How long covid could change the way we think about disability

By Frances Stead Sellers

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Mallory Stanislawczyk was hesitant to make the call. She hadn't spoken to her friend for years. But the friend, who gets around in a wheelchair, was the only person the 34-year-old nurse practitioner could think of who would understand her questions. About being ready to accept help. About using a wheelchair. And about the new identity her battle with long covid had thrust on her.

"I think she is the first person I said to, 'I'm disabled now'," Stanislawczyk recalled telling the friend. "'And I'm working on accepting that'."

The coronavirus pandemic has created a mass-disabling event that experts liken to HIV, polio or World War II, with millions suffering the long-term effects of infection with the coronavirus. Many have found their lives dramatically changed and are grappling with what it means to be disabled.

"It's an entirely new identity," Stanislawczyk said.

The dramatic influx of newly disabled Americans changes the calculus for disability advocates, who have in recent years been uniting around a shared identity, pushing back against historic marginalization by affirming their self worth and embracing their disabilities.

"We're taking a big-tent approach in the disability community," said Rebecca Vallas, a senior fellow at the Century Foundation.

The shift also underscores the challenges of creating common cause among people who have sometimes battled over limited resources. Those tensions resurfaced as some who share similar symptoms with covid long haulers, including persistent fatigue, saw research dollars pour into long covid.

“There were resentments,” said Diana Zicklin Berrent, who founded the long hauler advocacy group Survivor Corps. “It was, ‘We’ve been out here screaming from the rooftops for decades, and you guys show up’,” said Berrent, who emphasizes the importance of working together.

By joining forces, long haulers are forcing an existing conversation into the open.

“We’re at this real confrontational moment of trying to educate as many people as possible about disability and structural inequalities and trying to make sure [long haulers] get the resources they need right now,” said Mia Ives-Rublee, director of the Disability Justice Initiative at the Center for American Progress, who has osteogenesis imperfecta, or brittle bone disease.

Ives-Rublee said the movement already encompasses a huge variety of experiences and that somebody with dwarfism or spina bifida has an entirely different worldview from somebody with Lyme disease or long covid, which they did not experience from birth and which may not last a lifetime.

People of color and those from marginalized communities bring their own unique perspectives, shaped by factors such as lack of access to quality health care.

“Because of stigma and stereotype, things often go undiagnosed and untreated in the Black community,” said Andraéa LaVant, a wheelchair user who is Black and was a producer of Crip Camp, responsible for the social change message of the 2020 Netflix documentary that helped draw popular attention to disability rights.

As many as 61 million, or one in four, adults live with some form of disability, according to the Centers for Disease Control and Prevention. Those numbers are being bolstered by between 7 and 23 million long haulers — including a million who can no longer work — according to recent government estimates. Think tanks and others anticipate the numbers will rise as the coronavirus settles in among us as an endemic disease.

Not all long haulers meet the threshold commonly associated with being disabled, such as difficulty hearing, seeing, climbing stairs or dressing. Just over 30 years ago, the Americans With Disabilities Act was written broadly, and it has a legal definition that encompasses anyone who has a physical or mental impairment that substantially limits one or more major life activity.

“One of the things that is so beautiful about disability, is it is big enough to include children in Flint, black women with alopecia, and long covid,” said Rebecca Cokley, program officer for the Ford Foundation’s Disability Rights program who has achondroplasia, a common form of dwarfism.

For Stanislawczyk, her new identity is complete with its own vocabulary. In conversations with other long haulers, Stanislawczyk now calls herself a “spoonie,” referring to a common strategy for managing chronic illness, in which spoons are used to represent energy and people allocate themselves a limited number per day.. She calls days when her heart races “Potsie days” — an allusion to a blood circulation disorder known as postural orthostatic tachycardia syndrome, or POTS, that she and many other long haulers have been diagnosed with.

Dawn Gibson, who founded a weekly “spoonie chat” for people with invisible disabilities, is familiar with the shift in thinking.

“People don’t know that they are disabled. If I hadn’t lived this myself, I wouldn’t believe it, that it’s possible to be disabled and not know it,” said Gibson, who developed arthritis in 2001 when she was 24 and was later diagnosed with the inflammatory disease ankylosing spondylitis. She recalled both not wanting to stigmatize or segregate herself and worrying about diminishing the experiences of others whose disabilities were more severe than hers.

People with long covid, she believes, are facing similar qualms.

“We need to issue an official welcome to long-covid people,” Gibson said. “We need to roll out the red carpet.”

That approach is promoted by Cokley, who said there had been a generational change since the 1980s, when many people with HIV felt shunned.

“We feel like our responsibility is to fight alongside the long-covid community. This is their time to focus on what they need,” said Cokley, who said disabled people already understand the bureaucratic challenges long haulers will face if they need to apply for benefits and can provide peer support as well as what she calls “tips of the trade.” (They include: If a doctor doesn’t believe you or denies you a test, tell them to document the denial in your file; many will quickly change their view, Cokley said.)

