

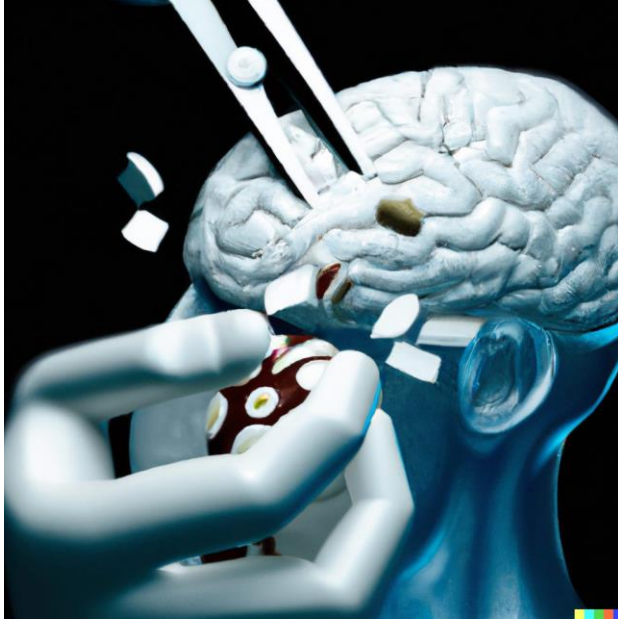
Why Disability Advocates Are Trying to Shut Down A Policy That Benefits Disabled People

A sad and fascinating case study from the new book "Chasing the Intact Mind"

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SEP 12, 2023

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In the very first sentence of [*Chasing the Intact Mind: How the Severely Autistic and Intellectually Disabled Were Excluded from the Debates That Affect Them Most*](#), author [Amy S.F. Lutz](#) explains the striking term in her book's title:

In her 2006 memoir *Strange Son*, Portia Iversen coined the phrase “intact mind” to describe the typical cognitive abilities she believed were buried within even the most seemingly impaired autistic individuals, like her son Dov—who, at nine years old, was completely nonverbal and spent much of his time “chewing on blocks and tapping stones.” Although he didn’t know the alphabet, colors, or numbers; although he “could hardly point or nod his head to show what he meant”; although doctors had diagnosed Dov as “retarded” and told Iversen she “shouldn’t wreck [her] marriage and destroy [her] other children’s lives for his sake, when doing so was utterly and completely useless”—although all these

things were true about her son, Iversen still imagined him “falling down a deep well, believed to be dead. And then years later, a light shone down that dark shaft and I could see him there, *somehow still alive*” (emphasis in original). [citations omitted here and throughout]

Lutz, a historian of medicine at the University of Pennsylvania who has [previously written a book](#) about her experiences raising a son (now an adult) with severe autism, goes on to lay out a fascinating history of this concept in the first half of *Chasing the Intact Mind*. She focuses heavily on memoirs written by parents of children with autism, showing how at every stage in the modern history of our understanding of this condition, such parents have pined for — and in some cases gone to herculean and frequently pseudoscientific lengths to free — the “intact mind” supposedly lurking behind their severely disabled child’s troubled exterior. It’s often quite difficult for these parents to accept that their experiences raising kids with severe autism, which can involve the everyday management of violent tantrums, obsessively repetitive behavior, and problems with toileting and basic communication, reflect not a temporary challenge that will be overcome, with a “normal” kid waiting at the other end of a journey, but rather simply who their child is and will always be. But sometimes, unfortunately, that’s the case.

Given my lack of familiarity with the history in question, I don’t have much to say about the first half of Lutz’s book except that it was brisk, stimulating reading. The second half is more relevant to real-world policy debates, because that’s where she argues that the myth of the intact mind has caused significant damage to disabled people — damage at least partially inflicted by activists claiming to represent that very same group.

