



The Deserving Disabled

BY KEVIN RHODES

If you're in a wheelchair, everybody's your friend. They say hi, give you the thumbs up, roll down the car window and shout encouragement, open doors, and hold the elevator. If you're on a bike path cranking out the miles, they shout "you're awesome!" as they whiz by; or sometimes they stop and ask what you're doing out here and how you came to be in a wheelchair. A bicyclist stopped to offer bandages and energy gels after I'd had a crash—she went on ahead, then circled back to check on me. She was a nurse, she said.

I read recently that you're not supposed to help a disabled person unless they ask for it; also, don't tell them they're inspiring, and whatever you do, don't say "wheelchair."¹ That advice came from the website of a company that makes ADA-compliant products, but this kind of advice is all over the place—even the United Nations repeats it.² Surely, it came from someone who's not in a wheelchair—probably some well-meaning able-bodied person who was trying to imagine what disabled people feel. "Let's see, if I were disabled, I'd feel kind

of self-conscious, so if someone asked if they could help me, I'd feel worse." Or maybe, "If I were disabled, I'd be insulted if somebody tried to help or told me I was inspiring."

I found the same kind of outlook on an advocacy website. It labeled the mentality behind offering help and asking about your wheelchair "ableism"—yet another "ism" based on "harmful stereotypes, misconceptions, and generalizations of people with disabilities."³

I think somebody who isn't disabled came up with "ableism." I don't define myself by

my disability—why would someone else? I’m okay, really. I just can’t walk very well, and some things don’t work how they used to. You don’t have to target people who can walk okay in order to advocate for me. I’m quite sure I’ve never experienced overt ableism. Oh, wait. One person volunteered that we should all stop using the term “disabled” and use “differently abled” instead. I’ll bet he heard that at an HR webinar. Seems like his HR department might be practicing ableism.

I like my wheelchair. I feel strong and quick and agile when I’m in it. It makes me feel, well, able. I wonder—does that make me an ableist?

If I’m struggling with a door (I’m always struggling with a door) or can’t reach something from an upper shelf (*this is “accessible”?*), I’m happy if somebody holds it or grabs the jar of chutney for me. A couple times somebody didn’t ask before pushing me up an incline, which I admit felt odd, but I appreciated the help and said so.

If somebody’s going to give advice about how to deal with me when I’m out in public (something that unfortunately happens a lot less than it used to), I’d rather it came from somebody who includes people like me in the process instead of somebody who’s trying to guess what I need and want.⁴ It seems like ADA compliance gets tacked on at the end, as an afterthought—*oh yeah, I almost forgot, isn’t there supposed to be a ramp in here somewhere?* How about if we reverse the order? How about we put accessibility first? How about we create spaces that people like me can only dream about? Then, of course, we’ll make sure it works for all you other people, too.

I’ll bet I’d get out more.

And what would I do then?

Get a Job

President George H. W. Bush said this when he signed the Americans with Disabilities Act into law: “Every man, woman, and child with a disability can now pass through once-closed doors into a bright new era of equality, independence, and freedom.”⁵

I can’t imagine what it must have been like before the ADA. Turns out, though, that there

was more to the ADA than a magnanimous wish to even out the accessibility playing field. There was another, ulterior motive that revealed the conservative mood of the times: the ADA’s endgame was to get disabled people back to work. People like me would no longer be a drag on the economy. We’d be “productive” again. Our worth to society would be reinstated.

Kind of takes the humanitarian shine off it.

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Welfare Becomes Workfare

The ADA was passed in the glow of the Reagan economic revolution’s renewed faith in capitalism, privatization, the free market, trickle-down economics, individual initiative and accountability, volunteerism, and the other hallmarks of traditional conservatism. The Bush

Sr. administration pushed for a “kinder, gentler” America and rhapsodized over a “thousand points of light,”⁶ but those days ended when Bill Clinton and Tony Blair took charge on their respective sides of the pond. It was time for fiscal conservatism to get tough and purge aid to the undeserving.

