DISABLING INEQUITY: HOW THE SOCIAL MODEL OF DISABILITY RESISTS BARRIERS TO SOCIAL SECURITY DISABILITY BENEFITS

ANDREW GERST[∝]

TARA SCHWITZMAN-GERST[∞]

ABSTRACT

The number of people in the United States receiving Social Security Disability Insurance ("SSDI") and Supplemental Security Income ("SSI") benefits has expanded significantly since the 1980s. However, current law still prevents many disabled Americans from receiving this financial assistance. The SSDI/SSI process relies on the medical model of disability, which locates the problem of not being able to work in an individual's capacities. The social model of disability, on the other hand, suggests that inaccessible work environments, rather than a person's physical limitations, exclude disabled people from gaining employment. In this Article, we use the social model to problematize the barriers that disabled people face when they seek SSDI/SSI benefits. In line with the social model, we highlight the narratives of disabled people seeking benefits to reveal the problems in the SSDI/SSI system. We conclude by utilizing the social model to suggest ways of reforming the SSDI/SSI process that recognize the agency of disabled people and are ultimately more humanizing than the current ways of thinking about and problematizing this process.

[∝] Andrew Gerst, NYU Law '18, RLSC '18, is currently the Sinsheimer Fellow at Mobilization for Justice. He wishes to thank his wife, Tara, for inspiring this article and for helping us see it through. He also wishes to thank the incredibly dedicated staff of *Review of Law & Social Change* for this opportunity. In particular, he wishes to thank: Gina Bull, NYU Law '19; Michael Diller, NYU Law '20; Kevin Reilly, NYU Law '20; and Efosa Akenzua, NYU Law '20.

[∞] Tara Schwitzman-Gerst is a Doctoral Candidate in the Department of Curriculum and Teaching at Teachers College, Columbia University and an Adjunct Professor of Women's and Gender Studies and Elementary and Secondary Education at New Jersey City University. Her current research utilizes Disability Studies and Critical Race Theory in Education ("DisCrit") to examine how professors at Hispanic Serving Institutions are supporting preservice teachers of Color and teaching about K-12 student diversity. She wishes to thank, first and foremost, her husband Andrew for his work and dedication to this article. She also wishes to thank her dissertation committee—Dr. Sriakala Naraian and Dr. Michelle Knight-Manuel—for their support in helping her develop as a scholar and teacher. Finally, she thanks the dedicated staff of *Review of Law & Social Change* for being so welcoming to someone's perspective outside of law and legal theory.

I.
INTRODUCTION

"Disability marks the last frontier of unquestioned inferiority because the preference for able-bodiedness makes it extremely difficult to embrace disabled people and to recognize their unnecessary and violent exclusion from society."

–Tobin Siebers, Disabled Scholar, Author of *Disability Theory*[1]

"There's a stigma about it. . . . Disabled. Disability. Drawing a check. But if you're putting food on the table, does it matter?"

–Desmond Spencer, Disability Applicant, Rural Alabama[2]

In 2017, 10,002 people died while waiting to receive Social Security Disability Insurance benefits ("SSDI").[3] How can this be?

Imagine that you have worked your whole life as a nursing home cafeteria assistant. Day in and day out, you have lifted twenty-pound crates of milk. You have ladled out cartons of soup to several hundred elderly people antsy from sitting for the last three hours. You have swept floors, picked up dirty napkins, washed silverware, taken out trash. You have done all of this work for minimum wage. Perhaps, like many cafeteria workers, you do not speak English as your first language. You have not finished college, or even high school. You are struggling to support three children. You do not own a car.

At age 50, you reach for a mop and know that you cannot lift it. Your hands and your arms and your feet feel shattered. Every ounce of you knows that you cannot return to your work if you have to continue lifting heavy objects. You go to one doctor, then another. They listen carefully, for five minutes. They prescribe you painkillers. They each tell you they understand you experience pain, but that there is nothing more they can do. A friend tells you that you might qualify for Social Security benefits. So, you fill out a form with confusing questions about your work history, your pain, and then you speak on the phone with someone who asks you more questions.

A few weeks later, you receive a letter in the mail. The letter states that the Social Security Administration has reviewed the evidence and has declared

---

[1] TOBIN SIEBERS, DISABILITY THEORY 6 (U. Mich. Press 2008).

[2] Terrence McCoy, *Disabled, or Just Desperate? Rural Americans Turn to Disability as Jobs Dry Up*, WASH. POST (Mar. 30, 2017), https://www.washingtonpost.com/sf/local/2017/03/30/disabled-or-just-desperate/?utm_term=.2332f2938d71 [https://perma.cc/9L58-H9AP].

[3] Terrence McCoy, *597 Days. And Still Waiting*, WASH. POST (Nov. 20, 2017), https://www.washingtonpost.com/sf/local/2017/11/20/10000-people-died-waiting-for-a-disability-decision-in-the-past-year-will-he-be-next/?noredirect=on&utm_term=.09837f4ad3ff [https://perma.cc/5Z9C-XHPK].

you "Not Disabled." You check another box indicating your wish to appeal this decision. You then wait—and wait—and wait. You may wait as long as two years or more.

Finally, you get your hearing. You nervously arrive in a bureaucratic office and wait for an hour. Finally, a clerk calls your name. The clerk takes you into a small, windowless room. A judge starts talking to you. The judge asks you questions—"tell me about your impairments; could you lift a carton of milk? Could you twist it?"—and wishes you the very best of luck. You leave the room confused. A few weeks later, you receive another letter in the mail. The letter says that the judge has carefully considered all the evidence and has again declared you: "Not Disabled." You wonder how you will put food on the table for your children.[4]

This outcome is typical under the highly "medicalized" criteria for SSDI eligibility, which focuses on the individual's physical limitations or capabilities. The scenario, with minimal variations, affects millions of people in the United States, and its focus on individual capacity aligns with public perceptions of disability.

In this Article, we examine the barriers that impact the people trying to secure SSDI benefits. We start by providing an overview of the social security disability determination process. Next, we introduce the social model of disability as an alternative, more humanizing way of thinking about disability identity and experience. We introduce this model because the current determination process focuses on disabled people's alleged deficits, thereby making it more difficult for them to voice their experiences and advocate for themselves. We then use this theoretical framework to review how the social and medical models have been utilized/discussed in prior literature on reforming the social security disability benefits process. Next, we use the social model of disability to problematize the current benefits process. Finally, we conclude with proposed solutions to the problems we outline within the current system.

II.

OVERVIEW OF THE SOCIAL SECURITY DISABILITY DETERMINATION PROCESS

More than 8.6 million people receive SSDI benefits each year. Under the program, disabled individuals who cannot work receive an average monthly benefit of $1,384.71.[5] SSDI has become a controversial program. Some observers have compared SSDI and its cousin SSI (Supplemental Security Income) to universal basic income, suggesting the programs could launch a wider basic income program.[6] Others have documented the growth of national "disability belts," in

---

[4] *Id.*

[5] SOC. SEC. ADMIN., DISABLED WORKER AVERAGE BENEFITS, https://www.ssa.gov/oact/STATS/dib-g3.html [https://perma.cc/45FY-S7SM] (last modified Aug. 2019).

[6] *See*, *e.g.*, Ellie Anzilotti, *Could Social Security be the Foundation for a Growing Basic Income System?*, FAST COMPANY (May 7, 2019), https://www.fastcompany.com/90343330/could-

Appalachia and the Deep South, where large percentages of people rely on SSDI for income.[7] In Hale County, Alabama, "nearly 1 in 4 working-age adults" receive SSDI benefits.[8] According to NPR's Planet Money, "[t]he federal government spends more money each year on cash payments for disabled former workers than it spends on food stamps and welfare combined."[9] National unemployment figures underreport the real number of Americans not working, as SSDI recipients are considered excluded from the labor force.[10]

The eligibility requirements for SSDI have shifted over time. While the program was originally envisioned for workers with severe physical impairments, "in 1984, Congress broadened the criteria, giving more weight to chronic pain and mental disorders."[11] Since then, the number of individuals receiving disabilities has continued to expand significantly: about 2.5 million workers received SSDI benefits in 1985, far lower than the roughly 8.6 million receiving benefits today.[12] Others have noted the growth of SSDI followed on the heels of welfare reform, suggesting that many people who previously received welfare subsequently sought SSDI instead.[13] Workers pay into SSDI through a tax on each paycheck and, after contributing for a sufficient length of time,[14] can claim benefits if a disability develops that renders them unable to work.[15]

---

social-security-be-the-foundation-for-a-growing-basic-income-system [https://perma.cc/B25V-WQRX]; Dylan Matthews, *What Happens if You Replace Every Social Program with a Universal Basic Income*, VOX (May 30, 2017), https://www.vox.com/policy-and-politics/2017/5/30/15712160/basic-income-oecd-aei-replace-welfare-state [https://perma.cc/23K7-YD4K].

[7] Brendan Greeley, *Mapping the Growth of Disability Claims in America*, BLOOMBERG BUSINESSWEEK (Dec. 16, 2016), https://www.bloomberg.com/news/features/2016-12-16/mapping-the-growth-of-disability-claims-in-america [https://perma.cc/X6TF-T85X]; *see also* McCoy, *supra* note 2.