I was most fascinated by the first chapter of the second half: “The Fight to Eliminate 14(c).” It’s quite a story. Let’s use a lengthy excerpt from the top of that chapter to fill in the basics:

In the waning hours of the Minnesota state legislature's June 2021 session, a few brief lines were slipped into a 300-plus page omnibus bill. Although this was in clear violation of parliamentary procedure—the proposal never had a hearing in the senate, as required—and few representatives realized it had been added, the bill was signed by the governor, and the Task Force on Eliminating Subminimum Wage was created. Section 14(c) of the 1938 Fair Labor Standards Act authorizes certificate holders to pay employees—typically individuals with significant intellectual and developmental disabilities or psychiatric disorders—wages commensurate with their productivity. Unless the bill is amended, such sheltered workshops, as they are often called, will be shuttered by 2025.

Minnesota has the largest number of 14(c) certificates in the country; 26,000 adults earn a subminimum wage at programs operated by nonprofit agencies across the state. One of those providers, Laura Johnson, the executive director of the Hubbard County Developmental Achievement Center, encouraged by the inclusion of 14(c) employers on the Task Force, accessed the application from the Department of Human Services website. She was stunned to find what can only be described as an ideological purity test she would have to check in order to be considered: “I understand the purpose of this task force is to develop a plan and make recommendations to phase out payment of subminimum wages to people with disabilities on or before Aug. 1, 2025. If selected, my role will be to support this purpose. This task force will not consider whether or not Minnesota should eliminate subminimum wages.” No spots were set aside for current 14(c) participants or their family members, those most impacted by the closures.

Although the fluid status of 14(c) in the state makes Minnesota a compelling case study, this represents an important national issue. Eliminating 14(c) has been a key plank of the Disability Rights agenda for decades. Vermont, Maine, New Hampshire, and Rhode Island have already closed their programs; Alaska, Maryland, Oregon, and Texas are in the process of doing so. At the federal level, Senators Bob Casey from Pennsylvania and Steve Daines from Montana introduced the Transformation to Competitive Integrated Employment Act

(TCIEA) in November 2021, which would phase out subminimum wage employment over five years. Much of the TCIEA was included in President Joe Biden’s proposed Build Back Better bill—although in lieu of an outright ban, this legislation would provide \$300 million to states that disavowed the practice. As of this writing, none of these bills has passed.

Yet, as committed as some disability advocates and policymakers are to abolishing 14(c), participants and their families are fighting to preserve it. In 2020, the U.S. Commission on Civil Rights (UCCR) released its Statutory Enforcement Report, “Subminimum Wages: Impacts on the Civil Rights of People with Disabilities.” After recommending the elimination of 14(c), the Commission admitted that, not only had it received many more public comments than it had regarding any other issue, but that 98% of the more than 9,700 comments were in favor of preserving 14(c). Noted Commissioner Gail L. Heriot, in a dissent, “It would be difficult to find an issue for which comments were more lopsided.”

Lutz goes on to explain that “In January 2022, I visited three Minnesota agencies that offer 14(c) employment and spoke with intellectually disabled participants, their parents, and administrators—all strong supporters of preserving this option.” Mixing together their testimony with a lot of research about the history of the 14(c) program and what happens when these sorts of workplaces are shuttered, she makes a very compelling argument that the decision to phase out the program is extremely shortsighted and likely to harm a very vulnerable group almost certainly incapable, in most cases, of finding much work elsewhere.

Lutz debunks some of the common claims activists make to justify winding down the program, including that 14(c) represents a form of nasty exploitation. For one thing, Lutz argues, most 14(c) certificate holders are nonprofit organizations dedicated to helping the disabled, with the subminimum wage work part of broader offerings (and obviously not mandatory). She also notes that no one is expecting the participants in these programs to live off their

meager paychecks; rather, the vast majority of them receive other forms of government assistance, and it's often quite significant.