The Deserving

Workfare is simple to understand: if you work, you’re worthy; if you could work but don’t, you aren’t. Working for a living is a badge of good character and honorable citizenship and the core determinant of cultural compassion.

When Clinton and Blair installed it, workfare was government’s hammer seeing everything as a nail. Workfare replaced welfare as the solution to unemployment, poverty, disability, urban blight, mental illness, addiction, and other social ills. Forty years of post-WWII economic success had positioned the steady job as the cornerstone of economic prosperity and upward mobility. That concept was already in decline by the 1970s, but policymakers didn’t see it, and neither did the people who voted for them. As a result, workfare became the one-size-fits-all solution for government assistance to the underperforming population.

“What Do You Do?”

Workfare was a natural fit in the United States, where work is a primary means of personal identity and social status.⁷ The cultural emphasis on work makes loss of it that much more personally devastating.⁸ Workfare mercilessly piles on the guilt and shame: the mere act of asking for help is suspicious; applicants have the burden of proving they aren’t out to cheat the system. To do that, you have to show that you tried and failed to get a job through no fault of your own.

Seriously—under workfare, you have to sound like a whiner to prove you aren’t one.

How’s That Working for You?

Twenty-five years after the ADA and workfare, if you’re disabled in the United States, you’re twice as likely to be poor than someone who isn’t.⁹ So much for the ADA’s vaunted enhancement

to economic opportunity for the 58 million Americans with physical and mental disabilities.

Turns out that disability—like poverty and the other social ills that workfare was supposed to fix—is a lot more complicated than putting the disabled back to work. Disability is both a cause and consequence of poverty:

It is a cause because it can lead to job loss and reduced earnings, barriers to education and skills development, significant additional expenses, and many other challenges that can lead to economic hardship. It is also a consequence because poverty can limit access to health care and preventive services, and increase the likelihood that a person lives and works in an environment that may adversely affect health.¹⁰

Proving Your Worth

Under workfare, the process of proving your worthiness has “devolved into a behemoth of control and humiliation.”¹¹ “An army of social services workers is needed to guide people through the jungle of eligibility, application, approval, and recapture procedures. . . . The welfare state, which should foster people’s sense of security and pride, has degenerated into a system of suspicion and shame.”¹²

Is it really that bad? Try applying for food stamps sometime.

Our bank account was thin during the early years of the health issues that eventually led to my being considered disabled. Following the advice of family, my wife applied for food stamps. Among other things, to prove her worthiness, she had to report for eight hours per week of wall-washing duty at a church community center. She washed the same walls every week—the same walls that other people were also washing every week. The cleanest walls in Denver. Washing walls—pointlessly, needlessly, endlessly—to prove she wasn’t a slacker.

The first time I used the card, the checker apologetically told me I had a balance due. Seems I had things other than “healthy food” in my cart. (The current name for food stamps is the Supplemental Nutrition Assistance Program.) Shame on me.

A couple of months of that and we dropped out. That was the point, I think.

Getting on the Dole

Qualifying for Social Security Disability Insurance (SSDI) wasn’t nearly so demeaning; it just took a long time.

Back when I was first watching my work-for-a-living worthiness fading away—well, trust me, when you see your work-for-a-living worthiness fading away, it’s terrifying. Truly. I mean, what are you going to do? Me, I got lucky—somebody told me about a physician’s assistant at my neurologist’s office who was also a lawyer, I talked to him, and he said he could help. The first thing that will happen is your application for SSDI will be denied, he said. That’s standard. Then it will be submitted for reconsideration, where it will also be denied. Then we’ll have to appeal.

Okay, no problem. I’ll just not work for a living for a couple years while that’s going on.