[8] Chana Joffe-Walt, *Unfit for Work: The Startling Rise of Disability in America*, NPR PLANET MONEY (2013), http://apps.npr.org/unfit-for-work/ [https://perma.cc/77K3-4BJF].

[9] *Id.*

[10] *E.g.*, *id.*

[11] Greeley, *supra* note 7.

[12] Joffe-Walt, *supra* note 8.

[13] *Id.*

[14] "Social Security Disability Insurance (SSDI) supports individuals who are disabled and have a qualifying work history, either through their own employment or a family member (spouse/parent)." Brandy Bauer, *SSI vs. SSDI: What Are These Benefits and How Do They Differ?*, NCOA BLOG (Apr. 6, 2017) https://www.ncoa.org/blog/ssi-vs-ssdi-what-are-these-benefits-how-they-differ/ [https://perma.cc/2QUF-EAE9]; *Accord* SOC. SEC. ADMIN., 2018 RED BOOK (2018), https://www.ssa.gov/redbook/eng/overview-disability.html [https://perma.cc/MRL6-J2G] (explaining that disabled individuals with little to no work history typically go through the Supplemental Security Income ("SSI") program instead of SSDI) [hereinafter 2018 RED BOOK].

[15] *See* 2018 RED BOOK, *supra* note 14 ("SSDI [Social Security Disability Insurance] provides benefits to disabled persons who are 'insured' by 'workers' contributions to the Social Security trust fund. These contributions are based on your earnings (or those of your spouse or parents) as required by the Federal Insurance Contributions Act (FICA).")

III.
(LEGAL) ASSUMPTIONS ABOUT DISABILITY IDENTITY AND EXPERIENCE

This Article contrasts two prominent ways of thinking about disability: the medical model and social model. These two models rely on fundamentally different assumptions about people with disabilities.

The medical model frames disability as an individual defect, or deficit, in need of diagnosis, treatment, and remediation.[16] Under the medical model, a person with cerebral palsy is understood to be inherently limited by the physical demands of her condition, as compared to a "normal" body. Society has traditionally relied on this model, and indeed many people may consider this model the *only* way to think of disability.

First developed in the field of disability studies,[17] the social model conceptualizes disability as constructed in the environment, rather than in the individual.[18] The social model recognizes a person with cerebral palsy is limited not by her body, but by places or institutions that are not designed to be accessible. The social model thus develops a more relational and holistic theory of disability, focused on the person, not the problem.

The social model of disability contextualizes medical realities in a social justice framework.[19] A person with cerebral palsy really does have differences in a biological sense from a person who does not have cerebral palsy. However, society can choose to make that cerebral palsy a defining aspect of their personality,[20] or merely an ancillary one, like brown eyes or dark hair. While many people would chafe in a society where worth was determined by eye color, people with cerebral palsy and other disabilities today face equally arbitrary barriers to social acceptance and survival.

The question of differential treatment may be complicated and highly personal for people with disabilities. For instance, some disability rights activists have likened disability to racial identity, noting that some disabled people may want to reclaim their disability and fight against the stigma.[21] Others may argue

---

[16] "The medical model defines disability as an individual defect lodged in the person, a defect that must be cured or eliminated." SIEBERS, *supra* note 1, at 3.

[17] David J. Connor et al., *Disability Studies and Inclusive Education—Implications for Theory, Research, and Practice,* 12 INT'L J. OF INCLUSIVE EDUC. 441, 442-43 (2008).

[18] Philip M. Ferguson & Emily Nusbaum, *Disability Studies: What Is It and What Difference Does It Make?*, 37 RES. & PRAC. FOR PERSONS WITH SEVERE DISABILITIES 70, 72-73 (2012).

[19] SIEBERS, *supra* note 1, at 25.

[20] The physical differences that require someone to use a wheelchair often "classif[y] an entire person 'disabled' even though the rest of the body and its functions remain 'normal.'" GARLAND-THOMSON, *infra* note 25, at 34.

[21] Beth Haller, *Journalists Should Learn to Carefully Traverse a Variety of Disability Terminology*, NAT'L CTR. ON DISABILITY & JOURNALISM (Jan. 7, 2016), https://ncdj.org/2016/01/journalists-should-learn-to-carefully-traverse-a-variety-of-disability-terminology/ [https://perma.cc/Y9MM-BTM6].

that disabled people should not be treated differently from able-bodied people in any way, regardless of the intentions behind differential treatment. Indeed, not everyone with a disability is proud to be disabled.[22] The social model of disability roots disability identity in repeated experiences with inaccessible rules, policies, and structures, rather than medical or biological difference.[23] Though there is no biological basis for race,[24] being a person of color can become a permeating part of one's identity because of the constructed norm of whiteness.[25] As such, even everyday interactions with white individuals or institutions signal to people of color the various privileges that white people receive at their expense.[26] The social model of disability posits a similar experience for people with disabilities. By focusing solely on the physiological nature of disability, the medical model tacitly accepts that society may accommodate some conditions more than others. The social model of disability demands a world designed for all abilities.

The social model also argues that when we design environments for everyone, they are improved even for the nondisabled. A pregnant woman may not need a ramp, but it may improve her overall experience accessing a building. Put differently, the medical model is inherently-diminishing, carrying implications of weakness, helplessness, and dependency, precisely because it tends to reduce an entire individual to her impairment,[27] while the social model recognizes that there are

---

[22] David J. Conner, *Social Justice in Education for Students with Disabilities in* THE SAGE HANDBOOK OF SPECIAL EDUCATION 111-28 (Lani Florian ed., SAGE Publications 2nd ed. 2013) (citing Torn Shakespeare & Nicholas Watson, *The Social Model of Disability: An Outdated Ideology?,* 2 RES. SOC. SCI. DISABILITY 9, 19 ("Many disabled people do not want to see themselves as disabled, either in terms of the medical model or the social model. They downplay the significance of their impairments, and seek access to a mainstream identity. They do not have a political identity, because they do not see themselves as part of the disability movement either.").

[23] The social model, then, emphasizes that even for disabilities with physical impairments and differences, the experience of being labelled disabled or abnormal and of experiencing a disabled identity are often more impactful than biological differences. *See* Alicia Broderick, *Autism as Enemy: Metaphor and Cultural Politics in* HANDBOOK OF CULTURAL POLITICS AND EDUCATION (Zeus Leonardo ed., 2010).

[24] *See Race: The Power of an Illusion* (California Newsreel 2003). This three-part documentary series debunks myths that the biological features that we have interpreted as racial differences explain human behavior. It also shows how race has been socially constructed and used to justify economic exploitation and the existence of various stratum in the United States.

[25] The norm in society is often what is unstated. Evidence that white people are the norm is that white people often do not see themselves as racial and/or ethnic: "Because they represent the societal norm, Whites can easily reach adulthood without thinking much about their racial group. . . . There is a lot of silence about race in White communities, and as a consequence Whites tend to think of racial identity as something that other people have, not as something that is salient for them." ROSEMARIE GARLAND-THOMSON, EXTRAORDINARY BODIES: FIGURING PHYSICAL DISABILITY IN AMERICAN CULTURE AND LITERATURE 93-94 (1997).

[26] Peggy McIntosh, *White Privilege: Unpacking the Invisible Knapsack*, PEACE & FREEDOM MAG., 10-12 (July – Aug. 1989).

[27] *See* GARLAND-THOMSON, *supra* note 25, at 34 ("Similar to other dualistic systems such as gender and race, the disabled/able-bodied dichotomy sorts people by interpreting physical traits that are in fact less easily categorized than the system admits. For example, although actual impairments usually affect particular body parts or physical functions, one specific difference classifies an entire

other aspects to a person's identity in addition to the diverse ways in which they move. Additionally, the social model emphasizes that the experience of being labeled disabled or abnormal is often more impactful for people with disabilities than biological differences alone.[28] For the cafeteria worker, the experience of being labeled disabled and the social stigma of applying for social security disability benefits is likely the source of anger and frustration, rather than the aging body.

IV.

HEGEMONY OF THE "MEDICAL MODEL": A REVIEW OF THE CURRENT DISABILITY STUDIES AND LAW LITERATURE ON REFORMING THE SOCIAL SECURITY DISABILITY BENEFITS PROCESS

Many scholars in the fields of disability studies and education have used the social model to propose reforms to laws intended to support people with disabilities. For example, Lennard Davis has applied the social model in discussing the history of the Americans with Disabilities Act and the important work of understanding people with disabilities as a cohesive minority group, rather than a group of people defined by specific impairments.[29] In theory, this framework would earn disabled people recognition as the type of "discrete and insular minorit[y]" entitled to protection under constitutional law.[30] Tobin Siebers uses the theory of complex embodiment, an extension of the social model, to challenge the very notion of humanity in human rights discourses, which he argues is premised on idealized able bodies and minds.[31] Other scholars have similarly drawn out the complicated interrelationship between disability and other social movements.[32] For example, women suffragists used disability as a foil to assert women's right to vote, arguing they were more qualified to vote than people with mental disabilities.[33]

---

person 'disabled' even though the rest of the body and its functions remain 'normal.'").