I'm not going to linger on those debunkings for too long. I found them convincing, and (what Lutz views as) certain activists' constant repetition of certain untrue and half-true catchphrases rang familiar to me, but truth be told this isn't an area where I have any expertise, so I can't quite evaluate those arguments.

What most stood out to me was how the intact-mind myth figures into all of this: the activists furious about 14(c) consistently argue that the participants should be allowed to earn minimum wage in the standard labor market. Which, of course, is an argument you can't make unless you believe that underneath the often rather severe disabilities afflicting participants in this program there lie intact minds capable of doing the same work as neurotypical people at the bottom of the labor market.

Lutz says this is ridiculous. I mean, I don't think she *says* it, per se — academics are rarely so explicitly acerbic in texts released by academic publishers — but, like, come on:

The high rate of challenging behavior among the intellectually and developmentally disabled is largely unacknowledged by anti-14(c) advocates who insist that everyone with a disability can hold competitive, integrated employment [meaning employment in which they are integrated with mainstream society/workers]. A 2006 Canadian study found that almost 52% of over three thousand subjects—clients at three rehabilitation agencies in Quebec—engaged in violent behavior over the course of a year, including self-injurious and aggressive episodes, as well as property destruction. These results are remarkably consistent with those of a 2013 study that looked at autistic children enrolled in the United States-based Autism Treatment Network and found that 53% were physically aggressive. The severity of these outbursts varies across the population—in the most extreme cases, autistic individuals have blinded or concussed themselves from repeatedly hitting themselves in the

head, or left their caregivers with bruises and broken bones—but the vast majority of employers obviously and necessarily have a zero-tolerance policy for such behaviors.

Contrary to the claim that the workers in question are being exploited by greedy, profit-maximizing monsters, 14(c) certificate holders often have to put a great deal of time and effort into figuring out how their disabled workers can safely — well — work.

Take the next paragraph, which concerns Lisa, one of the workers in question, and her mom, Debbie. Lisa, we know from a page earlier, “is autistic [and] also suffers from severe obsessive-compulsive disorder (OCD) and anxiety that can provoke very challenging behaviors,” including, as her mom puts it, “drinking out of every water fountain she sees,” “blowing out every table candle she sees,” and “touch[ing] the side of every teapot or kettle she sees, just to make sure it is hot.”

Thanks to 14(c), she is able to do work weaving rugs, which she enjoys and finds meaningful — she now actually makes minimum wage, though when she started out she did simpler work for less pay — at a facility where her special needs are accounted for:

“Lisa’s not even five feet tall, but she’s left big bruises on my husband and myself,” Debbie told me. “The staff at the DAC [the Hubbard County Developmental Achievement Center] know her so well, they can really help redirect her when she gets agitated. She needs that level of support all the time. Providing that in a competitive workplace, where the staff-to-client ratio would be much smaller—probably one-to-one if she were the only disabled employee—would be financially unsustainable when job coaches are typically paid \$40 an hour.”

So while it’s easy to understand why people might have a negative gut reaction to disabled people making less than minimum wage — and of course participants in such a scheme *could* be abused — the simplicity of that gut reaction might not fit the complexity of a situation like Lisa’s.

In her book, Lutz is critical of a certain brand of disability activism. Early on she writes:

Lowercase “neurodiversity” is a truism—minds obviously vary tremendously, including a broad range of intellectual, developmental, and psychiatric disorders, and all fully belong to our human community. But “Neurodiversity” with a capital “N” has come to represent a much more specific position: “that instead of viewing this gift [autism] as an error of nature—a puzzle to be solved and eliminated with techniques like prenatal testing and selective abortion—society should regard it as a valuable part of humanity’s genetic legacy.” The goal of this movement, as identified by the Autistic Self-Advocacy Network (ASAN), is to “celebrat[e] our differences . . . to make sure that everyone gets the accommodations we need . . . [and] to make sure that autistic people are in control of our own lives, and have a say in policies that affect us.”

