

Hello from the [RBHS Office of Disability Services!](#)

Would you like additional information or a presentation in your course? Let us know: odsrbhs@ca.rutgers.edu

We invite your feedback https://rutgers.ca1.qualtrics.com/jfe/form/SV_5tcPBj4uh1vpwqi

The RBHS Office of Disability Services (ODSRBHS (odsrbhs@ca.rutgers.edu)) provides the necessary tools, resources and support for disabled students to become responsible decision-makers and self-advocates in charge of their own future. We are also here to support faculty and staff.

October is Disability Awareness Month

The Rehabilitation Act of 1973 prohibits discrimination on the basis of disability in programs conducted by federal agencies, and the Americans with Disabilities Act of 1990 prevents discrimination against disabled people on everything from employment to parking to voting. Both bills received bipartisan support when clearing Congress.

[President Biden's remarks on October 2:](#)

"These laws are a source of opportunity, meaningful inclusion, participation, respect, and, as my dad would say, the most important of all, dignity," President Biden said. "Be treated with dignity. [Ensuring that the American dream is for all of us](#), not just for some of us."

(see facts and figures on page 2)

New Student Group for Disability Advocacy

RBHS Students for Disability Education and Advocacy

According to the CDC, one in four people in the United States are disabled. RBHS students may be disabled themselves, or work, take classes, socialize with disabled friends and colleagues, or treat disabled patients. The Office of Disability Services is working toward creating a student organization focused on issues that impact disabled people. The organization will focus on promoting disability education, advocacy, and awareness on campus and beyond. This will be the first RBHS student organization that is not school or program specific.

If you are an RBHS student and you would like to attend an interest session and/or have an interest in issues that impact disabled people, please contact Jenna Rose at jer298@rbhs.rutgers.edu.

Interests sessions: 10/30: 5pm-6pm; 11/7- 12pm-1pm

Doing Science With Disabilities

Scott [McLemee](#) (writer for *Inside Higher Ed*) reviews *Uncharted: How Scientists Navigate Their Own Health, Research, and Experiences of Bias*:

Writing in *The New York Times* last month, Sara J. Winston, the coordinator of the photography program at Bard College, [described the upheaval](#) of having various unpleasant bodily sensations diagnosed as symptoms of multiple sclerosis. She soon began a course of treatment that sounds effective and encouraging, but the condition itself is chronic. Even in remission, the illness sets the pace of her life, requiring her to travel every 28 days to receive infusions.

Accompanying the essay are Winston's photographs of her visits to the clinic: part of a series of portraits of the artist as a young patient. Each of us "exists on a spectrum of illness," she writes, "often dipping in and out of it," but also prone to avoiding the topic. But "in a culture where it is taboo to talk about being sick ... the taboo can allow shame to fester among those who are chronically ill." Her creative work might be called therapeutically shameless—a public acknowledgment that her own well-being is precarious and contingent. Losing access to ongoing care would place her, she writes, "at risk of severe disability."

Winston has allies on the other side of the seemingly impenetrable barrier between "the two cultures," with the arts and humanities on one side and the sciences on the other.

The contributors to *Uncharted: How Scientists Navigate Their Own Health, Research, and Experiences of Bias*—a collection of 32 personal essays edited by Skylar Bayer and Gabi Serrato Marks, published by [Columbia University Press](#)—come from an array of STEM fields and write about their firsthand experiences of chronic illness or disability. While one contributor estimates that people with disabilities represent 20 percent of the world's population, they are, the editors say, "highly underrepresented in science, technology, engineering, and mathematics."