[28] Broderick, *supra* note 23, at 237, 265.

[29] LENNARD J. DAVIS, ENABLING ACTS: THE HIDDEN STORY OF HOW THE AMERICANS WITH DISABILITIES ACT GAVE THE LARGEST MINORITY ITS RIGHTS 228 (Beacon Press 2015).

[30] *See* United States v. Carolene Products Co., 304 U.S. 144, 152 n.4 (1938) (describing that legislative acts affecting a discrete and insular minority might require the court to exercise "more searching judicial scrutiny.").

[31] SIEBERS, *supra* note 1, at 26, 180 (arguing that basic human rights in the United States, such as "[not being] forced [into] confinement, . . . the right to sue or to be sued in court, [to receive] money damages against employment discrimination for state jobs, [and to not be] blocked from polling places by inaccessible architecture and obsolete voting rules, and severely limited in [one's] ability to travel from place to place" are often not available to people with disabilities).

[32] Douglas C. Baynton, *Disability and the Justification of Inequality in American History*, *in* THE NEW DISABILITY HISTORY: AMERICAN PERSPECTIVES 33, 33-34 (Paul K. Longmore and Lauri Umansky eds., N.Y.U. Press 2001) (illustrating how advocates of women's suffrage and the civil rights movements distinguished themselves from the stigmatizing stereotypes often applied to the disabled).

[33] *Id.*

Much of the current literature on SSDI highlights discrete suggestions for improving the program, without any regard to the underlying theory of disability.[34] There has also been important recent scholarship operating outside of the medical model, such as the qualitative study of 14 SSDI/SSI applicants in California conducted by Doron Dorfman, now an associate professor of law at Syracuse University.[35] Dorfman focuses on "the relationship between how a person perceives herself (her disability identity) and how she believes the DDP [disability determination process] perceives her."[36] His piece analyzes the "procedural justice"[37] aspects of the SSDI/SSI process. Some of his findings comport with our recommendations, such as the finding that "[a]ll the interviewees (regardless of their identity group) felt they lacked the opportunity to voice their opinions and tell their stories during the DDP"[38] and the need for "dignity"[39] in the process. One point of difference is that Dorfman's work focuses more on these qualitative interviews, and less on the legal framework for SSDI/SSI itself. In other words, while Dorfman's excellent work discusses the experiences of his interviewees, it provides less of a global critique of the laws and systems themselves that comprise the substance of the SSDI/SSI universe.[40]

This Article also responds to scholars who have criticized the utility of the social model of disability in a legal context. For example, Adam Samaha, a professor at New York University School of Law, has questioned the utility of the social model outright, arguing that, "like all social construction accounts, [it] has essentially no policy implications. Its impact depends on normative commitments developed by some other logic, such as membership in the disability rights movement. . . ."[41] We argue that the social model does not depend on membership in any community, and that it can serve as a guiding principle for reforming SSDI.

---

[34] *See, e.g.*, Jon C. Dubin, *A Modest, Albeit Heavily Tested, Social Security Disability Reform Proposal*, 23 GEO. J. ON POVERTY L. & POL'Y 203 (2016); Hannah Weinberger-Divack, *Redefining Disability: Increasing Efficiency and Fairness in SSDI*, 21 ELDER L.J. 263 (2013); Max Bookman, *Reevaluating Administrative Evidence Policy: The Case for Two Exclusionary Rules at Social Security Administrative Hearings*, 11 CARDOZO PUB. L. POL'Y & ETHICS J. 69 (2012).

[35] Doron Dorfman, *Re-Claiming Disability: Identity, Procedural Justice, and the Disability Determination Process*, 42 LAW & SOC. INQUIRY 195 (2017).

[36] *Id.* at 204.

[37] *Id.*

[38] *Id.* at 214.

[39] *Id.* at 216.

[40] Note that Dorfman used the same 14 interviews for a second, similar law review article published earlier in 2015. *Compare* Doron Dorfman, *Disability Identity in Conflict: Performativity in the U.S. Social Security Benefits System*, 38 THOMAS JEFFERSON L. REV. 47 (2015) *with* Dorfman, *supra* note 35. Note also that some law articles on SSDI, while not focusing on the medical model *per se*, do attempt to use a more humanistic approach toward the process. *See, e.g.*, Christopher E. Pashler, *Mirror, Mirror, on the Wall: Stigma and Denial in Social Security Disability Hearings*, 43 U. MEM. L. REV. 419 (2012); Margaret C. Rodgers, *Subjective Pain Testimony in Disability Determination Proceedings: Can Pain Alone Be Disabling?*, 28 CAL. W. L. REV. 173 (1992).

[41] Adam M. Samaha, *What Good is the Social Model of Disability?*, 74 U. CHI. L. REV. 1251, 1251 (2007).

V.
PROBLEMATIZING THE CURRENT SSA APPROACH

A. Dehumanization and the Medical Model of Disability

Larry, an African American man who appears as part of a series of stories on the Social Security Administration's web site, worked as a cashier.[42] Larry experienced a heart attack and was subsequently diagnosed with congestive heart failure. He receives SSDI benefits and works part-time, as is permitted in the program.[43] Larry explains:

> My condition limits me to lifting 35 pounds. I can't stay on my feet for a long period of time, and the doctor told me not to do anything stressful. I am a cashier, and I stock shelves and do general maintenance cleanup. I work part-time, about 25 hours a week. Social Security has helped me not only financially but also medically, because I would not be able to pay for the medicine I receive, the treatments I've had, or my regular doctor visits. So, it's helped me tremendously.[44]

Larry's is a success story, but it illustrates how the medical model denies people with disabilities agency. To receive benefits, Larry must meet the criteria in a "listing"[45] to qualify for benefits. He is thus charged with proving there is something "wrong" with him, rather than advocating for ways in which he can combine employment and benefits to stabilize his life. Instead, the conversation focuses on Larry's heart defect—not the fact that Larry's employer may be unwilling to make accommodations for his heart condition. The SSA stories position the applicant as a victim of a medical affliction, with the SSA intervening to save the claimant. The social model of disability might tell a different story, particularly with respect to access to quality medical care. If society had provided Larry with greater access to preventive health care years earlier, he might have been able to take preventive

---

[42] *Larry's Story*, SOC. SEC. ADMIN. (Feb. 2015) https://www.ssa.gov/disabilityfacts/stories/larry.html [https://perma.cc/K84D-CLRF]. While the SSA presents individuals like Larry as "The Faces and Facts" of disability, the presentation of the stories suggests they may perhaps be composites or fictionalized accounts.

[43] *Id.*

[44] *Id.*

[45] SSA defines "listings" roughly as follows: "The Listing of Impairments describes, for each major body system, impairments considered severe enough to prevent an individual from doing any gainful activity (or in the case of children under age 18 applying for SSI, severe enough to cause marked and severe functional limitations). Most of the listed impairments are permanent or are expected to result in death, or the listing includes a specific statement of duration. For all other listings, the evidence must show that the impairment has lasted or is expected to last for a continuous period of at least 12 months." SOC. SEC. ADMIN., DISABILITY EVALUATION UNDER SOCIAL SECURITY: PART III – LISTING OF IMPAIRMENTS, https://www.ssa.gov/disability/professionals/bluebook/listing-impairments.htm. [https://perma.cc/MG4W-4733] (last visited Dec. 26, 2019) [hereinafter, LISTING OF IMPAIRMENTS].

steps—such as leading a healthier, less stressful lifestyle. Indeed, African American men like Larry are more likely to experience life stressors that can lead to heart disease.[46] If society had created a system where Larry and others could access universal health care, and where people of all races experienced the healthcare world in an egalitarian way, he would be less likely to become disabled in the first place.

In utilizing the medical model, the SSDI system reinforces that access to employment and the means for economic survival can rightly be conditioned on a person's presumed capacity to work individually and autonomously, without supports from the environment and/or employer. That inclusion and exclusion in the economic sphere are legitimized on the basis of capacity, is rarely challenged or questioned.[47] Indeed, even after the passage of the ADA, employment discrimination targeting people with disabilities is still rampant and not blunted by affirmative action.[48] As such, people with disabilities are caught between proving that they are sufficiently disabled to either receive benefits or prevail in an employment discrimination claim and denying their disability, and identity as a disabled person, to receive work. The binary nature of this choice makes it hard to imagine fully inclusive work places for people with disabilities and might also explain why the courts spend more time examining whether someone meets the "criteria" for certain disabilities, rather than examining the workplace discrimination claims brought forth by disabled people. People who are not "disabled enough" may even fall into a space without protection under the current law.[49]

Furthermore, the legal system has failed to problematize the ways in which people with disabilities contribute to society without compensation. As stated earlier, people with disabilities are often not the first choice for employment opportunities, even in spaces where their contribution and representation are necessary. For example, disabled characters on movies and TV shows are often portrayed by nondisabled actors.[50] Thus, disabled people provide the stories and inspiration for nondisabled workers. Yet, they do not receive compensation. In fact, disabled people are often positioned as "inspiration porn"[51] for nondisabled people in many

---

[46] David R. Williams, *How Racism Makes Us Sick*, TED, https://www.ted.com/talks/david_r_williams_how_racism_makes_us_sick?utm_source=newsletter_weekly_2017-04-07&utm_campaign=newsletter_weekly&utm_medium=email&utm_content=bottom_left_image [https://perma.cc/T9H7-H63E] (last visited Aug. 13, 2019).