Lutz is skeptical of this. There are millions of people like Lisa who are not in a position to have full control over their lives the way higher-functioning autistic people can. Those higher-functioning disability and autism activists, she argues, end up dominating the conversation and unduly elevating certain values over others.

In her 14(c) argument, she complains that

[I]nclusion advocates simply cannot imagine why anyone would choose a disability-specific setting—even though this has never been a consensus position across the broad disability community. One of the earliest and most prominent leaders of the Disability Rights Movement, polio survivor Judy Heumann, fondly recalled the warmth and connection she experienced at a summer camp just for disabled kids, where campers who felt self-conscious and excluded among their nondisabled classmates during the school year had the opportunity to dance, date, and share their similar experiences.

. . .

But instead of acknowledging that not everyone—disabled or not—shares the same hierarchy of values or definition of quality of life, the UCCR report, as Commissioner Peter Kirsanow critiques, “elevates ‘inclusion’ and ‘integration’ over every other concern.” For some people with intellectual and developmental disabilities, holding competitive, integrated employment may very well be extraordinarily important—and they should, without question, receive whatever supports necessary to succeed. But my interlocutors had other priorities that they believed were best met in their—or their children’s—14(c) programs.

It’s worth asking which sorts of life experiences are correlated with which sets of values. If you’re a high-functioning disabled person who moves around the world of nondisabled people with ease or relative ease — if you get to give talks and appear on radio programs and write for a public audience — then of course this sort of integration with the rest of the world is going to seem important, and is going to be something you want for other disabled people. It’s working out well for you, after all, and the last thing in the world you would want is to be excluded from the integrated world.

But I think there’s a risk that this is a narrow sort of empathy. Full empathy requires meeting people where they’re at. As Lutz’s interviews suggest, if you or someone you care for have such profound disabilities that it is hard for you to qualify for, let alone hold down, a minimum wage job, then of course your priorities are going to be different. Thriving in integrated settings isn’t a real option for you, let alone priority.

Imagine some American do-gooders parachute into “[Africa’s youngest capital](#),” Juba, South Sudan, and come to have significant influence over its governance despite having just arrived and having no real connection to it. They reflect on their own values and experiences, and they decide that what Juba needs is a subway system. After all, because the vast majority of them come from wealthy backgrounds, they’ve been able to live in and enjoy places like New York, Boston, the Bay Area, and Washington, D.C., and in these cities the subway systems are indispensable to everyday life. They decide, therefore, that they will wield their power to fight tooth and nail until the residents of Juba have a decent

subway system. If any of the other aid workers stand in their way, they'll say something like "Oh, so you don't think residents of African nations deserve the same public transportation we do?" (They don't have all that much interaction with non-wealthy, non-English-speaking residents of Juba, so they don't factor into the equation much, anyway.)

Of course this would be a mistake. Maybe someday Juba will have a subway system, but for now, if that *Guardian* article I just linked to is any indication, there are so many other problems to tackle and ways in which the city's growth needs to be managed, that diverting energy to a subway system would very likely do more harm than good — largely because it would fail to reflect what the city's most vulnerable residents actually need or value right now.

Maybe this analogy is a stretch when it comes to the 14(c) situation. For one thing, a neurodiversity activist would surely quibble with it on the grounds that whereas in this scenario my dastardly NGOers are somehow parachuting into Juba's affairs despite having no connection to it, *they* are speaking on behalf of a community they represent: disabled people.

But as Lutz notes at least a few times throughout the book, when you define certain terms loosely, problems arise. Ari Ne'eman, who comes up a couple times in *Chasing the Intact Mind*, is a good example. Unless [this website](#) is outdated, he's presently a PhD student in health policy at Harvard. Here's how his bio there reads:

Ari Ne'eman is a 4th year student in Harvard's PhD in Health Policy. He received his BA in Political Science from the University of Maryland, Baltimore County in 2010, and has since worked in disability policy advocacy. From 2006 to 2016, he served as executive director of the Autistic Self Advocacy Network, a national advocacy organization run by and for Autistic Americans. From 2010 to 2015, he served as one of President Obama's appointees to the National Council on Disability. Most recently, he worked as a consultant to the American Civil Liberties Union, the Department of Health and Human Services Office of Civil Rights, the Service Employees International Union and other organizations

interested in health and disability policy. He is currently a Visiting Scholar at the Lurie Institute for Disability Policy at Brandeis and his research interests include disability employment, long term services and supports and bioethics.

