not because of their health) or being unemployed but not working for reasons other than their health (such as parental leave, layoff due to COVID-19). We also eliminated cases with such low audio quality that the transcript was too difficult to read and cases with multiple respondents where it was not clear who was speaking. This left us with an analytic sample of 183 cases.

Our next step was to reread these transcripts and code each for discussions about work and health, the transition out of the labor market, and interactions with disability programs. These discussions about health problems, disability, and their link to work arose naturalistically, as an answer to queries about when the person last worked, or in response to one of the protocol questions (“Sometimes, health problems get in the way. They can even affect people’s ability to work or care for their children. How about you?”).<sup>3</sup> We held at least weekly meetings to discuss initial observations, and from these broad categories we developed codes to categorize the type of language respondents used to characterize themselves with respect to their health and work status, their labor-market transition, and any limitations they faced because of their health. For

these codes we examined how respondents told their story about leaving the labor market and how they described themselves and their functional challenges, given that they were no longer working. To further engage in this analysis, we drew from the techniques of narrative analysis as well as critical discourse analysis (Souto-Manning 2014). In narrative analysis, the “analyst is interested in how a speaker . . . assembles and sequences events and uses language and/or visual images to communicate meaning . . . interrogat[ing] intention and language” (Riessman 2008, 11). Examining narratives provides a researcher an opportunity to uncover the internal meanings that individuals ascribe to their lives but also the larger world in which they live (Smith and Sparkes 2007). Using critical discourse analysis allowed us to examine how these narrative accounts relate to larger institutional levels, namely notions of stigma and deservingness.<sup>4</sup> We follow the approach of Myriam Winance (2007) and suggest that the choice of words people use are ones that allow them to define the world in which they live and thus are worthy of examination and analysis. Either through analyzing a discrete unit of text or by piecing together several, we were able to examine the language respondents used to talk about work as it related to health and the structure of their story, thereby providing insight into respondents’ meaning-making processes (Floersch et al. 2010) around labor-market exits driven by health. We primarily used Microsoft Excel to code and analyze the data, copying relevant units of text into cells, applying codes to those cells, and then

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before focusing on the emergent phenomenon of respondents explaining their decision to leave the labor market due to health. We later confirmed the comprehensiveness of our analysis of health-related labor-market exits by reviewing the transcripts of all other labor-force nonparticipants and workers receiving disability benefits.

3. Among the 183 transcripts within the analytic sample, the amount of relevant text to our research questions varied between transcripts. We coded a random selection of sixty-six transcripts from the analytic sample in NVivo, allowing us to calculate the proportion of transcripts we had identified in which respondents talk about health-related labor-market exits. The mean amount of coverage of codes about work transitions, health issues affecting respondents’ lives, and social and disability benefits program use within this subsample of transcripts was 7.5 percent (SD = 0.060).

4. Marvin Scott and Stanford Lyman (1986) describe accounts as linguistic devices used “whenever an action is subject to valuative inquiry.” Narrators use accounts to “verbally bridge the gap between action, and expectation.” We use the term account alongside justifications to describe the presence of such narration within AVP transcripts.

sorting the data to determine the frequency of categories and codes, discussed in the Findings section.

Table 1 summarizes selected demographic and program-use characteristics of our analytic sample (those with health-related exits) relative to those of the whole population and of other people who did not work, were not looking for work, or were full-time students.

Eleven percent of the total respondents are included in our analytic sample of those with health-related labor-market exits. Among those not in the labor force permanently, our analytic

sample represents 47 percent of respondents. Those between fifty-five and sixty-four were most likely to have left for health-related reasons. Relative to the entire population, respondents in the analytic sample were more likely to have not completed high school, live in rural areas, be people of color, and receive SSDI or SSI. These patterns are consistent with demographic predictors of people who retire early or involuntarily for health reasons as estimated from conventional surveys (Szinovacz and Davey 2005; Munnell, Hou, and Sanzenbacher 2018).