[47] Nirmalla Erevelles, *Understanding Curriculum as Normalizing Text: Disability Studies Meet Curriculum Theory*, 37 J. OF CURRICULUM STUD. 433 (2005).

[48] DAVIS, *supra* note 29.

[49] *Id.*

[50] Alyssa Andrews, *TV Is Still Failing People with Disabilities, and Here's Why*, TV GUIDE (Aug. 31, 2018) https://www.tvguide.com/news/tv-tropes-disabilities-comic/ [https://perma.cc/B47M-6N9V].

[51] Stella Young, *I'm Not Your Inspiration, Thank You Very Much*, TEDXSYDNEY at 3:03 (April 2014) https://www.ted.com/talks/stella_young_i_m_not_your_inspiration_thank_you_very_much.

places of employment. For example, the manager of a supermarket might reap the psychological benefits of feeling good about themselves for hiring a cashier with an intellectual disability. Yet, the same cashier might have inadequate protection under law if they are fired for not working at a quick enough pace. While the SSDI system itself cannot solve this problem alone, it can partially offset some of the paid and unpaid benefits that nondisabled people receive at the expense of people with disabilities.

In order to receive Social Security benefits, the claimant must also demonstrate some degree of suffering.[52] This suffering must be quantifiable and needs to fall into the correct quantity or category of pain.[53] To qualify for benefits, the claimant needs to show that their pain is severe and permanent enough to meet the agency's standards. Pain is considered a static, stable, and uniform experience. In reality, the ways in which pain affects the lived experiences of individuals is hardly static. Disabled scholar Rosemarie Garland-Thomson writes that physical impairments are almost never static, and instead are "dynamic, contingent conditions affected by many external factors and usually fluctuating over time."[54] Furthermore, fluctuation and/or unpredictability may even be integral to the very definition of mental disabilities, such as bipolar disorder.

Similarly, two people with the 'same' impairment may not experience it in the same way, especially if they are different along the lines of race and class. For example, a poor Black person and a middle-class white person may have different experiences as "wheelchair users," given the intersection of their other identities. Mental "impairments," or disabilities, similarly fluctuate in terms of how people experience them. For example, a Black child in school with a learning disability is more likely to be excluded from the general education classroom than a white child in school with the same label.[55] Or, a Black child and a white child exhibiting similar (disabled) behavior will likely receive different disability labels.[56] The white child may receive the label of learning disability, which is less stigmatizing, than the more likely label a Black child would receive, such as emotionally disturbed. The same dynamic affects SSDI claimants: a 1992 national study by the General Accounting Office found that Black people were denied both SSDI and SSI benefits at a greater rate than white people. The study, which covered 30 years' worth of SSA data, found that in 1988 "whites had an 8 percent better chance of receiving benefits after being initially turned down for Disability

---

[52] *See, e.g.*, LISTING OF IMPAIRMENTS, supra note 45. ("Most of the listed impairments are permanent or expected to result in death. . . .").

[53] See discussion in section B below.

[54] GARLAND-THOMSON, *supra* note 25, at 13.

[55] Subini Ancy Annamma, David Connor & Beth Ferri, *Dis/ability Critical Race Studies (DisCrit): Theorizing at the Intersections of Race and Dis/ability*, 16 RACE ETHNICITY AND EDUC. 1, 7 (2013).

[56] Beth HARRY & JANETTE KLINGNER, WHY ARE SO MANY MINORITY STUDENTS IN SPECIAL EDUCATION 148-49 (2014).

Insurance and a 4 percent advantage under the Supplemental Security Income program. This was the case . . . even when accounting for the applicants' age, education, and types of disabilities."[57]

B. Legal Complexity and the Incomprehensibility of a "Listing"

The SSDI system presents claimants with two routes to eligibility: meeting a "listing," or showing a "residual functional capacity" ("RFC").[58]

The listing is a highly medicalized approach to understanding disability. A "listing" refers to a diagnosis that matches the exact requirements of a listed impairment in the Social Security Administration's Listing of Impairments.[59] For example, a home health aide with arthritis must prove to the Social Security Administration ("SSA") that she meets the requirements for Listing 14.09, "Inflammatory arthritis."[60] But this listing, like others, requires a claimant to meet complex standards. In the "listing" process, a worker must meet the exact, idiosyncratic criteria the SSA has established for a particular disability. These definitions are unclear. According to SSA, even the disability administrative law judges ("ALJs") themselves may not fully comprehend what a disability means.[61]

The SSA's approach reflects the medical model of disability by reducing the complex aspects of alternate ability to a set of boxes to check. In other words: at present, the SSA essentially asks an applicant: "Do your symptoms meet the agency's notion of a disability?" The social model of disability asks: "Does the world you work and live in prevent you from participating fully?" This analysis changes the process by allowing claimants who cannot participate fully in the workforce, but who may not be able to articulate their struggle through the listing process, to claim benefits they sorely need.

The listing approach attempts to be objective and mathematical. This model may have certain advantages—for instance, with less apparent room for

---

[57] Stephen Labaton, *Benefits are Refused More Often to Disabled Blacks, Study Finds*, N.Y. TIMES (May 11, 1992), https://www.nytimes.com/1992/05/11/us/benefits-are-refused-more-often-to-disabled-blacks-study-finds.html [https://perma.cc/745V-KW4R].

[58] SSA describes residual functional capacity ("RFC") as: "Your impairment(s), and any related symptoms, such as pain, may cause physical and mental limitations that affect what you can do in a work setting. Your residual functional capacity is the most you can still do despite your limitations. We will assess your residual functional capacity based on all the relevant evidence in your case record." Your residual functional capacity, 20 C.F.R. § 416.945 (2012).

[59] SOC. SEC. ADMIN., LISTING OF IMPAIRMENTS - ADULT LISTINGS (PART A), https://www.ssa.gov/disability/professionals/bluebook/AdultListings.htm. [https://perma.cc/RVK4-PFRH] (last visited Oct. 15, 2019).

[60] 20 C.F.R. pt. 404 subpt. P, app. 1 (2016).

[61] Mark Green, Barry Eigen, John Lefko, & Scott Ebling, *Addressing the Challenges Facing SSA's Disability Programs*, 66 SOC. SEC. BULL. 3 (2005/2006), https://www.ssa.gov/policy/docs/ssb/v66n3/v66n3p29.html [https://perma.cc/F7HS-4M27] ("In addition, experience in using the listings in adjudication suggests changes that should be made to ensure that the listings both appropriately identify individuals with disabilities and that they are *able to be understood and applied uniformly by all adjudicators*") (emphasis added).

subjectivity, a disability evaluation process may be less vulnerable to implicit bias. But, in doing so, it detaches the lived experience of claimants from the evaluative disability process. Whether a person who cannot work meets three required characteristics of an SSA listing and becomes "disabled", or meets only two and is "not disabled," it is entirely possible and indeed likely that they both face structural opposition to participation in the workforce. The listing approach also provides a false sense of fairness. There may be just as much subjectivity in determining whether an applicant "meets" criteria X, Y, and Z as there would be in performing a more holistic review of the person's experience overall.[62]

Supposedly objective approaches to understanding disability often depend on false assumptions. For example, the SSA has taken recent action to reduce the number of claimants granted each year—for instance, using Facebook to spy on claimants receiving benefits,[63] and changing the ALJ hiring process to allow more political control from the executive branch.[64] These actions reflect the idea that disability must be somehow subject to uniform standards across a society, such as distribution across a "normal" curve, as theorized by nondisabled statisticians and authors such as Charles Murray.[65] This "myth of the normal curve"[66] posits that the presence of disability in individuals within a society follows a predictable mathematical distribution. Recent scholarship, however, has shown human traits and intelligence do not distribute randomly.[67] In other words, it is the

---

[62] For example, the SSA regularly issues "Policy Interpretation Rulings" which clarify how the agency will change its interpretation of a disease or condition. This notion may seem strange when nothing in the underlying disease or condition itself has changed. *See, e.g.*, Social Security Ruling, SSR 14–2p; Titles II and XVI: Evaluating Diabetes Mellitus, 79 Fed. Reg. 31,375, 31,375 - 31,376 (June 2, 2014) ("On April 8, 2011, we published final rules in the Federal Register in which we removed the listings for evaluating [Diabetes Mellitus] in adults and in children from the Listing of Impairments (listings) because they no longer accurately identified people who are disabled. We added listing 109.08 for children from birth to the attainment of age 6 who have any type of [Diabetes Mellitus] and who require daily insulin.").

