HELPING CAN BE UNHELPFUL

‘Over-helpers’ not always appreciated by those with disabilities

WELCOMING PEOPLE WITH DISABILITIES

Tracy Schuhmacher

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Chris Hilderbrant doesn’t need help, at least most of the time. But people can’t seem to help themselves.

• Hilderbrant, 46, has earned a degree, run for office and owned a company. He’s a husband, a father and executive director of a nonprofit.

• But when people encounter him in his daily life, they often don’t recognize an independent, capable man. Instead, they see the wheelchair he’s used since he was injured in a diving accident at 14.

Adam Holmes

Above, a 45-year-old Black man who was born with caudal regression syndrome, which causes his legs to fold up beneath his body PHOTO ILLUSTRATION BY PETER PIETRANGELO/USA TODAY NETWORK; ROBERT BELL PHOTO/ROCHESTER DEMOCRAT AND CHRONICLE

The man who plays wheelchair rugby — a full-contact sport that combines elements of ice hockey, rugby, basketball and handball — can’t do a simple task like return bottles for recycling or make a trip to the drugstore without someone offering help. “I take a fair amount of offense sometimes to people offering help,” he said. “I try not to.” Jeiri Flores, 32, uses a wheelchair and is familiar with over-helpers. “They trip over themselves,” she said. “They want to be super helpful.”

Flores, who works as an advocacy specialist for a health care institution, is not a fan of people fussing over her. “That is frustrating to me,” she said. “Because now you’re really highlighting how different I am to everybody. ... It is not that intense.” Here’s the reality: People with disabilities want to be autonomous, independent and selfsufficient. But just like non-disabled people, they sometimes do need assistance. Here are some of the strange ways people have tried to help — and tips on how to actually be helpful.

Offering unneeded suggestions

When Hilderbrant drives anywhere, there’s a process involved with getting in his car. First, he transfers himself from his wheelchair into the driver’s seat. He takes one wheel off the chair and places it in the back seat. Next, the other wheel goes into the back seat. The frame folds down and is placed on the passenger seat. When he gets out, the process happens in reverse: Set up frame. Put on one wheel, then the other. Transfer into the seat and go. One day, Hilderbrant was running an errand at a drugstore. He had gotten the frame out of the car and had attached one wheel.

A man walked up and asked, “Are you missing a wheel?’” Hilderbrant pondered a few sarcastic responses, but instead told the man the wheel was in the back seat. But after that, the man continued to watch and offer suggestions.

“On good days, you laugh them off,” Hilderbrant said. “But like, sometimes, people will offer assistance in the most trivial, trivial, trivial things. And that to me, is offensive.”

Stopping traffic

Wayne Beaudreaux, 62, lives in Gates but is originally from Louisiana. Until recently, his primary mode of transportation was his wheelchair. There are times he's had no choice but to wheel down the shoulder of a busy road in areas that don't have sidewalks. "I lost count how many times I almost got hit," he said. While inadequate infrastructure is infuriating, he also has had dangerous encounters with people trying to be helpful in this situation.

People have stopped at green lights and motioned for him to cross.

"Are you nuts?" he said. "You're about to get rear-ended. I'm not going across. "Like okay, they go out of their way to be helpful but you're really just putting yourself and everybody else in peril. It's not good. "It's like I say, you're the one with the steering wheel and the gas pedal. Get the hell out the way and let me go. I can cross the street."

Calling the police

Adam Holmes, 45, was born with caudal regression syndrome, which causes his legs to fold beneath his body. He has always used a wheelchair. He finds that his experience of help depends on which neighborhood he is in.

Holmes is Black. "People see my color before they see my chair," he said. If he's sitting for too long on the mostly nonwhite North Clinton Avenue, "I'll have five or six people come up to me and make sure I'm OK. Make sure my chair's OK. Anything they could do — just random people," he said. One day, Holmes was on South Avenue near Costco — a more mixed area — when his wheelchair broke down. He called a wheelchair company for service and waited for help to arrive.

Nobody stopped to offer assistance, but a police car rolled up and an officer asked what was going on. Holmes suspected that someone had seen him and called the police. Holmes explained his predicament, and the officer stayed with him until the wheelchair company arrived. He's found most of his interactions with the police to be positive, but he still found the situation stressful. "It's just the craziness of dealing with it," he said.