I went for a morning of tests at an occupational therapy clinic, bouncing from one therapist to another, testing physicality and cognition. The idea was to do your best—and fail—if you wanted to qualify for benefits. The temptation to game the system was palpable. I thought I did okay on the tests, but the write-up gave us reasons to stay in the process. As predicted, my application was rejected, we appealed, it was rejected in “reconsideration,” and we appealed again. Then we waited a couple years.

Part of the problem is that I have multiple sclerosis (MS), which is an “invisible” disease—it happens in the brain and spinal cord where you can’t see it. The Rocky Mountain MS Center gave me a card to carry in my wallet in case I got “stopped.” I still have it. It reads:

The person named on this card has multiple sclerosis and may have the following symptoms:

- loss of balance and coordination
- difficulty walking or writing
- numbness or partial paralysis
- double or blurred vision
- slurred speech
- extreme fatigue.

Not good. My invisible disease made me look like the ultimate in unworthy.

Beating the Odds

Around 2 million people apply for SSDI every year, and about one-third are ultimately ap-

proved. (Does that mean the other two-thirds are fraudsters?) My claim took a little over two years to get through all the appeals, which was about normal back then (2016). Since COVID-19, the wait time has increased by 83%. What happens to people while they wait? A 2015 report by the Government Accountability Office found that roughly 10,000 applicants die and 8,000 file for bankruptcy while waiting for a decision on their application. One of those happened to me. (Hint: I’m not dead yet.)¹³

And Yes, You Do Need a Lawyer

“The fact that I needed a lawyer, it took me a long time to wrap my head around. Because what other federal benefits do people receive that you need to hire a lawyer for? I thought, this doesn’t make any sense.”¹⁴

I had two friends who tried to DIY their SSDI applications. Their applications were rejected. That’s just normal, I told them, but now you need to quit fooling around and get a lawyer. They were qualified on appeal. A survey conducted by Nolo showed that having legal representation doubles the odds of a favorable determination. And your best odds are in front of an administrative law judge (ALJ).¹⁵ A disability lawyer is paid a statutory fee—25% of your backpay award, up to a maximum of \$7,200—a pittance, when what’s at stake is an unfunded economic future—something that 67% of applicants still face. And I seriously doubt they’re all fraudsters.

Beyond the Numbers

I had a lawyer who’d been there before, and the numbers fell in my favor. At the time I thought I’d been given a favorable determination because I was, well, disabled. Now, besides realizing that I beat the odds, I also wonder if it was at least in part because ableism was working in my favor. Turns out, I’m on the right side of all those assumptions and stereotypes and generalizations.

It’s been extensively researched that people make first impression judgments about whether disabled people are deserving or not. Often, a visible indication like a wheelchair helps convey a message that you’re disabled for no fault of your own—a key factor in determining

worthiness. I wasn't in a wheelchair when I went to my appeal hearing before the ALJ, but I benefited from being on the good side of other social stereotypes:

- Claimants with characteristics that suggest “genuineness”—either medical legitimation, or conditions/impairments associated with medical proof and observable cues—will be seen as more deserving.
- Claimants with characteristics that suggest blamelessness—via either direct cues or conditions seen to be uncontrollable—will be seen as more deserving.
- Claimants with more permanent, serious, and work-limiting disabilities will be seen as more deserving.
- Claimants who have contributed to the system and who are members of ethnic/racial in-groups will be seen as more deserving.¹⁶

I was a white guy who used to be a lawyer and now wasn't getting around all that well, plus I'd lost a lot of executive function and got tired easily—and my condition was caused by a disease with a recognizable name that makes people say, “Oh, I'm so sorry.”

Good enough, apparently.

I had in fact contributed to the system enough that I qualified for the maximum amount of monthly benefit. That meant I would receive roughly 15% of what I'd made as a lawyer—well below the government's poverty line, where I would stay the rest of my life.

I've learned that it's expensive to be poor and disabled. Studies have estimated that it costs about 28% more to reach the same standard of living as someone without a disability. Plus, there are all the hidden administrative burdens—the “disability tax” imposed on disabled people's time, energy, and physical and mental well-being.¹⁷

But it's still true that hearing the ALJ say she was going to approve my application was one of the best days of my life.