[63] Robert Pear, *On Disability and On Facebook? Uncle Sam Wants to Watch What You Post*, N.Y. TIMES (March 10, 2019), https://www.nytimes.com/2019/03/10/us/politics/social-security-disability-trump-facebook.html [https://perma.cc/5BQP-SFWC].

[64] Patricia Kalla Zonnenberg, *New Qualifications for ALJs Are Bad News for Social Security Beneficiaries, Legal Experts Warn*, SPECIAL NEEDS ANSWERS (July 30, 2018), https://specialneedsanswers.com/new-qualifications-for-aljs-are-bad-news-for-social-security-beneficiaries-experts-warn-16780 [https://perma.cc/ZKS3-PVD9].

[65] *See, e.g.*, Charles Murray, *IQ and Economic Success*, THE PUBLIC INTEREST 71-72 (Summer 1997), available at https://www.nationalaffairs.com/storage/app/uploads/public/58e/1a4/ee2/58e1a4ee219c5159778416.pdf. [https://perma.cc/PJ58-34YQ] ("At the far-left side of the distribution are the bottom 5 percent of the IQ distribution, the *Very Dull*, with IQs under 75. These include the retarded, but many people with IQs in this range are neither retarded nor incapacitated. They find it difficult to cope with school but still can be productive employees at menial and semi-skilled jobs, and sometimes at skilled jobs as well if their shortfall in intellectual capacity is counterbalanced by other abilities.").

[66] Curt Dudley-Marling & Alex Gurn, *Troubling the Foundations of Special Education: Examining the Myth of the Normal Curve*, *in* THE MYTH OF THE NORMAL CURVE 9, 10 (Curt Dudley-Marling & Alex Gurn eds., 2010).

[67] *Id.* Note that even if what is being measured produces a normal curve, it does not mean

measurement of someone's intelligence, rather than the objective existence of intelligence itself, that socially constructs people as "gifted," "low-achieving," or "normal."[68]

A close reading of an SSA listing shows how the medicalized approach to disability creates unnecessary complexity. Under section 14.09, a claimant can meet the inflammatory arthritis listing under four separate tracks: 14.09(A), 14.09(B), 14.09(C), or 14.09(D). Many listings combine "or" and "and" logical operators to make a confusing "choose-your-own adventure" approach to disability. Under 14.09(A), for example, a claimant must establish "[p]ersistent inflammation or persistent deformity of: (1) [o]ne or more major peripheral weight-bearing joints resulting in the inability to ambulate effectively (as defined in 14.00C6); *or* (2) [o]ne or more major peripheral joints in each upper extremity resulting in the inability to perform fine and gross movements effectively (as defined in 14.00C7)."[69] Here, the "or" operator between (1) and (2) here means a claimant can meet *either* of these requirements to qualify for 14.09(A).[70]

The arthritis definition in 14.09(B) is even more complex. Under 14.09(B), a claimant must establish "inflammation or deformity in one or more major peripheral joints with: (1) [i]nvolvement of two or more organs/body systems with one of the organs/body systems involved to at least a moderate level of severity; *and* (2) [a]t least two of the constitutional symptoms or signs (severe fatigue, fever, malaise, or involuntary weight loss)." The "and" operator between (1) and (2) here means a claimant must meet *both* of these requirements to qualify for 14.09(B).[71]

To prove her simple inability to work, a claimant must effectively marshal both familiarity with complex medical diagnoses and mastery of semantic logic. To navigate this process claimants need a lawyer, but public interest lawyers are often in short supply. A robust private bar has also developed, assisting often-desperate applicants in exchange for a percentage of the back pay and benefits.[72] The listing approach illustrates how the seemingly straightforward medical model of disability collapses when it is applied to the diverse forms in which people actually experience disability.

---

that what is being measured distributes normally.

[68] SHARON L. SNYDER & DAVID T. MITCHELL, CULTURAL LOCATIONS OF DISABILITY 70 (2006).

[69] SOC. SEC. ADMIN., SECTION 14.00, IMMUNE SYSTEM DISORDERS – ADULT, https://www.ssa.gov/disability/professionals/bluebook/14.00-Immune-Adult.htm. [https:// perma. cc/63TS-Y8Z7] (last visited Jan 14, 2020) (emphasis added).

[70] Pt. 404 subpt. P, app. 1.

[71] *Id.*

[72] *See, e.g.*, Chana Joffe-Walt, *Expanded Definition of Disability Created Million Dollar Opportunity for Lawyers*, NPR (Mar. 26, 2013), https://www.npr.org/2013/03/26/175396983/expanded-definition-of-disability-created-million-dollar-opportunity-for-lawyers [https://perma.cc/GC45-J5WV].

VI.
PROBLEMATIZING THE SSA "RESIDUAL FUNCTIONAL CAPACITY" APPROACH

A. Lived Experience and the Deterministic Approach to Legal Decision-making

The RFC approach attempts to reflect an applicant's lived experience by allowing a claimant to explain how a disability affects her life so severely that she cannot work, even if she does not qualify for a listing. However, even the role of lived experience ultimately remains limited by "the grids," which filter disability claimants based on their age and other social statistics.

Mental health conditions often require an applicant to share lived experience, since it may be harder to assess using physical criteria. Heidi Scott, for instance, tried to commit suicide four times. The first three times, according to Ms. Scott, doctors simply "drugged [her] up" without analyzing the root cause of her issues. Finally, after the fourth attempt, a doctor observed Ms. Scott for six months. This doctor diagnosed Ms. Scott with bipolar disorder. While her employer at a nursing home was sympathetic, eventually she could no longer work:

> She worked at a nursing home, and her boss was a doctor who was determined to help her work around her disorder. But despite everyone's best efforts, she gradually had to cut back on her work because of her stress. First, she dropped her work schedule down to three days a week. Then her duties were cut. Finally, it got to the point where she couldn't function at work. It was wearing on the other employees, and her psychiatrist instructed her to stop. The company understood, but Ms. Scott was now in a financial dilemma.[73]

Heidi's unemployment—as told by a national Social Security representation firm called Allsup—led to her filing for SSDI, which she received. Heidi said that she had "no idea" that she could qualify for SSDI with a mental impairment. Heidi's story is an example of how lived experience is not a significant part of the SSDI process. She did not have an opportunity to bring her story into the disability context until a law firm made her aware of this possibility. The social model emphasizes the importance of lived experience and presumes that historically and multiply marginalized people have the competence to tell their own stories.[74]

---

[73] *SSDI & Bipolar Disorder: A Personal Story,* TRUEHELP.COM, https://www.truehelp.com/ssdi-benefits/ssdi-representation/personal-stories/ohio-woman-with-bipolar-disorder-getting-by-on-ssdi-benefits/ [https://perma.cc/W9SP-9MYP] (last visited Aug. 13, 2019). Note that "Heidi Scott" is a pseudonym to protect the individual's identity.

[74] *See* Annamma, Connor, & Ferri, *supra* note 55, at 11. In this article, the authors argue that disability (and race) are socially constructed when discussing Tenet 3 of Disability Critical Race Theory. Specifically, they state, "DisCrit emphasizes the social constructions of race and ability and yet recognizes the material and psychological impacts of being labeled as raced or dis/abled, which sets one outside of the western cultural norms" In Tenet 4, they discuss the importance of "privilege[ing] [the] voices of marginalized populations, traditionally not acknowledged within research."

Claimants in disability cases do not have the opportunity to voice their lived experiences in trying to be a "productive" member of a capitalist society. They can only demonstrate whether they meet the threshold of unproductivity to qualify for benefits. By binding disability to a list of impairments and conditions, the law neglects both the lived experiences of disabled individuals and the ways in which disability itself is experienced as a form of identity. If disabled claimants were afforded a chance to voice their lived experience, they might feel more invested in the disability process. They might also feel vindicated simply by having a moment to share their story, on the record and before a representative of the government. This value may be intangible, but might also be greatly appreciated by some claimants.

B. The "Grids" and Disability by Algorithm

As noted earlier, the second way (in addition to the "listings" approach) to qualify for disability is by demonstrating a qualifying reduced "residual functional capacity."[75] The RFC process requires a complex evaluation of a claimant's age, educational level, and other factors in determining whether a claimant can return to other jobs. While the process requires the same basic evidence as the "listings" approach—submission of medical information, work history data, etc.—the formula for determining eligibility is more convoluted. Yet it is ultimately an algorithmic decision—using the same inflexible bright-line approach as the listings. In this way the grids are a misguided attempt to incorporate social model of disability-related ideas into the SSA system.

To make the decision of who will receive thousands of dollars in benefits each year and who will not, the SSA relies on "Grids," a set of tables created by the SSA.[76] These tables contain the following columns: "Rule," "Age," "Education," "Previous work experience," and "Decision."[77] These tables provide a deterministic approach to justice: the ALJ merely decides which "box" a claimant falls into and makes the decision accordingly. For instance, Rule 202.10 describes a

---

[75] Pt. 404 subpt. P, app. 1. ("If we find that you cannot do your past relevant work, you do not have any past relevant work, or if we use the procedures in § 416.920(h) and § 416.962 does not apply, we will use the same assessment of your residual functional capacity at step five of the sequential evaluation process to decide if you can adjust to any other work that exists in the national economy. (*See* §§ 416.920(g) and 416.966.) At this step, we will not use our assessment of your residual functional capacity alone to decide if you are disabled. We will use the guidelines in §§ 416.960 through 416.969a, and consider our residual functional capacity assessment together with the information about your vocational background to make our disability determination or decision.").