**Table 1.** Demographic and Program-Use Characteristics of Sample, by Labor Force Participation

Characteristic	In Labor Force N = 1,228 (%)	Not in Labor Force	
		Other Nonparticipants N = 2,050 (%)	Health-Related Exits N = 183 (%)
<b>Age</b>			
18–24	141 (11)	24 (12)	*
25–34	271 (22)	56 (27)	*
35–44	198 (16)	51 (25)	*
45–54	157 (13)	21 (10)	35 (19)
55–64	165 (13)	27 (13)	79 (43)
65 and older	260 (21)	16 (8)	47 (26)
<b>Gender</b>			
Man	547 (45)	40 (20)	67 (37)
Woman	666 (55)	163 (80)	113 (63)
<b>Race and ethnicity</b>			
American Indian and Alaska Native alone, not Hispanic or Latino	*	*	*
Asian alone, Not Hispanic or Latino	46 (4)	*	*
Black or African American alone, not Hispanic or Latino	218 (18)	46 (23)	53 (30)
Hispanic or Latino	240 (20)	63 (31)	29 (16)
Native Hawaiian and Other Pacific Islander alone, Not Hispanic or Latino	*	*	*
Some Other Race alone, not Hispanic or Latino	*	*	*
Two or more races, not Hispanic or Latino	44 (4)	*	*
White alone, Not Hispanic or Latino	647 (54)	81 (40)	83 (46)
<b>Education</b>			
Less than high school	99 (8)	37 (18)	45 (25)
High School	262 (22)	63 (32)	58 (32)
Some college	379 (31)	64 (32)	55 (30)
Bachelor's degree or higher	473 (39)	36 (18)	24 (13)

(continued)

**Table 1.** (continued)

Characteristic	In Labor Force <i>N</i> = 1,228 (%)	Not in Labor Force	
		Other Nonparticipants <i>N</i> = 2,050 (%)	Health-Related Exits <i>N</i> = 183 (%)
<b>Marital status</b>			
Cohabitation	117 (10)	29 (14)	*
Divorced	160 (13)	17 (8)	48 (26)
Married	435 (36)	86 (42)	44 (24)
Separated	36 (3)	*	*
Single or never married	388 (32)	55 (27)	46 (25)
Widowed	83 (7)	*	25 (14)
<b>Urbanicity</b>			
Rural	180 (15)	42 (20)	46 (25)
Suburban	524 (43)	87 (42)	67 (37)
Urban	524 (43)	76 (37)	70 (38)
<b>Interview mode</b>			
Face-to-face	556 (45)	94 (46)	89 (49)
Phone	671 (55)	111 (54)	94 (51)
SSI receipt	48 (4)	26 (13)	37 (21)
SSDI receipt	58 (5)	23 (11)	87 (48)
Pension or retirement receipt	189 (16)	14 (7)	26 (15)
Social Security receipt	250 (21)	32 (16)	46 (26)
Medicare receipt	244 (20)	26 (13)	90 (50)
Medicaid receipt	214 (18)	84 (41)	89 (49)

Source: Authors' tabulation.

\*number of respondents in a characteristic less than or equal to ten. Within a given group of characteristics (for example, race and ethnicity), if only ten or fewer respondents had only one characteristic, the number of respondents for the second smallest characteristic was also starred. Such starring is used in all tables.

## FINDINGS

In this section we present the results of our narrative and critical discourse analysis. Much like other articles in this double issue that use interpretivist qualitative methods (Morales 2024; Casselman-Hontalas, Adams-Santos, and Watkins-Hayes 2024), we developed typologies for the words people used to describe their status relative to their labor-market nonparticipation and the stories they told about why they were not working or were receiving disability benefits. To the extent that having a disability, being out of work, and using government benefits might all contribute to a spoiled identity (Goffman 1963), we identify four ways that participants used to describe themselves with re-

spect to their social position, including how they justify that position. By “justify” we do not wish to imply that this group of respondents should have had to explain to an interviewer why they were not working, or that their reasons should be evaluated for their worth. Instead, we are interested in how respondents talked about not being able to work and what that might mean for the ways in which they understood their labor-market exit, including the cause of the exit.

We highlight the narratives that respondents presented to identify legitimacy in their social position that may be in response to norms of stigma and deservingness that our review of the literature suggests might be pres-

ent for people who are not working due to health issues and who may be receiving public benefits to replace that income. In doing so, we note that the AVP protocol did not specifically ask respondents how the experience of leaving the labor market due to health affected their sense of self, nor did the protocol ask about potential stigma surrounding their health or benefit receipt. Therefore, our analysis is limited to the narratives, accounts, and justifications that people invoked at multiple points during a single interview. These narratives highlight ways that larger ideas around stigma and deservingness may operate to shape the story they tell an interviewer about their health-related exit from the labor market. The four narrative categories that emerged are mostly, though not entirely, mutually exclusive.<sup>5</sup> Table 2 summarizes selected demographic and program-use characteristics of respondents by their primary narrative typology.<sup>6</sup>