As is suggested by the name of the organization he executive directed, Ne'eman has autism. But he's at the far end of the bell curve when it comes to societal outcomes for those with the condition. As Lutz notes, "The spectrum of impairment in this population is impossibly broad, including college-educated self-advocates like Derek Manners and Ari Ne'eman and nonverbal, cognitively impaired adults like [two of the lower-functioning interlocutors she interviewed when she went to Minnesota to visit 14(c) sites,] Alex S. and Eddie K., who don't understand the concept of the money they earn, never mind why the amount is so controversial. It seems completely obvious to supporters of 14(c) that we need a similarly broad range of supports to reflect such diverse needs and preferences."

But if you're Ne'eman, you probably have different experiences, and therefore different values. Elsewhere in the chapter, Lutz bristles at the "utter contempt with which disability advocates dismiss 14(c) participants: 'Someone compensated to the tune of a few cents an hour is hardly employed,'" sniffed. . . Ne'eman[.]" Right, maybe Alex S. and Eddie K. are "hardly employed" by the standards of those of us in a position to attend Ivy League institutions, and maybe that's something we wince at because we wouldn't want a (neurotypical) friend or a loved one in such a situation unless it was by choice, but. . . what about Alex S. and Eddie K.? What reason is it to think they have the same values and priorities as we do, despite having very different minds?

I just think the labels are doing a tremendous amount of work here, and the tissue supposedly connecting all these disparate individuals is strained. I guess Ari Ne'eman, Alex S., and Eddie K. are all "disabled," technically speaking. But there are limits to treating them as members of the same meaningful group, in much the same way there are limits to reading all that much into the fact that Nikole Hannah-Jones, a subway operator in New York City, and an impoverished 5-year-old black kid suffering from malnutrition in the

Mississippi Delta are all “black.” It would be shocking if, by dint of their blackness, these three very different individuals ended up having the same priorities. It would be shocking if Hannah-Jones were able to speak effortlessly for those other two individuals without consulting with them (or their parents, in the case of the malnourished child).

Such are the perils of essentialism. When we make our groups too big and too broad, the most privileged members are almost always going to seize disproportionate control, because that’s how privilege works. It’s a lesson worth keeping in mind, because it pops up endlessly. I’m very much looking forward to reading Freddie deBoer’s [*How Elites Ate the Social Justice Movement*](#). In the meantime, you should buy Lutz’s book if you’ve found any of this interesting or provocative.

Before I published this, I reached out to Lutz through my publicity contact to ask if any noteworthy updates to the 14(c) story had occurred since she finished her book.

She replied:

In February senators Bob Casey (D-PA) and Steve Daines (R-MT), together with Reps Bobby Scott (D-VA) and Cathy McMorris Rodgers (R-WA) introduced the Transformation to Competitive Integrated Employment Act, which would end the sub minimum wage at the federal level. I believe this bill was first introduced in the House in 2021.

The Association of People Supporting Employment First (APSE) has a page on its website that tracks state bills to eliminate 14c: <https://apse.org/state-legislation/>

So the fight to end these programs is picking up pace, it looks like. And the myth of the intact mind isn’t going anywhere.

Questions? Comments? Wild generalizations about what other people with brown eyes want and need? I'm at singalminded@gmail.com. The image was generated by DALL-E [in response to my prompt](#): "a brain has been shattered into pieces, and in this science fiction image there is an attempt to repair it."