[76] TOM JOHNS, SSA'S SEQUENTIAL EVALUATION PROCESS FOR ASSESSING DISABILITY 24, https://www.ssa.gov/oidap/Documents/Social%20Security%20Administration.%20%20SSAs%20Sequential%20Evaluation.pdf [https://perma.cc/L6Z5-N6GG].

[77] *E.g.*, pt. 404 subpt. P, app. 2 ("Table No. 1—Residual Functional Capacity: Maximum Sustained Work Capability Limited to Sedentary Work as a Result of Severe Medically Determinable Impairment(s)").

claimant with the following profile: age defined as "closely approaching advanced age" (considered to be ages 50-54); education defined as "limited or less—at least literate and able to communicate in English;" and previous work experience defined as "unskilled or none."[78] Under these circumstances, an ALJ is instructed to find the claimant "not disabled." There is no room for negotiation, case law, or other arguments: the claimant is simply determined "not disabled" as a matter of law.[79]

This rigid approach is combined with broad discretion for ALJs hearing appeals, who have authority to weigh hearing evidence. Under either the "listings" or RFC approach, the ALJ retains broad discretion to disregard a worker's own treating physician—especially with the elimination of the "treating physician" rule in March 2017.[80] For instance, a worker may submit a letter or evaluation written by her own primary care physician supportive of a finding of disability. An ALJ may view this letter with skepticism, given that a long-term patient-physician relationship means the doctor may have an incentive to exaggerate a patient's disability.

However, presuming the competency and agency of people with disabilities, the doctor may simply be responding to the patient's own, deliberate exaggeration. Exaggerating or "masquerading" one's disability has been conceptualized in the disability community as a way to reclaim a stigmatized turn of phrase. For comparison, there has been similar discussion of the decision by some members of the LGBTQ community to reclaim "queen," "queer," "dyke," and other words.[81] Some disabled people seek to continue this movement by making use of a cane, walker, or other stigmatized device, into a point of pride that can be strategically used to push against ableist systems, structures, laws, and policies.[82] Masquerading disability allows people to claim their identity and agency—even in systems

---

[78] *Id.*

[79] *Id.*

[80] Previously, the SSA relied on a "treating physician" rule. The SSA defined a treating physician as a doctor who has treated a patient/claimant multiple times. This rule required that ALJs must usually give "controlling weight" to the opinion of a treating physician. However, in March 2017, the SSA eliminated this rule, because patients today generally "do not 'develop a sustained relationship with one treating physician.'" Michael N. Rhinehart, *Treating Physician Rule Eliminated in Social Security Regulations*, THE FEDERAL LAWYER (Oct. 2017), http://www.fedbar.org/Resources_1/Federal-Lawyer-Magazine/2017/OctoberNovember/Columns/At-Sidebar.aspx?FT=.pdf [https://perma.cc/V77A-UGZ2] (citing Revisions to Rules Regarding the Evaluation of Medical Evidence, 81 Fed. Reg. 62560-01, 62573 (Sept. 9, 2016)).

[81] "The concept of the masquerade, long a staple of feminist and queer theory, offers an opportunity to rethink passing from the point of view of disability studies because it claims disability as a version of itself rather than simply concealing it from view." SIEBERS, *supra* note 1, at 101.

[82] *Id.* at 102. ("The masquerade represents an alternate method of managing social stigma through disguise, one relying not on the imitation of a dominant social role but on the assumption of an identity marked as stigmatized, marginal, or inferior.").

that require that they pass as nondisabled in order to be positioned as fully human (and in this case, fully employable.)[83]

Just as the determinism of the "Grids" works against claimants, so too does the procedural complexity of appeal hearings. The evidentiary record in a case routinely spans several hundred pages of medical records. These documents may include inscrutable hand-written doctors' notes, medical jargon, private details from surgeries, and therapist notes. However, the ALJ has no duty to explain the evidence in simple terms to the claimant. While the judge is expected to make a decision on the basis of all the medically appropriate evidence before her or him, there is also no duty of the judge to develop the record beyond what is present. The hearing process can involve supposedly impartial expert testimony from "vocational experts" or "medical experts," whom the judges work with frequently but whom the claimant almost surely does not know.[84] In some senses, these "experts" may work to mitigate the alleged improper influence of a patient's primary care physician discussed above.[85]

VII.
PROPOSED SOLUTIONS

Disability studies in education scholar Anne Baines cautions that ". . . when people are called on to solve social problems, they imagine solutions conditioned by the same categories and practices within which the problems emerged."[86] Our suggestions are informed by the social model of disability to avoid replicating the problems of the current SSDI system. This more humanizing way of understanding disability as part of someone's identity and experience, rather than a checklist, will center the voices and experiences of people marginalized within the current system. The field of disability studies is about calling attention to deficit thinking and reframing supposed deficits as assets. It also emphasizes looking for a reasonable explanation as to why someone is acting the way they are, rather than assuming their actions, behavior, and/or thinking can only be the result of an inherent lack of capacity.[87] Presuming competence means understanding that people are

---

[83] *See, e.g.*, *id.*

[84] SOC. SEC. ADMIN., OFF. HEARING OPERATIONS & OFF. THE CHIEF ADMIN. L. JUDGE, MEDICAL EXPERT HANDBOOK 1, 23 (2017), https://www.ssa.gov/appeals/public_experts/Medical_Experts_(ME)_Handbook-508.pdf [https://perma.cc/6DCT-82TK].

[85] *See, e.g.*, *The Use of Vocational and Medical Expert Witnesses*, THE LAW OFFICES OF MARTIN AND JONES, https://www.theatlantadisabilitylawyer.com/abcs-of-cross-examining-2/ [https://perma.cc/8SJL-5CD6] (last visited Dec. 26, 2019) ("While the expert witness may be called by the ALJ to give impartial testimony, which could help or impede the grant of benefits, many expert witnesses testify as if their purpose is to 'help' the ALJ deny benefits.").

[86] ANNMARIE D. BAINES, (UN)LEARNING DISABILITY: RECOGNIZING AND CHANGING RESTRICTIVE VIEWS OF STUDENT ABILITY (Alfredo J. Artiles, Elizabeth B. Kozleski eds., 2014).

[87] Douglas Biklen & Jamie Burke, *Presuming Competence*, 39 EQUITY & EXCELLENCE IN EDUC. 166, 166 (2007).

making the best choices they can in the context they are in.[88] For this reason, we feel it is more important to instead focus on the ways in which we can challenge these assumptions with alternative conceptualizations of disability, as we believe these alternate ways of thinking about disability can provide a better avenue for advocating within the system.

Considering the number of Americans who rely on the SSDI, and the vigorous conservative resistance to the program,[89] it may be difficult to overhaul SSDI from the ground up. As such, we suggest concrete changes to make the process more inclusive for claimants, more democratic, and more in keeping with the social model of disability.

Expand who is an "Acceptable Medical Source." Until 2017, the Social Security Disability law excluded a number of healthcare professionals from qualification as an "acceptable medical source" ("AMS").[90] In early 2017, the SSA finally expanded the AMS definition to include "Advance Practice Registered Nurses (APRN), audiologists, and physician assistants (PA) for impairments within their licensed scope of practice."[91] However, this definition still excludes individuals who do not fall into this category and who work closely with the claimant, often spending much—if not more—time with them. For instance, neither home health aides nor medically trained family members qualify as an AMS.[92] The extra time these home health aides, medically trained family members, or others may have spent might mean they have more knowledge about the claimant, beyond their medical diagnosis. Put differently, people who spend more time with the claimant may lean on the social model of disability—i.e., they may provide a more accurate diagnosis by knowing the person better and in different ways—when evaluating the claimant's needs in the workplace. By seeing the patient/claimant as a whole person, rather than a set of boxes to check, an evaluating physician or other medical source might be more likely to listen to what the patient/claimant actually says about their lived experience. The gender and racial

---

[88] *Id.*

[89] For a summary of conservative perspectives, *see, e.g.*, Gene B. Sperling, *The Fuzzy Claims Used to Justify Cutting Social Security Disability Insurance*, THE ATLANTIC (May 23, 2017), https://www.theatlantic.com/business/archive/2017/05/ssdi/527802 / [https://perma.cc/R74Q-HLSD].

[90] An acceptable medical source (AMS), according to SSA, is a medical or healthcare professional who is qualified to establish the existence of a medically determinable impairment. *See* SOC. SEC. ADMIN, PROGRAM OPERATIONS MANUAL SYSTEM (POMS) § DI 22503.003 *Evidence from an Acceptable Medical Source* (2017), https://secure.ssa.gov/apps10/poms.nsf/lnx/0422505003 [https://perma.cc/QGF9-BHX9] [hereinafter, POMS] ("We require objective medical evidence (signs, laboratory findings, or both) from an AMS to determine that an individual has an MDI(s) at step 2 of the sequential evaluation process.").