### “Disabled”

Of the 183 respondents in our sample, fifty-nine primarily referred to themselves as “disabled,” used the word disabled to describe their status, or identified directly with a particular health condition (such as “I’m bipolar”). The manner in which these respondents claimed a disabled identity varied, although several themes emerged. Some, like Lawrence, an older Black man who used a wheelchair after being injured in a vehicle accident when he was a younger adult, repeatedly included the phrase “because

I’m disabled” during the interview each time he was describing how his health affected his ability to work, go to school, or receive disability benefits.<sup>7</sup> For example, as Lawrence described his experience of not being able to complete trade school, saying, “I passed [on] that. . . . I needed some help to pick that stuff up, because I’m disabled. I can’t pick anything up.” Brenda, a White woman, when asked to describe her health immediately said that she was “born disabled” and that she “had been written off by the government so that [she] did not receive health services,” unlike others that she perceived as having similar health conditions. For respondents like these, having lived with the condition for most of their life may have given them more time to develop an identity around being disabled (Heller and van Heuman 2013), hence this label resonated with their experience. Describing oneself as disabled may also be a way for these individuals to counter an expectation that they should be working. In this sense, the use of “disabled” may reflect a claim of deservingness. Brenda in particular faced challenges accessing benefits despite believing she had a valid claim to them as someone who was “disabled.”

Others used “disabled” to describe a transition that had occurred, usually from worker to someone no longer in the labor market. This type of justification or account was often used to explain behavior subject to valuative inquiry, such as an “early” labor-market exit (Damaske 2013). Lanette, a Black woman in her sixties,

5. All respondents were assigned a primary narrative category for the purposes of providing quantitative counts.

6. Quantitative analysis did not confirm relationships between respondent use of these narrative typologies and gender, race and ethnicity, education, and geographic distribution (nor do they rule such relationships out, particularly given the relatively small sample size of each typology when divided by group). Within the analytic sample, we compared the relationship between prevalence of our narrative typologies and gender ( $\chi^2 [6, N = 183] = 10.51, p > .05$ ), combined race and ethnicity ( $\chi^2 [12, N = 183] = 9.55, p > .05$ ), education ( $\chi^2 [12, N = 183] = 12.71, p > .05$ ), and urbanicity ( $\chi^2 [6, N = 183] = 4.18, p > .05$ ). None of these tests allow us to reject the hypothesis that there is no systematic variation between groups. Respondents who use retired were statistically significantly more likely to be older than sixty-five than other respondents in the analytic sample,  $\chi^2 (6, N = 183) = 25.42, p < .001$ . Further, at the time of writing, the AVP dataset does not provide enough information (for example, strata across the two rounds of sampling) to conduct these statistical tests while incorporating the complex sampling design. We therefore hesitate to make strong claims about prevalence of narrative typologies by groups at the population level.

7. Respondents are identified by a pseudonym. We changed minor details in descriptions of respondents and removed certain demographic identifiers to protect respondent confidentiality and ensure at least 10,000 people in the U.S. have the same combination of descriptors.

**Table 2.** Demographic and Program-Use Characteristics of Sample by Narrative Typology

Characteristic	Disabled N = 59 (%)	Got Hurt N = 37 (%)	Bad Health N = 68 (%)	Retired N = 19 (%)
<b>Age</b>				
18–24	*	*	*	*
25–34	*	*	*	*
35–44	*	*	*	*
45–54	13 (22)	*	18 (26)	*
55–64	28 (47)	17 (46)	28 (41)	*
65 and older	*	12 (32)	13 (19)	13 (68)
<b>Gender</b>				
Man	16 (27)	14 (39)	25 (38)	*
Woman	43 (73)	22 (61)	41 (62)	*
<b>Race and ethnicity</b>				
American Indian and Alaska Native alone, Not Hispanic or Latino	*	*	*	*
Asian alone, Not Hispanic or Latino	*	*	*	*
Black or African American alone, Not Hispanic or Latino	15 (26)	13 (35)	19 (28)	*
Hispanic or Latino	*	*	13 (19)	*
Some Other Race alone, Not Hispanic or Latino	*	*	*	*
Two or more races, Not Hispanic or Latino	*	*	*	*
White alone, Not Hispanic or Latino	26 (46)	15 (41)	32 (48)	*
<b>Marital status</b>				
Cohabitation	*	*	*	*
Divorced	22 (38)	*	13 (19)	*
Married	12 (21)	*	16 (24)	*
Separated	*	*	*	*
Single or never married	14 (24)	*	23 (34)	*
Widowed	*	*	*	*
<b>Education</b>				
Less than high school	15 (26)	12 (32)	16 (24)	*
High school	12 (21)	14 (38)	24 (35)	*
Some college	22 (38)	*	21 (31)	*
Bachelor's degree or higher	*	*	*	*
<b>Urbanicity</b>				
Rural	16 (27)	*	19 (28)	*
Suburban	24 (41)	14 (38)	22 (32)	*
Urban	19 (32)	14 (38)	27 (40)	*
<b>Interview mode</b>				
In-person	20 (34)	21 (57)	36 (53)	*
Remote	39 (66)	16 (43)	32 (47)	*
SSI receipt	17 (30)	*	11 (16)	*
SSDI receipt	31 (53)	21 (58)	29 (43)	*