Paying the check

Flores has noticed a trend at restaurants that's both amusing and insulting, depending on her mood. She often dines with people in connection with her job at a hospital. She has found that she rarely pays for a meal at a restaurant. Just about everyone picks up the check — even medical students or recent graduates that she knows are short on funds. This may not sound like a problem, but she recognizes that the practice stems from people's beliefs about what people with disabilities have, or are capable of having.

"Obviously this is ableism right?" she said. "Because you think I don't have the capital to afford my own meal."

It's awkward, she said, but she usually lets the situation go.

"I can't make everything in life a teachable moment," she said. "Because I never leave it, right? I have to do it with my family, I have to do it with my friends and then I have to do it at work. So there's never a pause of all of that. .... It's too much to do it all the time."

Lifting him up

Michael Bliss, 35, of Greece, enjoys what many people of his age enjoy: hanging out with friends, going out to bars and restaurants, heading to the beach and taking in concerts. He has a bachelor's degree and works full time in finance. He also uses a wheelchair. He works out at the YMCA, where people are happy to help. People will offer to pick up weights for him, for example.

The strangest circumstance took place when he was transferring from his chair to a weight bench. Someone he didn't know reached around him, picked him up and placed him on the bench. He knew the person had good intentions. "I don't take offense to it," he said. But given the choice, he'd rather have YMCA members help him by staying out of the accessible parking spots. Parents picking their children up from day care sometimes park in

those spots. “I get it,” he said. “You’re going in for one second. But if everyone did it…” Even worse, when he’s left the YMCA, he’s encountered a car parked in the striped area next to his parking spot. He couldn’t access the ramp he needs to get in and out of his vehicle. He had to wait until the scofflaw returned.

Pushing wheelchairs

A common issue: People pushing wheelchairs without asking first. A push from behind not only is intrusive upon people’s personal space, but also can throw off their balance. Hilderbrant’s experience has been that wheelchair pushers often don’t pay careful attention to things like bumps and cracks in sidewalks, which can result in falls. He has had enough unwelcome pushes that his chair no longer has handles on the back, even though they could come in handy now and then.

Luticha Andre Doucette, 37, an author, activist and small business owner, finds this kind of assistance traumatic. Years ago, she was visiting a friend in Brooklyn when she got lost late at night. A man came up behind her and started pushing her wheelchair at a rapid pace.

“I was punching him, yelling for help,” she said. He hit a crack in the sidewalk and she flew out of the chair and landed hard on the ground. As he was trying to pick her up and put her back in the wheelchair, she screamed and fought for her life.

Finally, some men heard her screams and came running. Her assailant ran away, but she was injured and traumatized. Now she, like Hilderbrant, no longer has handlebars on her wheelchair.

Helping blind people

Kirstyn “Kiki” Smith, 50, is a busy, active, social person who works part-time. She was diagnosed with uveitis, a degenerative autoimmune disease, at the age of eight, and was completely blind by the age of 39.

When people try to help her navigate a space, they will sometimes take her arm and push her forward, which makes her feel like she’s being propelled into darkness. “It feels like you’re on the Jack Rabbit,” she said. “If I wanted that feeling, I’ll go to Seabreeze.” Instead, she prefers to hold a person’s elbow, which gives her a more secure feeling while walking. She frequently uses ride apps like Uber. She generally isn’t bothered by over-helpers, and appreciates when drivers help her to the car door. But she wishes they wouldn’t fasten her seat belt. “Somehow I feel like that is just a basic daily living task that being blind has absolutely no bearing on,” she said.

Helen Jones, 46, is a runner, avid sports fan and single mom. She has a quick sense of humor and a wicked laugh. She loves to cook. She started losing her sight as a teen due to retinitis pigmentosa. She is completely blind and uses a cane.

She’s had people attempt to help by grabbing her cane and telling her where to place it. It’s not how she’d prefer people interact with her, but she tries to be patient.

“They don’t know,” she said. “I usually tell them, ‘next time, if you’re with a blind person, this is how you do it.’ It’s just like, giving knowledge to them.” She knows blind people who have gotten frustrated at unneeded offers of help. Her concern is that a sighted person might second guess offering help the next time, when someone really does need help. “Sometimes we make it hard,” she said. “You get offended, but it’s no point … Because they don’t know anything about us, you know, and sometimes we are the one that tells them off.”