[91] SOC. SEC. ADMIN., REVISIONS TO RULES REGARDING THE EVALUATION OF MEDICAL EVIDENCE, https://www.ssa.gov/disability/professionals/bluebook/revisions-rules.html [https:// perma.cc/P2QV-ZKT9].

[92] POMS, *supra* note 90 ("If a person who is a medical source provides evidence in his or her capacity as a friend or family member, evaluate that evidence as if from a nonmedical source.").

bias in defining acceptable medical sources also warrants attention. Medical doctors are disproportionately white[93] and men;[94] while nurse practitioners, nurses, social workers, and therapists are disproportionately women. Furthermore, only 2% of doctors are disabled.[95] Thus, utilizing the social model to reimagine "acceptability" also makes the law more inclusive not only of disability experiences, but also of people marginalized in other ways.

Update Mental Health Criteria More Frequently. The SSA recently changed how it evaluates mental health in disability cases. Among other changes, which went into effect in January 2017, the SSA added three new disability-qualifying listings: 12.11 neurodevelopmental orders ("conditions characterized by an onset in childhood/adolescence"); 12.13 eating disorders, and 12.15 trauma- and stressor-related disorders (e.g. PTSD).[96] These changes are welcome and overdue: the SSA had not fully updated the mental health listings since 1990.[97] The SSA should continue to make updates to the disability listings more frequently, rather than letting 28 years go by, in order to stay current with contemporary understandings of health and disability. From a disability studies perspective, these updates should be informed by people in the disability community, specifically those who have mental health impairments. Just as governing boards often reserve seats for different stakeholders—the New York City Rent Guidelines Board, for instance, reserves seats for both landlord advocates and tenant advocates—the SSA should consult with people who actually present with the types of mental and other disabilities described. Updating the list more frequently, with input from the disability community, is aligned with the social model because it humanizes people with disabilities.

Updating mental health criteria is also important considering the fluid nature of disability, or the ways in which the boundaries set in society between who is disabled and who is not are more a result of cultural and social norms, rather than objective, biological impairments. Many disability diagnoses have shaky relationships to biological difference. For example, the biological diagnostic criteria for

---

93. Imam M. Xierali & Marc A. Nivet, *The Racial and Ethnic Composition and Distribution of Primary Care Physicians*, 29 J. HEALTH CARE POOR UNDERSERVED 556, 556-70 (March 28, 2018), https://muse.jhu.edu/article/686983/pdf [https://perma.cc/BB55-DERL].

94. Carrie Pallardy, *Male & Female Active Physicians: 70 Statistics by Specialty*, BECKER'S HEALTHCARE (Feb. 13, 2015), https://www.beckersasc.com/gastroenterology-and-endoscopy/male-female-active-physicians-70-statistics-by-specialty.html [https://perma.cc/NG7G-PK9E] ("The majority of active physicians, 69.9 percent, were male as of 2010.").

95. Dhruv Khullar, *Doctors with Disabilities: Why They're Important*, N.Y. TIMES (July 11, 2017), https://www.nytimes.com/2017/07/11/upshot/doctors-with-disabilities-why-theyre-important.html [https://perma.cc/6D5Z-AZ7W].

96. SSI/SSDI OUTREACH, ACCESS AND RECOVERY (SOAR) TECHNICAL ASSISTANCE CTR., *SSA Revises Criteria for Evaluating Mental Health Disorders*, SOARWORKS (Nov. 16, 2016), https://soarworks.prainc.com/sites/soarworks.prainc.com/files/SSA_Revises_Mental%20Disorder_Listings_111616.pdf [https://perma.cc/A66G-NLWY].

97. *Id.*

autism are very generalized and vague, and it is not clear how that biology translates into particular experiences of people with autism.[98] On the other hand, sometimes the criteria changes in a way that "cures" people's disabilities. For example, when the criteria for mentally retarded shifted from one standard deviation to two standard deviations below the mean IQ in 1973,[99] many people were "cured" of their mental retardation. This does not mean that their mental capacity suddenly changed. Rather, it means their capacities were no longer interpreted as deficient or in need of remediation. In the context of SSDI benefits, this might not change how accessible the workplace is for people one standard deviation below the mean. Thus, changing criteria should not come at the expense of continuing to make work places more accessible and inclusive for all people.

Update Job Listings. The Dictionary of Occupational Titles, which the SSA uses to determine appropriate jobs for a claimant to perform,[100] has not been updated since 1991.[101] While SSA is currently revamping this process, it should use another source of occupational listings. For instance, the U.S. Department of Labor already retains an extensive listing of occupational information in its searchable, free Occupational Outlook Handbook.[102] In updating this document, plain language and other accessibility measures should be prioritized. These measures comport with the social model of disability by ensuring that more people—especially more vulnerable and/or historically marginalized people—can participate meaningfully in the SSA disability decision-making process. The social model also emphasizes that even people who do not need accessibility measures can benefit from them as well.

Require Pre-Hearing Conferences. Currently, ALJs are not required to explain to claimants how the SSDI process works, though they generally read a boilerplate statement about the process. ALJs should provide mandatory pre-hearing

---

[98] Broderick, *supra* note 23, at 245 (". . . despite widespread disagreement over the particular nature of autism (apart from a very generalized and vague agreement that autism likely encompasses a biological basis or bases), and in light of the more common nomenclature of 'autism spectrum disorders,' a phrase that is intended to include a variety of difference experiences under the overall umbrella of a 'spectrum' of (plural) 'disorders;' autism is nonetheless represented as a singular subject . . . "). In fact, the autism "epidemic" may have more to do with more public awareness and broadening diagnostic criteria than a significant increase in individuals with autism. *See id.* at 255.

[99] Christine E. Sleeter, C.E, *Learning Disabilities: The Social Construction of a Special Education Category*, 53 EXCEPTIONAL CHILDREN 46, 52 (1986).

[100] *Dictionary of Occupational Titles*, DISABILITY BENEFITS HELP, https://www.disability-benefits-help.org/glossary/dictionary-of-occupational-titles [https://perma.cc/TF6U-FBKQ] ("The DOT was created as a national standardized job database to help document the physical requirements of a job. When an applicant's case is reviewed by Social Security, the reviewer will compare their condition to the DOT entries of their current and previous jobs to see if they are qualified for work.").

[101] *See* David Fahrenthold, *It's Just Maddening. There's Nothing You Can Do*, WASH. POST (Oct. 18, 2014), https://www.washingtonpost.com/sf/national/2014/10/18/the-biggest-backlog-in-the-federal-government/ [https://perma.cc/8Q3Z-RX23].

[102] *See* U.S. DEP'T OF LAB., BUREAU OF LAB. STAT., OCCUPATIONAL OUTLOOK HANDBOOK, https://www.bls.gov/ooh/about/occupational-information-included-in-the-ooh.htm [https:// perma.cc/CQF3-CP8E] (last modified Sep. 4, 2019).

conferences, which are routine in other areas of the law,[103]with a disability advocate. This individual would help a claimant understand the process *before* the day of the hearing, rather than when it is too late. During this conference, the applicant should be informed that notes by medical and other professionals may comprise a substantial part of their case file. Thus, if they have mental health issues or if there is other information they do not wish their family to know about, then they need to know this is a part of the hearing process, so they can make an informed decision. Again, this change would comport with the social model of disability by providing a claimant with more tools to participate in the decision-making process.

Improve Outreach to Initial Claimants. A federal program called SOAR (SSI/SSDI Outreach Access and Recovery) is designed to assist claimants at a particularly high risk of homelessness. In one study, this program helped homeless individuals receive SSI/SSDI initial approval at a rate of 50%, nearly double the 28% approval rate for non-SOAR homeless applicants. Expanding this type of approach would vastly help improve the SSI/SSDI process, as it would allow more claimants to make a successful application without resorting to a lengthy ALJ hearing process. It would also realign the SSI/SSDI process with the social model of disability, allowing claimants to present their stories of self and risks of homelessness in a hearing context as a strength, rather than a weakness.

Prioritize the Experiences of the Disabled. Decisions affecting individuals within the disability community are often made by nondisabled people.[104] Our Article suggests that additional criteria—such as first-person narrative accounts—should be considered in conjunction with medical criteria. Importantly, people with disabilities should be considered the first experts to consult regarding these criteria at all stages—at the hearing level, when crafting regulations, in appeals, and beyond. The SSA should include people receiving SSDI/SSI benefits directly in the decision-making process, in a board of experts or in another advisory capacity.