**Table 2.** (continued)

Characteristic	Disabled N = 59 (%)	Got Hurt N = 37 (%)	Bad Health N = 68 (%)	Retired N = 19 (%)
Pension or retirement receipt	14 (25)	*	*	*
Social Security receipt	13 (23)	11 (31)	13 (19)	*
Medicare receipt	31 (54)	18 (50)	30 (44)	*
Medicaid receipt	29 (50)	23 (64)	33 (49)	*

Source: Authors' tabulation.

\*number of respondents in a characteristic less than or equal to ten. Within a given group of characteristics (for example, race and ethnicity), if only ten or fewer respondents had only one characteristic, the number of respondents for the second smallest characteristic was also starred. Such starring is used in all tables.

described her health history before turning to the event that made her “disabled” and which she pointed to as the reason she stopped working. Lanette recounted that she was nearing the end of recovery from a knee replacement when she suffered a fall, breaking one of her hips. When describing the surgery and extended recovery that followed, she noted that “when I broke my hip, that made me disabled.” Similarly, Lashay, a Black woman in her fifties, initiated the topic of disability when asked about her recent work history. She claimed the identity of being disabled and used it to support the reason why she did not work. Lashay revealed the specific injury after first saying, “And I can’t do too much work because I’m disabled.” Later in the interview, though, she called herself “healthy” even while acknowledging that she had “messed her back up.” Here, being “disabled” is something that happened to the individual, a condition that is used to mark an event, including the end of being a worker. Also implied in these statements is that being disabled is the opposite of being a worker—when one is disabled, one cannot work. This binary representation of disability is difficult to analyze in terms of what it may say about stigma. It may reinforce the notion that being disabled is deviation from one of the norms of adult life (Titchkosky 2020)—working—and thus stigmatized, or, alternatively, that disability is an acceptable reason not to work, implying that people who are disabled are deserving of the expectation not to work.

Respondents who used language about being “disabled” also distinctly described their

health with specific medical terms and linked that to their receipt of disability benefits and exit from the labor market. For Laurel, a White woman in her sixties, pain was medicalized—a syndrome—which justified not working. Asked to provide the “story of her life,” Laurel concluded her brief self-reflection by saying, “I have chronic pain syndrome, chronic pain condition that has been disabling so I get Social Security Disability.” Laurel’s identification of a pain as a “syndrome” that disables is in contrast with other respondents who described pain generally as part of their “bad health” and may reflect an account to legitimize her health experience, deservingness of benefits, and social position. This subsample’s use of medicalized language around disability, health, and work is consistent with the analysis by Corey Abramson and his colleagues (2024, this issue) of how respondents use medicalized language around pain to establish credibility with health-care providers, similarly using “legitimate” terms to manage and minimize stigma.

Finally, a few respondents put distance between themselves and the word “disabled,” indicating that the label had been assigned to them by others. Toni, a respondent of two or more races in her fifties who was dealing with severe mental health problems, said she could access mental health care because “the judge disabled me [based on] my childhood,” referring to the psychological impacts of childhood abuse. Later in the interview, Toni described family members who “were disabled” as a result of physical health conditions, and she distanced herself from them by invoking the as-

signed label. When recounting her family members' multiple diagnoses, such as diabetes, breast cancer, and arthritis, she remarked, "I'm not particularly diagnosed with anything." For Toni, disability was a status assigned to her through interacting with the legal system, not something brought on by physical health, as was true for members of her family. Jesse, a woman in her fifties, talked about how she experienced muscle pain and injury that doctors were unable to diagnose or effectively treat. Jesse said that even though doctors could not give her an "official diagnosis," she took comfort in the fact that she was "actually considered disabled now" once the doctors indicated that she was eligible to receive disability benefits. For these respondents, the use of the word "disability" implied a status given to them that could, if needed, provide them with language to validate their claim to the status and thus manage some of the stigma associated with "disability." Their conditions were serious enough that a bureaucracy and medical professionals said they were unable to work and thus may reflect a way to claim deservingness.