The editors note their surprise at finding "how many authors (including ourselves) had shared common experiences despite having vastly different diagnoses." Winston's observation in her *Times* piece about how the taboo on candor "allow[s] shame to fester" is echoed by a number of contributors. As a graduate student in geology, Jenn Pickering kept her diabetes a secret from her peers, dreading that someone might think she'd only been accepted into her program by "help[ing] the university attain some disability quota." She experienced a potentially fatal "severe hypoglycemic event" while in transit to Bangladesh on a research expedition. "I remember fumbling desperately with a brownie wrapped in an impenetrable plastic wrapper," she writes, "probably cursing at it while somebody or everybody noticed and stared." Extracting it, Pickering

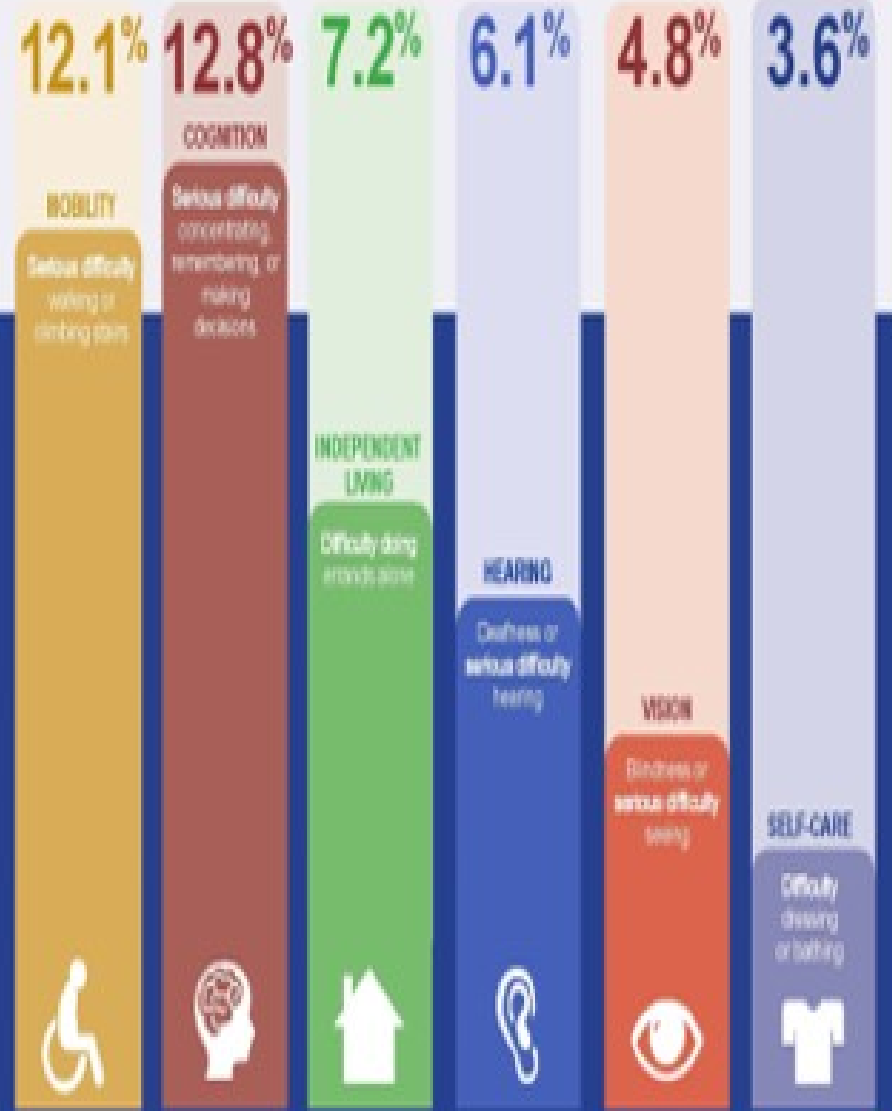
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Disability Impacts
ALL of US



Up to **1 in 4** adults in the United States have some type of disability (27%)



(45-64 years)

Making A
DIFFERENCE



PUBLIC HEALTH IS FOR ALL OF US

Join CDC and its partners as we work together to improve the health of people with disabilities



Disability and
HEALTH

Adults with disabilities are more likely to

	With Disabilities	Without Disabilities
HAVE OBESITY	41.6%	29.6%
SMOKE	21.9%	10.9%
HAVE HEART DISEASE	9.6%	3.4%
HAVE DIABETES	15.9%	7.6%