Increase Access to the SSA Process for People with Multiple Disabilities. The paperwork completed by clients and the hearings they attend should, and can, be made more accessible. Any required documents should have accessibility options, such as enlarged font and plain language. People should be able to fill out documents online so they can use technological supports, such as speech-to-text software. The hearings should also be conducted in plain language. At present, SSA does offer limited accommodations for people in need. For instance, people

---

[103] *See, e.g.*, *Prehearing Conferences*, U.S. DEP'T OF HEALTH & HUM. SERV., https://www.hhs.gov/about/agencies/dab/different-appeals-at-dab/appeals-to-alj/procedures/prehearing-conferences/index.html [https://perma.cc/C3XM-3UV7] (last visited Dec. 26, 2019) ("At any time before the hearing, the ALJ may call a prehearing conference. In addition to any matter deemed appropriate by the ALJ or required by regulation, a prehearing conference will generally be used to clarify the issues in controversy and to discuss how the case should proceed…").

[104] *See* Broderick, *supra* note 23, at 265; *see also* SIMI LINTON, CLAIMING DISABILITY 18 (1997) (ebook).

who are deaf or hard of hearing may request a reasonable accommodation. These accommodations may include a "certified and qualified sign language interpreter," "handwritten notes," "lip-reading or speech reading," and/or "telephone devices for the deaf."[105] Blind or visually impaired claimants, meanwhile, can request notices in Braille, large-print notices, and with other modifications.[106] However, claimants may not know about these options—and other claimants who do not identify as blind, visually impaired, or deaf or hard of hearing may also benefit from them.

Other courts have helped increase access in other ways for litigants. For example, New York City's housing court offers a Court Navigator Program for unrepresented tenants. The program notes: "Specially trained and supervised non-lawyers, called Court Navigators, provide general information, written materials, and one-on-one assistance to eligible unrepresented litigants. In addition, Court Navigators provide moral support to litigants, help them access and complete court forms, assist them with keeping paperwork in order, in accessing interpreters and other services, explain what to expect and what the roles [are] of each person in the courtroom."[107] This approach—and particularly the "moral support" these Court Navigators provide—seems to align especially well with the social model of disability. Especially given that SSA applicants may be more likely than others to be disabled, this type of support would seem especially appreciated in SSDI/SSI proceedings. These strategies are especially important for people who are multiply marginalized. Similarly, the social model suggests that these accessibility options can improve hearings for people across *all* ability levels, even if they do not have a prescribed disability. They may also set a new, more accessible precedent for hearings in other legal matters.

Increase Funding for SSDI/SSI Beneficiaries. The United States spends relatively little on disability insurance. According to the Center on Budget and Policy Priorities, the U.S. spends slightly less than 1.0% of GDP on public disability benefits. This figure is substantially less than many developed nations, such as Denmark (around 2.25% of GDP), Spain (nearly 1.5% of GDP), and the United Kingdom (around 1.25% of GDP).[108] Increasing funding for SSDI/SSI beneficiaries would go a long way toward helping some of America's poorest and most vulnerable individuals. This change would comport with the social model of

---

[105] *How to Request a Reasonable Accommodation*, SOC. SEC. ADMIN., https://www.ssa.gov/people/deaf/ [https://perma.cc/G9HA-SU5F] (last visited Dec. 26, 2019).

[106] *If You are Blind or Visually Impaired—Your Choices for Receiving Information from Social Security*, SOC. SEC. ADMIN., https://www.ssa.gov/people/blind/ [https://perma.cc/2JDX-8SKU] (last visited Dec. 26, 2019).

[107] *Court Navigator Program*, NYCOURTS.GOV (Feb. 10, 2014) https://www.nycourts.gov/courts/nyc/housing/rap.shtml [https://perma.cc/RPX9-N7NA].

[108] Kathy Ruffing, *U.S. Disability Benefits Modest by International Standards* (Nov. 1, 2016), https://www.cbpp.org/blog/us-disability-benefits-modest-by-international-standards [https://perma.cc/BKW3-8GRX].

disability by contributing more resources from the public at large, rather than further straining the families of people with disabilities. It would also strongly assert disability as an identity—like race, gender, sexuality, religion, etc.—worthy of political consideration and government attention, rather than simply a medical diagnosis. Some consider being perceived as a minority group an important first step in receiving access to equal rights.[109] Yet, for people with disabilities, the only thing they have in common is that they are considered abnormal.[110] As such, asserting themselves as a minority group is difficult because disability is more fluid than other identities, such as race, ethnicity, class, or even gender and sexuality.[111] Anyone at any point in time can become disabled, through accident, illness, or old age.[112] The able-bodied/minded are all only temporarily nondisabled. Since some disabled people also do not want to see themselves as disabled, this means there is often not as clear of a notion of what it means to belong to disability culture.[113] It is possible that increasing funding for SSDI/SSI beneficiaries may lend more legitimacy to their experiences if the government deems them worthy of more care than they are currently receiving. This has the potential to strengthen disability minority identity, and perhaps provide a more solid foundation for further disability civil rights advocacy.

Dispel SSDI/SSI Misconceptions. Finally, too many people believe that SSDI/SSI applicants are simply "faking it."[114] These individuals, so the narrative goes, are too lazy to work. They have allegedly resorted to scamming the government out of money. According to another common tale, millions of Americans continue to collect the SSI benefits of another individual after this person has died.[115] In reality, neither of these scams takes place with anywhere near the frequency alleged. While disability fraud does take place, experts say there is no

---

[109] Tara Schwitzman, *Dealing with Diversity and Difference: A DisCrit Analysis of Teacher Education Curriculum in a Historically Marginalized Space*, 34 J. CURRICULUM THEORIZING 50, 53 (2019).

[110] GARLAND-THOMSON, *supra* note 25, at 14 ("Because disability is defined not as a set of observable, predictable traits—like racialized or gendered features—but rather as any departure from an unstated physical and functional norm, . . . the concept of disability unites a highly marked, heterogenous group whose only commonality is being considered abnormal.").

[111] *Id.* ("That anyone can become disabled at any time makes disability more fluid, and perhaps more threatening, to those who identify themselves as normates than such seemingly more stable marginal identities as femaleness, blackness, or nondominant ethnic identities.").

[112] *Id.* ("The fact that we will all become disabled if we live long enough is a reality many people who consider themselves able-bodied are reluctant to admit.").

[113] Rosemarie Garland-Thomson, *Becoming Disabled*, N.Y. TIMES (Aug. 19, 2016), https://www.nytimes.com/2016/08/21/opinion/sunday/becoming-disabled.html [https://perma.cc/Z9QB-LYDD] ("Since most of us are not born into disability but enter into it as we travel through life, we don't get acculturated the way most of us do in our race or gender.").

[114] See, for instance, the Trump Administration's proposal to surveil social media posts of SSDI/SSI claimants for evidence of them engaging in physical activities supposedly demonstrating fraud. *See, e.g.*, Pear, *supra* note 63.

[115] For example, the fictional character Frank Gallagher in the TV show *Shameless* is known for collecting his long-deceased Aunt Ginger's disability benefits.

evidence that it is rampant: the real reason for the increase in disability benefit payments is simply an aging American population, with the 50-64 age bracket growing.[116] The SSA also offers free services for people seeking employment through its Ticket to Work program; in other words, the agency seeks to help people receiving SSDI/SSI benefits to find jobs and exit the SSA benefits program.[117] While perhaps challenging, schools and other educational sources should attempt to spread awareness regarding SSDI/SSI realities. Teachers and others can reduce the stigma associated with receiving benefits.

VIII.

CONCLUSION

This Article argues that the social model of disability provides a better orienting principle for the Social Security Administration than the traditional medical model. The social model allows for greater inclusion of individuals with disabilities. It also places more of the onus on people in power—employers who must make accommodations, society at large, and other actors—rather than people with disabilities, who remain marginalized in multiple facets of today's society. Using the social model would destigmatize disability generally and also provide better support for the concrete policy changes we recommend above.

Let us return for a moment to our cafeteria worker. Imagine now that instead of the medical model of disability, you work in a world that has embraced the social model. You still reach for a mop and know you lack the strength to keep working—but now, when you file for disability, the SSA tells you about the process in language you will understand. The SSA interviews your co-workers and nurses who know you best, not just a physician the agency hires for the occasion. You are provided with a clean copy of all your medical records months in advance of the hearing, ready for you to review. You are told exactly what evidence will be used in the process. The local office arranges for you to meet with an SSA disability expert before your hearing, and you learn the ins and outs of the proceeding. When your disability hearing comes, you feel empowered and ready to proceed. The social model of disability can be the foundation of a system where all SSA applicants and claimants have this experience. Furthermore, we hope that this model may inspire implementing workplace accommodations more broadly, so that everyone can participate more fully in the economic sphere. When workplace accommodations are made available to everyone, regardless of who 'needs' them, difference is both included and celebrated as an asset, rather than erased.

---

[116] Teresa Tritch, *Busting the Myths About Disability Fraud*, N.Y. TIMES: TAKING NOTE (Sept. 8, 2015, 10:32 A.M.), https://takingnote.blogs.nytimes.com/2015/09/08/busting-the-myths-about-disability-fraud/ [https://perma.cc/5868-GJPQ].

[117] SOC. SEC. ADMIN., HOW IT WORKS, https://choosework.ssa.gov/about/how-it-works/index.html [https://perma.cc/7C52] (last visited Oct. 15, 2019).