In none of these instances, though, did respondents use any language that might indicate that they held a "positive disability identity." Some, like Lawrence, discussed being disabled in negative terms, noting the difficulty of being incarcerated while mobility impaired and a sense that he was a target in the neighborhood for robbery because of limited mobility. For others, disability was a word to mark a transition or a label placed on oneself by a bureaucratic agency or medical provider. Many of these respondents had worked for many years, had children and sometimes grandchildren, and had other identities which may have been more important. Or, by using disability to describe an event, including a bureaucratic one, respondents may have been negotiating stigma and deservingness by attributing their status to the decisions of others rather than an identity that they actively sought.

### "I Got Hurt"

Other respondents ( $n = 37$ ) reported that they had left the workforce because of an injury, accident, or another discrete health event, but

they also never used the word "disabled" in relation to themselves. They were also more likely to explain the nuance of the injury, illness, or diagnosis, rather than using broad language such as "disability" (or "bad health"). Typically, these accounts were given in response to an inquiry about work or when they last were employed. Sam, a woman of two or more races in her fifties, described when asked about her work history how she injured her head after falling in the restaurant where she worked. She repeatedly used the phrase "got hurt" as she demarcated her time not working from her time working; for example, when later describing her financial position, she said, "I get by. If I never got hurt, I'd be living on Easy Street. I'd be making more; I'd be working overtime." Sam did not use the word "disabled" or describe her health condition in depth, but instead returned to the logic of "getting hurt" to structure her health narrative. Workplace injuries were not uncommon in this group, with numerous stories of accidents involving heavy equipment, injured backs from repeated lifting, and slip and fall accidents that damaged bodies. According to the Bureau of Labor Statistics (n.d.), between 2.6 and 2.8 million workplace accidents occurred each year from 2017 through 2021, and many of these injuries will result in eventual receipt of Social Security Disability Insurance benefits (O'Leary et al. 2012). That an injury is narrated as the direct result of harm experienced at work may help individuals legitimate their claims about being deserving of help, in that the job, and not the individual, was responsible for their condition.

Other respondents who were injured in settings other than work also used the language and logic of "getting hurt" to structure their narration about stopping working. Beth, a White woman in her fifties, slipped outside and broke her wrist. Uninsured at the time, she reported that the break was bad enough to require surgery, but that she could not afford it. So the bones did not heal as they should have and her hand did not function properly. Beth indicated she no longer could work in food service, saying, "I can't physically do it anymore because of the restaurant pots and stuff, they're so heavy, I can't physically do it with this hand. You know, I can't work the can opener, you

know, we're talking industrial everything. I can't do it anymore." Beth, along with other respondents, was able to clearly relay exactly how their injury or other health condition was directly related to not being able to do their job, deploying logic to bolster their claim (for example, my job requires that I use a can opener; my hand isn't functional; therefore I cannot do my job). Analyzing these statements through the lens of stigma and deservingness, this type of logic provides Beth with a legitimacy of her status as someone out of the labor force—an injury simply rendered the job impossible to do.

### **"My Health Is Bad"**

Other respondents ( $n = 68$ ) did not call themselves "disabled" and did not identify specific accidents when they "got hurt," but did refer to their "bad health" as the reason they were no longer working. Claudia, a White woman in her sixties, had worked a variety of jobs, some involving lifting and other manual labor, starting when she was sixteen years old. After she recounted her work history, Claudia noted that "just, my body just got wore out and started deteriorating" as she described why she stopped working. Similarly, Diana, a Black woman in her mid-seventies, said that "my health got bad. I was having problems with my knees and ankles," when she was asked about when she stopped working. She did not refer to herself as disabled (though she did mention that she received disability benefits) or speak in depth about her health beyond what she called these "problems." Like respondents who "got hurt," these respondents described "bad health" as an inevitable or natural explanation for why they were not working.