View infographic and references at: www.cdc.gov/disabilities/

Contact us: disabilityandhealthbranch@cdc.gov

Twitter: [@cdc_ncbddd](https://twitter.com/cdc_ncbddd)



“According to the [CDC](#), as many as 25 percent of all American adults have some type of disability. It stands to reason, then, that many individuals at all stages in their academic journey—whether in the first year of their undergraduate career or on the tenure track—experience disability. As an academic profession and community, we can do more to normalize disability—both visible and invisible—and provide meaningful accommodations. ***We shouldn’t be celebrating institutions and individuals for their efforts to help people with disabilities succeed. [Providing the necessary resources](#) should be simply par for the course***”

From “[Learning to Live With Disability in Grad School](#)”

Disability is Not a Bad Word

The first deafblind person to graduate from Harvard Law School, Haben Girma is now a human rights lawyer advancing disability justice. A few years ago, [Girma posted a helpful reminder](#):

“If you say I have special needs, I’ll assume you’re referring to my need for fresh-picked figs. I’m a Californian & this is non-negotiable. But if you’re not referring to figs, then just say the word: #disabled. Euphemisms [such as differently abled or disabled) only fuel ableism. #Disability is not a dirty word.”

[Great advice for allies everywhere.](#)



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“dutifully chewed [the brownie] like a robot, my mouth dry, no joy in the experience because my taste buds had been cut off by my brain minutes before to preserve more important bodily functions like breathing and circulating blood.”

Crisis averted, Pickering and her colleagues pursue their research. And with time and experience, she learns to live with her condition—to manage it without feeling compromised in the eyes of her colleagues. She is able to refer to shame in the past tense. Various contributors express an aversion to being called “brave” or a “warrior” or to “overcoming” their disability. Such expressions tacitly accept what the editors call “the typical deficit-focused narrative of disability” and, however well-meaning, do little to allay feelings of stigmatization beyond covering them with a saccharine glaze. The editors prefer to frame the personal essays in their collections as narratives of “driving ourselves forward as whole people, including our disabilities.”

One of the memorable instances of this is Daisy Shearer’s account of her autistic nervous system’s navigation of the route between her front door and her physics laboratory. The sidewalks and railway train are a blooming, buzzing confusion even on an ordinary day, or especially then.

“My brain is in overdrive,” she writes, “trying to process everything, desperately attempting to predict everyone’s movement to make sure I don’t bump into anyone and cause an unexpected sensory experience that I know could push me into a meltdown or shutdown. My brain craves certainty and control, so being around so many people can be a challenge unless I’m very focused on my objective.” At the end of her quest is “a split-coil superconducting solenoid with optical access from all four sides ... basically a huge magnet that you can shoot lasers into.” Her first encounter with it (“so many knobs and valves and gauges to keep track of”) was terrifying, but familiarity led not just to confidence but what sounds like a kind of affection for the device.

The inner drama in a large majority of these personal essays unfolds in a higher ed environment, often experienced as a zone of conflict. Seldom are academic institutions or their personnel depicted as any more welcoming than the Americans With Disabilities Act makes absolutely mandatory. And sometimes less, as emerges from Alma C. Schrage’s memoir of her conference-going and research fieldwork as a young, deaf biologist (one of the two or three best pieces in the volume, in my opinion).

Attending her first academic conference as an undergraduate leaves her unable to “read or look at a screen because of eyestrain from lipreading,” despite sitting on the front row of every session she attends. Shortly before another conference, she writes, “the hosting university realizes that I am a student visiting from another institution, and it immediately retracts its previous offer of providing interpreters.” This second conference tale has a better outcome: a conference organizer (“a leading scientist in our field”) rallies together a team of volunteer note takers.

