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U.S.

Coronavirus Strains Safety Net for People With Disabilities

About one in four Americans has some form of disability, making them more vulnerable to Covid-19



Damian Gregory, left, and Darren Gregory have cerebral palsy. 'When the able-bodied community gets the sniffles, we get pneumonia,' Damian Gregory said.

PHOTO: SCOTT MCINTYRE FOR THE WALL STREET JOURNAL

By Elizabeth Koh

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Damian Gregory worries about the things that have quickly become normal to worry about in the coronavirus era: Is there Clorox at the grocery store this week? When will social distancing end? Will he and his family stay healthy until a vaccine is found?

But the 46-year-old consultant and advocate, who has cerebral palsy, says he carries an extra layer of fear.

He has to worry if he will be able to navigate in his wheelchair at the store or arrange for services to transport him. He wonders when social distancing will end so his twin brother, who has a more severe form of cerebral palsy, can welcome back the personal care assistant who used to help him wake, eat, dress and go to work every day.

He worries most of all that he or his loved ones might be infected by a virus that has been particularly deadly for the elderly and those with compromised immune systems. He and his brother live with their mother and aunts, who are in their 70s and have become caregivers for the twins even as they are socially distanced in their home near Kendall, Fla.

“When the able-bodied community gets the sniffles, we get pneumonia,” Mr. Gregory said of people with disabilities. “The difficulties are multiplied 10-fold.”

For millions of the nation’s people with disabilities, the retreat forced by the coronavirus is stripping away much of the patchwork safety net that helps them maintain independent lives.

About one in four Americans has some form of disability, and though a much smaller fraction have what is considered a severe condition, they are among the most vulnerable population for Covid-19.



Damian Gregory worries that he or his loved ones might be infected by coronavirus, which is particularly deadly to people with compromised immune systems.

PHOTO: SCOTT MCINTYRE FOR THE WALL STREET JOURNAL

Many live in group homes and other institutions that provide round-the-clock nursing care or supervision, facilities that have proven susceptible to the virus’ spread. Scores of such facilities have reported cases, from New York to Illinois to California. In Texas, at least 54 residents and 47 staff members at one state-run facility, the Denton State Supported Living Center, have been diagnosed with Covid-19.

People with disabilities are also uniquely at risk, in part because many have additional chronic conditions that can weaken their immune systems. Because of their disability status, they also harbor fears their medical care could be rationed if they do contract the coronavirus—and be denied treatment if lifesaving equipment like ventilators run short. Some states have assembled ethics guidelines for providers who may have to decide who gets treatment if resources are limited, favoring the patient more likely to have the better outcome.

Those who continue to live in their own homes and communities often do so through a painstakingly pieced-together network of caregivers and providers who help them complete daily activities, from eating and bathing to cleaning and traveling. Such providers are the definition of social closeness, building ties that keep an otherwise isolated population connected.

But the virus has forced many people with disabilities to ask those home aides and assistants to stop visiting, fearing they might unintentionally carry the virus.

Nonurgent medical treatments have been put on hold, indefinitely postponing appointments like physical therapy or checkups that many need to stay in shape. The self-described lucky ones have families that are stepping back into caregiving—often aging parents or older relatives who can also be vulnerable to the disease.

It all strains a group that already struggles to make ends meet and often feels unseen, advocates and people with disabilities say.

Like many initially faced with the virus, Sarah Goldman said she hoped taking sensible precautions against spreading germs would be enough.

Ms. Goldman, who uses a wheelchair and has cerebral palsy, said she used to have six rotating caregivers who would come by her apartment in St. Petersburg, Fla., daily to help her get up, prepare for the day, then return and help her with similar tasks in the evening.

At first, she asked “the girls,” as she called her caregivers, to bring their own utensils and towels with every visit to minimize the spread of germs.

“I had them wash their hands every single time they came into the house,” Ms. Goldman recalled.



The Gregory brothers live in Miami-Dade County with their mother and aunts, who are in their 70s and have become caregivers for them.

PHOTO: SCOTT MCINTYRE FOR THE WALL STREET JOURNAL

When restaurants began to shut down and her city neared a stay-at-home order, Ms. Goldman, 28 years old, said she knew she needed to make sure she and her caregivers remained healthy. They agreed to suspend her caregiving services and Ms. Goldman moved back in with her parents in nearby Tampa.

She is grateful her parents can help, she added, noting not everyone has that option.

But “my whole life is now different,” she said. “My whole independence has gone away.”

Many of the social resources that people with disabilities rely on at group settings like long-term care facilities are strained, said Jim DeBeaugrine, whose brother-in-law Peter Prater has Down syndrome.

“It’s not just a risk—it’s all-consuming,” said Mr. DeBeaugrine, a consultant on disability issues and former Florida disabilities agency head. “It’s affected our workforce, it’s affected all the natural support systems that our people have come to rely on. It’s affecting providers’ ability to provide services that are critical.”

His brother-in-law, he said, had moved into a group home a few years ago after having strokes that prompted his need for 24-hour nursing care. But group activities continued to enrich his life, until the virus also shut those down.

Mr. Prater was recently diagnosed with Covid-19 and is recuperating in a nearby hospital.

Mr. Gregory, the disability advocate and consultant, says he fears what would happen if he gets the disease. He has a history of pulmonary embolism, in addition to his existing condition.

To minimize his and his family's exposure, he said they recently started receiving Instacart deliveries, though the platform nationwide has had delays as it seeks to recruit additional shoppers to meet demand.

Meanwhile, much of his limited income has also dried up—the consulting work from which he made most of his living has seen “everything from now until August canceled,” he said.

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In some ways, the virus only amplifies for others what the experience of having a disability has always been, Mr. Gregory said. “The isolation of not being able to leave your house? Well, nobody's leaving the house. The financial uncertainty of not being able to make ends meet because you only have a fixed amount of money? That's the reality of your life now, at least for the foreseeable future.”

He said he hopes if there is a silver lining to the pandemic, that it encourages others to empathize more with the day-to-day difficulties of living with a disability. “We're all just trying to live and survive,” he said.

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