Some respondents who used vague language around "bad health" may have done so to explicitly avoid discussions of health that would cause others to negatively judge them. Anita, a Hispanic woman in her forties who experienced whole body pain that grew more severe after a car accident, used vague language throughout the interview to describe her health. She later described trying to avoid talking about her pain to her own family: "They would look at me and they'd say, 'nothing is wrong with you, you're okay, you can work.' I'm

like, I may look okay from the outside, but inside of me I'm just, you know, my bones hurt, my body hurts. . . . My daughter was like, 'what's going on now, you know, it's always something.' And that's why I don't want to burden nobody or tell anyone, like, I'm hurting."

Here, Anita's vagueness as the interviewer questioned her may be rooted in the stigmatizing actions of her family and the recognition that others may not believe in the severity of her pain.

Other respondents did not always provide clues about their health or the root of any stigma they were seeking to avoid. For example, Stanley, a White man in his sixties, described receiving disability benefits but never identified the condition or circumstances that led to his labor-market exit and subsequent benefit receipt. When repeatedly asked for clarification by the interviewer for details of the damage to what he referred to as his "nerves," he responded, "It just came on. One time, I don't know what happened. . . . I got a bad back." These respondents may have been trying to minimize stigma and talk of status loss, while in other cases, they might have been answering in good faith but having difficulty narrating details of their health or health-related labor-market exit.

### **"I'm Retired"**

A smaller number of respondents ( $n = 19$ ) used the language of retirement to describe their current situation with respect to employment, even if they received a disability benefit or described having experienced a major health event prior to stopping work. Patrice, a Black woman in her sixties, concluded the description of her work history by noting that "I worked for [my previous employer as a customer service representative] until I retired. I had to retire." Patrice repeatedly described this transition of "having to retire" when describing when she stopped working. She indicated that she had to retire because of a heart condition, and she started collecting disability benefits after stopping working. Echoing the distinction drawn by respondents who narrated "disability" as separate from their labor-market exit, Rimalda, a woman in her seventies, discussed an accident at the hospital kitchen where she

worked that led to her labor-market exit, as well as a number of surgeries she had to correct health problems. Still, she primarily identified as retired. She described her job responsibilities and how that led to her “retirement”: “I worked for twenty years. . . . They were very heavy pots! . . . you have to sweep the floor and mop, lift heavy things. I developed a few hernias. I have two in my spine. Yes. I have this ear—they took this ear out and put in an eardrum. One hernia, two hernias. My gallbladder. My womb, intestines, and bladder. Yes. I’m starting to walk. Not too long ago I did my knees. . . . I quit working because I had an accident and fractured two disks.”

Like many of the respondents in the “bad health” group, Rumalda also listed out numerous health problems, some of which she likely developed after she stopped working. She also invoked language around being hurt (“I had an accident”). Yet Rumalda described the exit itself as being “retired.” At more than seventy years old and being out of the labor force for twenty years, “retired” could also be the word for Rumalda that, from a life course standpoint, made the most sense as an identity and reflected her current position. Overall, respondents who called themselves retired tended to be older than fifty, so retired would be an identity more readily available than it would be to someone who was thirty-five years old.

From a standpoint of stigma management and asserting deservingness, being retired is associated with having put in years in the labor market and paying one’s dues as a worker. People can retire precisely because they have worked. Older adults have also historically fallen into the category of “the deserving” (Watkins-Hayes and Kovalsky 2016), and retirement typically occurs in the early to mid-sixties (Center for Retirement Research 2017). Claiming an identity of being retired could allow individuals to be viewed as deserving, both because of age and because of the status of having been a worker.

### Strategic Application of Narratives

Across the analytic sample, respondents invoked different words or phrases or drew on different rationales to describe their status of

being out of the workforce. Although most were receiving disability benefits, only a portion described themselves as disabled. Even when the word was used, respondents deployed it differently based on the context of different, potentially stigmatized settings, some as an identity, others to describe the point that marked the end of their time in the labor force, and others noting it as a label applied to them.

This strategic application of narratives within an interview is exemplified by Devonte, a Black man in his twenties who was stabbed. Devonte mentioned his health for the first time in the interview when describing his daily routine. He initially emphasized the stabbing’s effect to introduce why his daily routine did not involve working, despite his young age. He then continued his narrative by using language about “getting hurt”: “Right now, I’m trying to take care of some things with social services. Because [I’m] working on getting my disability. I had some [physical] issues. . . . I got stabbed.” At the close of the interview, when asked to share what he most wanted changed in society, Devonte explicitly invoked his “disabled” identity as a way to indicate that he truly deserved benefits, unlike others in his community he seemed to deem unworthy: “Man, where my check at? That’s what I be wanting to know. Where my check? (Interviewer: Yeah? Disability?) Disability, yeah. Mainly, that’s it. Just trying to get my disability because they keep denying it so I might have to get a lawyer. And I’m *really* disabled. I’m not really able to work, but some Black people here get checks. I don’t get a check.”