Occasionally, I have something akin to survivor's guilt because I've learned that trauma and chronic stress can trigger the onset of MS—especially in males who come down with it later in life (like me). Two years before I came down with it, I had a ski accident with broken

bones and a hospital stay. Then two years after that, I had a more serious repeat after a cycling accident and literally woke up from surgery with MS. (It took a few more years to figure out that's what happened, which explained why I wasn't rehabbing.) Plus, I'd spent a couple decades in a high-stress career.

Was I undeserving because I'd caused my own MS?

Nobody ever asked.

It Never Ends

Once you've been approved for SSDI and are “in the system,” workfare's insistence on deservedness never stops. The ADA and workfare were about making you economically productive again—to get you back on the job—but since you can't do that anymore, the free market economy converts you into a commodity in the health-care system. You become a profit center.

For example, you can't just go out and buy a wheelchair because you need one. First you have to see your doctor and get a prescription for it. Then you need a home well-being evaluation. And an occupational therapist evaluation. And a physical therapist evaluation. And then you need a wheelchair company that's also in the system along with everybody else.

Then there's the implied maintenance agreement. A couple of years ago, I got hit by a car as I was crossing the street. *Hit by a car. In my wheelchair. Crossing the street. In the crosswalk.* My chair needed some repairs and new wheels. I thought maybe I could DIY it. Not a chance. First, I needed a prescription, and all the rest, for wheelchair repairs and replacement wheels. After being *hit by a car. In my wheelchair. Crossing the street. In the crosswalk.*

You'd think I'd know that my wheelchair needed help, right? Ah, but was I trustworthy?

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Was I going to defraud the US government to get some new wheelchair wheels? “I felt from the beginning, and just continue to feel from Social Security, the constant presumption that I’m committing fraud, in spite of my doctors making strong written statements that I am unable to work.”¹⁸ “I have to ask, ‘Is it really cost-effective in the SSDI and SSI system to spend so much effort and people-hours trying to see if people are committing fraud?’”¹⁹

I’m lucky—my need for help from “the system” is minimal (my MS is medically untreatable), which relieves me from much of the administrative load. That’s not the case for people on the wrong side of the assumptions and stereotypes and generalizations.

Programs targeted to low-income people typically present far more hurdles for applicants to overcome in order to gain access than do programs targeted to middle and upper-class people. Likewise, disabled people, people of color, LGBTQ people, women, and the elderly are, for a number of reasons, hit harder by administrative burdens. Whatever the reason, this often results in these people’s exclusion from benefits that they desperately need and that, in some cases, could be lifesaving.

Moreover, because administrative burdens tend to have the largest impact on people with worse medical conditions and lower prior earnings as well as lower education levels, they exacerbate and entrench inequality.²⁰

There Must Be a Better Way

Under workfare, the only work that counts is the kind somebody makes a profit from—which discounts all the work we do all the time because we like to or need to, and also the work we would do for free if we only had the chance.

Yeah, right. Who has time for that?

Me—now that I’m disabled and spend most of my time at home.


Makes you wonder if we could start with new ideas about work and what it means to be healthy and put them right at the front of the conversation with disabled people invited. Kind of like putting the ADA upfront in the design process, instead of tacking it on as an afterthought.

One Last Thought

It’s deflating to think I might have gotten my SSDI because I meet the stereotypical deservedness standards. Or that people are nice to me when I’m riding my wheelchair for the same reason. Mostly, I don’t think about it—it’s not hard to enjoy their good cheer and forget the ableism and workfare guilt trips. But I confess,

there is one more thing I’m thinking but will never say out loud because it would ruin the moment:

Thanks for your kindness, but the truth is I would trade all the awesomeness you think I possess for just one chance to be standing in your shoes . . .

. . . instead of sitting where I am. 



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NOTES

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