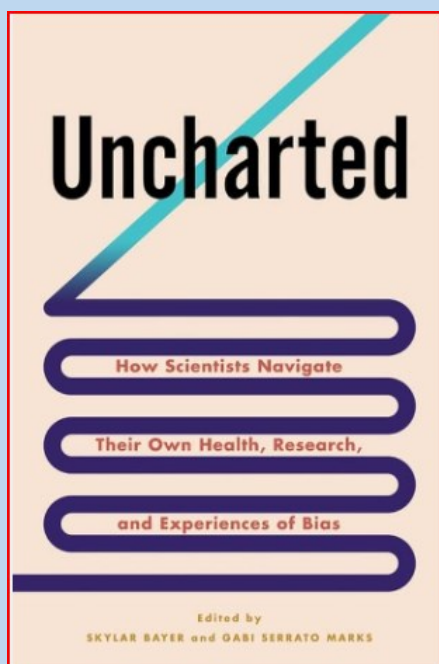
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"Her action means a lot," writes Schrage. "My advisors and hearing mentors always treated accommodations as something they could not be bothered with beyond sending a couple of emails or turning on captions. When these failed, they shrugged and gave up, leaving me to struggle on my own." Other essayists write about the toll of ruthless professionalization on their colleagues' capacity for meaningful empathy—a topic Schrage does not pursue, but which certainly comes to mind in reading her narrative.

Alternating with Schrage's conference experiences are short accounts of remote fieldwork with her colleagues, in small groups. "In a matter of weeks, my coworkers gradually adjust to my deaf tempo; sometimes grudgingly, sometimes unconsciously, sometimes intentionally, they become aware of communicating with someone whose perception of the environment is different from theirs."



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Tildesley said he had contacted the cruise line before the journey telling it that he didn't need much help, just a guide to bring him from his cabin to the restaurant and help with reading printed materials.

When he was asked to leave, he told news site [Daily Hive](#): "I thought, 'Is this some sort of joke?'"

Tildesley, who has been on cruises before, was left in Miami as the ship sailed off without him.

However, soon after, Virgin's senior vice president of fleet operations, Frank Weber, got in contact to apologise, with an offer to fly him business class to the next port of call.

Tildesley took him up on his offer and he rejoined the ship. He even received a handwritten apology from Virgin founder, Sir Richard Branson.

It read: "That for giving us the chance to make things right. I hope you're having a brilliant getaway."

Tildesley thanked the cruise line, calling it a teachable moment.

"I've taken it one step further in that I've asked Frank to invite me to speak at a corporate Virgin meeting next year to talk about accessibility and inclusiveness.

"Because that's false advertising. If you say on your website that you're completely accessible to people who are blind and you have braille on the elevators and in your rooms and everything, you've gotta walk the walk if you're gonIn [*sic*] a post on Instagram, he added: "It says a lot about a company when they can recover from a mistake. @virginvoyages did that and then some.

"Sunday I was escorted off the cruise ship because they weren't sure they had the supports in place for a solo blind traveler. Today I am flown business class to Honduras to rejoin the same ship, and I am enjoying drinks on the #Rockstar Deck.

"Thank you for everyone's help and support over the last couple of days!!"

Virgin Voyages admitted it was "infinitely sorry" for the way he was treated.

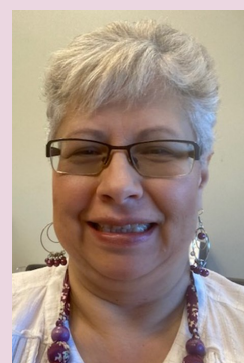
And the story gets better . . . it led to a [job](#) offer. "It took a few months to iron everything out, and to make a long story short, I am now contracted to Virgin as an accessibility consultant," he said.

Richard Branson apologises to blind passenger kicked off Virgin Voyages cruise

A man who was asked to leave a Virgin Voyages cruise, only to be brought back on board after he made his plight known, has thanked the company for admitting to its mistake.

Donovan Tildesley, a competitive swimmer, was booked on the Valiant Lady for a six-day cruise around the Caribbean. The Canadian was only on the ship for a brief time when he was approached by staff saying he would have to leave as the crew couldn't support his needs as a blind solo traveler.

Continued on next column



Cindy Poore-Pariseau,
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