Tracy Schuhmacher is food, drink and culture reporter for the Rochester Democrat and Chronicle. This story was created as part of an Atlantic Region How We Live Fellowship that focused on welcoming people with disabilities in our communities. Follow Tracy on Twitter or Instagram: @ rahchachow.

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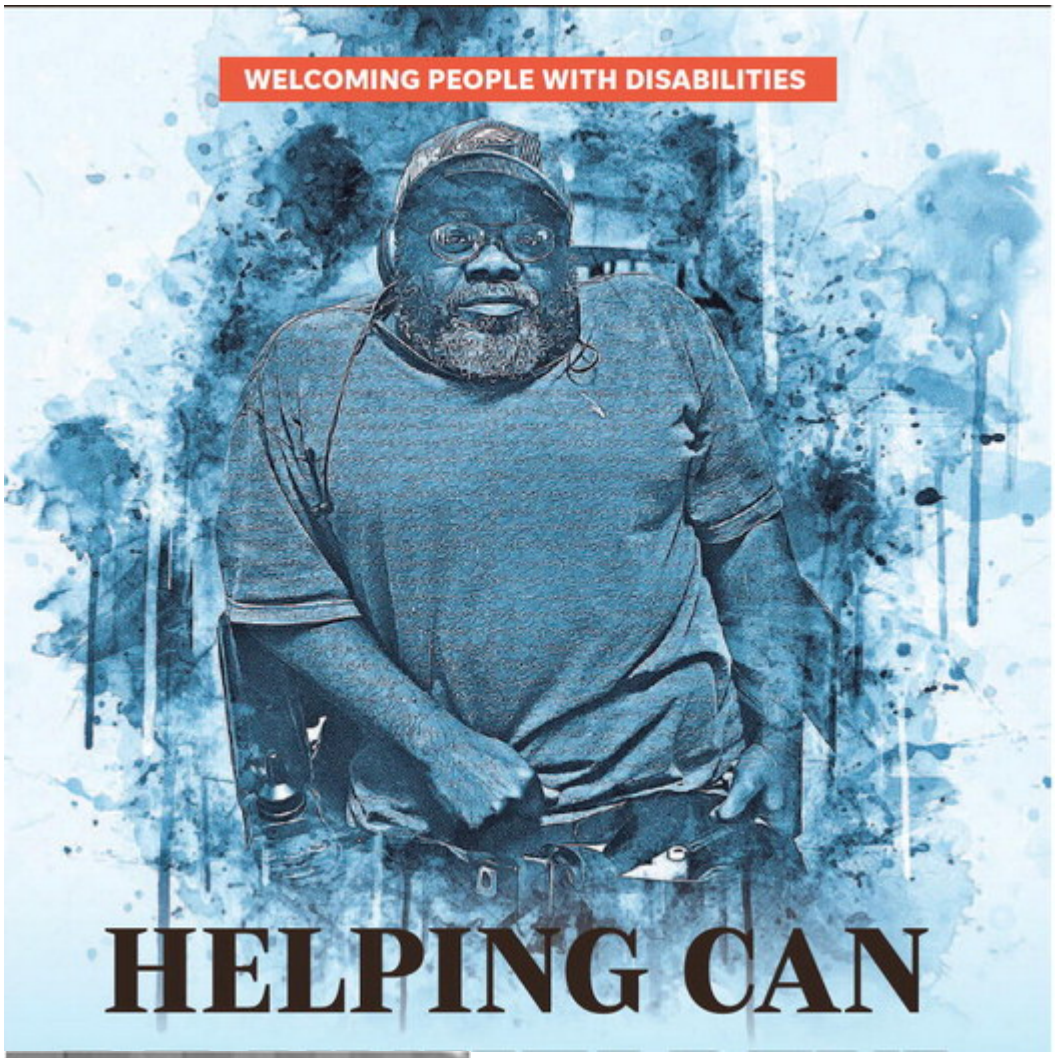

Chris Hilderbrant, executive director of the Rochester Spinal Association. ROBERT BELL/ROCHESTER DEMOCRAT AND CHRONICLE