

Disability rights activist pushes government to let him participate in society

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Garret Frey refuses to be sidelined. Frey has been paralyzed from the neck down for more than 37 of his 42 years. He has spent decades rejecting the government's excuses when he and others with disabilities

are denied the support they need to live in their own homes and to participate in society.

The Iowan won a landmark case before the U.S. Supreme Court in 1999, after his school district refused to pay for the care he needed to continue attending high school classes in Cedar Rapids. He recently scored another victory when a complaint he lodged with federal officials pressured Iowa to agree to increase Medicaid payments for caregivers to stay overnight with Frey so he won't need to move into a nursing home.

"These are civil rights issues," he said. "They are human rights issues."

Frey makes his points a handful of words at a time. The cadence of his speech follows the rhythm of a mechanical ventilator, which pushes air into his lungs every few seconds through a tube in his throat.

His voice is soft, but he makes sure it's heard.

Frey was paralyzed in an accident at age 4. He uses sip-and-puff controls to drive his wheelchair into courtrooms and through the halls of the Iowa Statehouse and the U.S. Capitol, where he demands policies that allow people with disabilities to live full lives.

"We'll get there. It takes time, but I'm not going to just let things go or let things slide," he said in an interview on the sunny patio of his Cedar Rapids home.

Frey emphasizes that anyone could find themselves needing assistance if they suffer an accident or illness that hampers their ability to care for themselves. He encourages other people with disabilities to cite his victories when seeking services they're entitled to under federal law.

He has served on numerous local, state, and national boards and

committees focused on protecting disability rights. He composes emails and updates his website using voice commands and a sticker on his chin that can interact with his computer's camera.

His activism has drawn admirers nationwide.

"People like Garret are critically important, because they are the trailblazers," said Melanie Fontes Rainer, director of the Office for Civil Rights at the U.S. Department of Health and Human Services.

In June, Fontes Rainer's office announced an agreement with the state of Iowa to settle Frey's complaint that Medicaid pay rates were insufficient for him to hire and retain overnight caregivers at his home.

Frey said he filed his federal complaint after being rebuffed by state officials. The resulting agreement increased his workers' pay from about \$15.50 to \$22 an hour, the federal agency said. It also made other changes designed to allow Frey to continue living in the home he shares with his mother and brother.

Fontes Rainer said [state officials](#) cooperated with her office in settling Frey's complaint. She said she hopes other people will take notice of the result and report problems they have in obtaining services that help them remain in their communities.

The federal administrator said she gets emotional when she sees how hard Frey and others fight for their rights. "You shouldn't have to advocate for health care," she said. "When I think about all that he's been through, and that he continues to use his voice, I think it is so powerful."

The Iowa Department of Health and Human Services declined to comment on Frey's case. But spokesperson Alex Murphy said the department is "committed to ensuring access to high-quality behavioral

health, disability, and aging services for all Iowans in their communities."

This summer, Frey and his mother visited Washington, D.C., where they participated in a 25th anniversary celebration of the Supreme Court decision *Olmstead v. L.C.* In that landmark case, the justices declared that people with disabilities have a right to live in their own communities, instead of in an institution, if their needs can be reasonably accommodated.

Frey was reminded during the ceremony that others are still buoyed by his own Supreme Court case, *Cedar Rapids Community School District v. Garret F.*

The 1999 case focused on the Frey family's contention that the school district should pay for help Garret needed to safely use his ventilator so he could continue to attend classes. School district leaders said they shouldn't have to pay for such assistance because it was health care.

The court, in a 7-2 decision, described Frey as "a friendly, creative, and intelligent young man" who had a right to services enabling him to attend school with his peers.

At the recent Washington ceremony, a California teenager approached Frey. "He said, 'You're Garret F? Thank you. Without you, I'd never have been able to go to school,'" recalled Frey's mother, Charlene Frey.

The 13-year-old fan was James McLelland, who breathes through a tube in his throat because of a genetic issue that impedes his windpipe. His breathing apparatus needs constant monitoring and frequent cleaning by a nurse.

His mother, Jenny McLelland, said she shows printed copies of the

Garret F. court decision to school officials when she requests that James be provided with a nurse so he can attend regular classes instead of being sent to a separate school.

Because of the Supreme Court precedent, "we didn't have to litigate, we just had to educate," she said in an interview.

James, who is entering eighth grade this school year, is thriving in classes and loves playing percussion in a band, his mother said. "James has had the life that people like Garret had to fight to get," she said. "These are the kinds of rights that are built brick by brick."

Frey said he found inspiration from earlier advocates, including Katie Beckett, a fellow Cedar Rapids resident who, four decades ago, drew national attention to the plight of children with disabilities who were forced to live away from their families.

Beckett, who was partly paralyzed by encephalitis as an infant, was kept in a hospital for about three years. At the time, federal rules prevented payment for Beckett to receive care in her home, even though it would have been much less expensive than hospital care.

In 1981, President Ronald Reagan denounced the situation as absurd and told administrators to find a way to let the young Iowan go home. The Republican president's stance led to the creation of what are still known as Katie Beckett waivers, which make it easier for families to get Medicaid coverage for in-home care for children with disabilities.

Frey knew Beckett and her mother, Julie Beckett, and admired how their outspokenness prompted reforms. He also drew inspiration from meeting Tom Harkin, the longtime U.S. senator from Iowa who was the lead author of the 1990 Americans with Disabilities Act.

Harkin, a Democrat, is retired from the Senate but keeps tabs on disability issues. In an interview, he said he was glad to hear that Frey continues to push for the right to participate in society.

Harkin said he is disappointed when he sees government officials and business leaders fail to follow requirements under the Americans with Disabilities Act. To maintain the law's power, people should speak up when they're denied services or accommodations, he said. "It's important to have warriors like Garret and his mother and their supporters."

Iowa's agreement to increase Medicaid pay for Frey's caregivers has helped him hire more overnight workers, but he still goes some nights without one. When no outside help is available, his mother handles his care. Although she can be paid, she no longer wants to play that role. "She should be able to just be my mom," he said.

At a recent board meeting of The Arc of Iowa, a disability rights group, Frey told his friends he's thinking about applying for a civil rights job with the federal government or running for public office.

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