Devonte’s case also exemplifies how when providing justifications for not working that reflect narratives of who is deserving, respondents invoked other systems of stereotyping and group separation, including racialized perceptions of deservingness.

Some respondents invoked shifting identities as they described navigating the disability benefit application system. The judgment of a bureaucracy provided respondents both benefits in the form of financial assistance and legitimacy to not be in the labor market. Martin, a man in his forties, described being trapped between “getting hurt” and being “disabled.” After an initial injury, Martin’s back deteriorated

rated, causing increasing pain. A series of treatments were unsuccessful, and he asked a doctor for a medical exemption from work, yet the Social Security Administration declared him able bodied: “I told [the doctor] that ‘‘You already know you had burned the nerves and I still have pain in my back.’’ So that’s when the doctors classified me as disabled, and they told me that I can’t go to work. So, that’s how we’ve been trying to fight the state and trying to fight the class, am I a disabled worker now? I don’t want to go to work no more but they still say I’m able to go to work.’’

Martin’s responses show how the shifting judgments of bureaucracy affected both the availability of benefits and the language and identities employed by respondents.

In light of data limitations, we cannot always make direct links between respondents’ narratives and an experience of stigma or a claim of deservingness, as is the case with Martin. Yet, that some people described in great detail how an injury or health problem interfered with their ability to work suggests some internalization of the idea that nonworkers need a justifiable reason for being in that category. Further, opting to use the term “retired,” a status in the United States that is widely considered to be earned, rather than “disabled” may suggest a need to reframe a health-driven labor-market exit.

Finally, the narratives a respondent invoked were affected by the mode and context of the interview. The AVP shifted from face-to-face to phone interviewing after the COVID-19 pandemic began and found significant differences in the language respondents used to describe their health-related labor-market exits. Face-to-face respondents were more likely to indicate they were retired rather than opposed to disabled, whereas phone respondents were more likely to say disabled than retired. Respondents who used the word “retired” may have been

more likely to answer an in-person interview request (a coverage effect) because they had fewer constraints on their time. Respondents who used the word “disabled” may have felt less stigma conducting their interview over the phone than in a face-to-face setting (a social desirability effect)—further indicating the role of these terms as a way to manage deservingness.<sup>8</sup>

## DISCUSSION

Our study finds that people who leave the labor market for health reasons use several discursive and narrative techniques to describe their exits, and many of the ways that they tell their stories could imply a need to manage a stigmatized identity and provide a deserving rationale for not working. The tensions illustrated in respondents’ discourse demonstrates a need to rethink the status of “disabled,” at least as it relates to benefit receipt and absence from the labor market. Although some respondents presented their health condition as a legitimate reason for not working, only 32 percent of this sample reported that they were “disabled,” indicating that this term is not embraced by many who, for the most part, meet the Social Security Administration’s definition of being disabled. Some had other identities on which to draw (including being retired), whereas others referred to their general health or injury. We suggest that the importance of work in the United States has rendered even labor market exits on the basis of a health problem as an event that carries stigma and for which individuals believe they must make claims of deservingness. This runs counter to much of the literature that categorizes beneficiaries with a disability as automatically deserving that help. Many of the people in that status, though, may have internalized a shift in the popular discourse about disability and disability benefits, one that casts suspicion on a previously deserv-

8. Even though COVID-19 is associated with increased likelihood for disability, such differences are unlikely to be driven by the health effects of the COVID-19 pandemic itself (Deitz 2022). No respondent in the sample discussed COVID-related health effects as the reason they had exited the labor market. Further, no difference between the proportions of the whole AVP sample who reported having a health-related labor market exit before and after the onset of the pandemic was statistically significant:  $\chi^2(2, N = 1616) = 0.82, p > .05$ . However, differences in the proportions within the analytic sample who used disability and retirement language before and after the pandemic were significant:  $\chi^2(3, N = 183) = 8.21, p = .041$ .

ing group of people as possible shirkers who are not pulling their weight.

Additionally, although other studies have found that many of those who are disabled reject the term (Bogart et al. 2017), our study demonstrates the ways that people use these narratives to make sense of their situation, with some finding other ways to define themselves in ways that gives them claims to being deserving of not working. Moreover, we are able to do this with a nationally representative sample of people with a variety of health conditions, not analyzing the experiences of people with a particular type of disability.