Plus there is strength in numbers.

Matthew Cortland, a senior resident fellow at Data for Progress, a think tank dedicated to advancing liberal causes, is working on furthering the conception of disabled Americans as a recognized constituency — one that “should be treated by politicians and policymakers with the respect of any other voting bloc,” they said.

Recent polling conducted by Data for Progress in partnership with the Century Foundation’s Disability Economic Justice Collaborative found that just three in 10 disabled voters believe that leaders in Washington care about people with disabilities, while large majorities of voters of all political stripes support policies that would improve their economic conditions, including investing in home- and community-based services, which allow many disabled people to live independently.

A collaborative of think tanks and disability groups launched earlier this year aims to rectify some stark statistics: Their analysis of the Census’s 2020 Supplemental Poverty Measure suggests people with disabilities experience poverty at double the rate of nondisabled people. They earn on average 74 cents on the dollar compared with nondisabled workers. And they experience food insecurity at three times the rate of nondisabled people.

The pandemic has provided some evidence of new legislative attention to disability. There was minimal reference to disability in the initial covid relief bills, despite growing recognition in 2020 of the disproportionate impact of the pandemic on disabled Americans, according to Kimberly Knackstedt, a senior fellow at the Century Foundation.

The American Rescue Plan was the first relief bill that provided direct support for programs that assist people with disabilities, with specific funding such as a one-year increase to Medicaid for home- and community-based services. The now-defunct Build Back Better bill took a much more comprehensive approach to disability in the development of programs and policies.

“It’s not tacked on,” said Knackstedt. “It’s a good example of conceiving the entire policy thinking about disability.”

In July 2021, on the 31st anniversary of the ADA, the Biden administration announced that long covid could be considered a disability under the civil rights law.

But the pandemic also put a spotlight on deep-seated inequities in what we know about the disabled populations compared with other marginalized communities, according to Bonnielin Swenor, an epidemiologist and director of the Johns Hopkins Disability Health Research Center. In key places, like electronic health records, where data is collected on gender, ethnicity and age, there is a lack of data on disability that could be used to support policy, she said.

Covid also put a focus on how disabled people are often marginalized. In January, 150 disability organizations united in outrage after CDC director Rochelle Walensky said that research results showing that large numbers of united in outrage after CDC director Rochelle Walensky said that research results showing that large numbers of covid deaths occurred among people with four or more comorbidities were “encouraging.”

Walensky later acknowledged that her words were “hurtful, yet unintentional.”

The big-tent approach depends not only on disability groups welcoming long haulers, but overcoming internal rivalries. Cokley and others said the chronic illness and disability communities have not always been allies.

“The dirty secret is that we do have infighting,” said Swenor. “Certain groups have histories of fighting for scarce resources.”

Ken Thorpe, a former deputy assistant secretary for health policy at the Department for Health and Human Services who chairs the Partnership to Fight Chronic Disease, believes long covid offers opportunities to update many aspects of health policy in part because the condition is affecting “a different mix of people than what we’ve seen in the traditional disability population.” They include Sen. Tim Kaine (D-Va.), who suffers from long covid.

Long covid “puts a different and important face on whole problem of long-term care,” Thorpe said. “Collectively, we can be more effective highlighting the policy issues.”

Still, people whose lives have recently been changed by chronic disease sometimes resist the idea that they belong in the disabled community.

Alba Azola, a physiatrist at Johns Hopkins, said that helping long-covid patients make that transition is one of the most challenging parts of her job as co-director of the Physical Medicine and Rehabilitation Post Acute Covid Team Clinic.

Azola sees patients on the hospital system’s Bayview Campus at a clinic repurposed for the new population of long haulers, often drawing on findings from other chronic conditions to inform their care. That can involve helping patients to readjust expectations and conserve energy — sometimes, as in Stanislawczyk’s case, by deciding to use a wheelchair.

“To look at a 30, 40-year-old and tell them we are not going to be able to say that in two months she can go back to work, or to recommend a wheelchair and special accommodations, it’s really heartbreaking,” Azola said. “It’s probably one of the hardest things I have to do.”

Some long haulers are beginning to see the shared benefits of uniting with the disability community.

Lisa McCorkell, a co-founder of the Patient-Led Research Collaborative who got covid early in the pandemic, joined the Century Foundation’s launch of its new disability initiative.

McCorkell began to identify as disabled in December 2020 after she pushed herself too hard and spent a week nearly bed-bound. She recalls the moment as both emotional and empowering.

“I allowed myself to accept my body for what it was, what it could do and be more grateful and more honest about my limitations,” McCorkell recalled. “The people who really understand how I now view the world are other disabled people.”

It has also given her a better understanding of the barriers disabled people are working to break down.

“It’s all so interconnected,” McCorkell said. “The benefit of millions of people getting sick all at once, is we have remarkable access to people and power that others have struggled to get for a long time. I want to make sure that I am representing those people.”

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