Our finding that some respondents adopt the term “retired” to describe their health-related labor-market exit also shows the persistence of the perceived stability and status of “lock step” or “traditional” retirement. Research on retirement and meaning-making (Kojola and Moen 2016) has sought to understand the meaning of retirement given macro-level changes in institutional support available for nonworkers (such as the decline of defined benefit retirement plans) and demographic transitions (such as populations living and working longer) that make “traditional retirement” less prevalent. Our study, however, indicates that adults who experienced health-related labor-market exits, who themselves were less likely to have access to pension or retirement savings and instead receive SSDI or SSI, use this language to narrate their experiences.

The legitimization discourses in which people engaged to explain why they were not working centered on invoking experts and using logic. In particular, respondents who logically spelled out why they could not work drew on the required job tasks that their condition no longer allowed them to perform. These techniques gave respondents the opportunity to justify their absence from the labor market in a way that portrayed them as a group who were reasonably not working (as opposed to shirking) and thus deserving of their status.

The emergent narratives among people who left the labor market for health reasons have implications for future research, including in survey and qualitative research, the design and outreach of social services, and for public policy. Before discussing those, we note that our study is not without limitations, which we highlight here.

First, we are unable to make strong claims about whether respondents’ narratives were shaped by actual experiences of stigma from other people and subsequent needs to assert deservingness. The design of the AVP provided breadth of topic areas over depth or thickness of qualitative data and provided no opportunity for secondary analysts to ask probing questions (just as the original data collection guide did not allow for much probing) or conduct follow-up interviews. For example, although we observed that some respondents brought up racialized stereotypes when drawing distinctions between themselves and those who they perceived as undeserving, we had no opportunity to systematically ask all respondents about this subject in follow-up questions during the interview. Thus we do not confirm or refute whether respondents’ racial identity affects their use of narrative schemes. Similarly, the length and richness of respondents’ discussion of their health and work meant that not every respondent provided information that constituted a narrative in its idealized form. Future qualitative research on respondent’s narratives about their health and work should address the roots of these accounts (and in this way, the AVP can serve as a public resource to establish new areas of research). In addition, future interpretive qualitative research that uses the AVP corpus should note this inherent variation among the focus of respondents’ interviews.

Second, our study is limited by the AVP’s sampling frame and design, which selected respondents who lived independently and served as the “household head.”<sup>9</sup> The narrative findings presented here may not generalize to the population of people who live in group quarters

9. We reviewed a sample of the 149 transcripts of respondents who themselves were not in the analytic sample but who had other household members who were labor market non-participants. We decided that the primary respondent in these cases did not consistently provide enough content about the experiences of these other household members to allow for narrative analysis.

(such as group homes or assisted-living facilities) or who are being supported by another member of their household.

Finally, we note our positionality during the secondary analysis of interview content as researchers who do not identify as having a disability. Our identities too may both shape how we interpreted our findings as well as what we overlooked.

Our findings can inform future qualitative work on people who leave the labor market for health reasons. By analyzing a nationally representative sample of the population and then selecting respondents who shared health-related labor-market exits, we find that respondents share no one set of language and may not consider themselves disabled even if they are receiving benefits from a disability program. Future research with people with disabilities can provide important depth of qualitative detail, but recruitment of those participants should consider that some people with lived experience of disability will not identify as disabled. Similarly, future qualitative research on retirement and meaning-making should seek to include respondents who might otherwise be excluded from sample selection because they experience a health-related labor-market exit. Finally, future studies might consider whether individuals' perceptions of stigma and deservingness change over time, are more prevalent across different subpopulations, adapt to different conditions (such as economic downturns, major policy shifts), or are sensitive to the type of survey or interview mode.

We recommend attention be given to the role stigma plays in health narration and service delivery. Policymakers and practitioners alike should be aware that not all individuals will be quick to identify as "disabled" or outline the specific ways in which injury impacts occupational functioning. Moreover, despite the history of disability as being perceived as a deserving category in the United States, the narratives of those with health-related labor-market exits indicated that this status is fraught. We find that respondents take efforts to prevent stigma and present a deserving story in narrating their health-related labor-market exit. The process of applying and being approved for disability benefits can be arduous

and for some, take years (Dorfman 2017), also reflecting a level of mistrust of those seeking to claim the benefit. Perhaps it is time to recognize that deviations from a presumed norm of "worker" are inherently imbued with stigma, unless larger cultural shifts occur.

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