northjersey.com

NEWS

In NJ, managed care means delays and denials for disabled patients: 'Not a fair fight'

Gene Myers and Scott Fallon NorthJersey.com

Nov. 6, 2025, 4:31 a.m. ET

Key Points AI-assisted summary

- New Jersey's Medicaid managed-care system allows private insurers to decide on essential services for residents with disabilities.
- Families and advocates argue that insurers often deny or reduce care, like in-home nursing, to control costs.
- Patients face a difficult appeals process that they say is stacked against them, even when doctors deem care medically necessary.

Josh Gargano knew what would happen when his therapy was cut.

His body would seize up. Without regular physical and occupational therapy, his spastic quadriplegia — a severe form of cerebral palsy — would lead to increased stiffness, reduced mobility and, eventually, chronic pain.

“You take these services away, I regress,” said Gargano, 35, who uses a wheelchair. “You put me back on them, I improve. It’s as simple as that.”

Like many New Jerseyans with disabilities, Gargano's care is funded by the state's Medicaid program. But in April of 2023, United Healthcare, the private managed-care company that administers his coverage, announced that it would be cutting his in-home nursing care from 16 hours a week to eight.

“I started having more pain in my legs,” said Gargano, who lives in Somerset County.

The two sides eventually compromised, but it followed a months-long fight in which the insurer overruled Gargano’s own doctor and nurse. In the interim, Gargano lost control of his neck muscles and developed an abscess due to his immobility, his mother said.

Gargano's plight highlights problems that many with disabilities complain about under New Jersey’s Medicaid managed-care system, in which five private companies oversee the publicly funded, $22.5 billion-a-year program.

In our Hurdles to Health Care series, The Record and NorthJersey.com have examined the many challenges disabled patients face in getting good care, from inaccessible clinics to poorly trained doctors and inadequate insurance payments.

The Medicaid managed-care system may be among the most pervasive obstacles. The system gives insurers wide latitude to decide who gets essential services like therapy and in-home nursing. Families say the result is often denials and delays — and opaque reasoning.

How Medicaid managed care works

Disability advocates say Medicaid managed-care organizations, known as MCOs, lean on proprietary assessment tools, force families through multilayered appeals and still prevail even when doctors deem treatment “medically necessary.”

“This system has tilted too far in favor of the insurance companies,” said Paul Aronsohn, New Jersey’s ombudsman for people with intellectual and developmental disabilities. “It’s too easy for them to say no, and too hard for families to push back.”

The state contracts with five MCOs: United Healthcare, Horizon Blue Cross Blue Shield, Aetna, WellCare and Wellpoint (formerly Amerigroup). Together, they administer NJ FamilyCare, New Jersey's Medicaid program, which covers 1.8 million low-income and disabled residents.

In the U.S., where per-person health care spending is far higher than in the rest of the world, managed care has been touted as a way to control costs. New Jersey gives insurers a fixed monthly payment for each enrollee. Companies are expected to manage an individual’s care within that budget. The goal is to control costs and improve coordination.

Horizon Blue Cross Blue Shield, the MCO with the most enrollees, says it follows state guidelines for denials and appeals and participates in regular quality reviews**.** By law, a spokesman noted, MCOs must spend at least 85% of premiums they collect on medical care.

Critics in the disability community argue that the industry too often treats that 85% as a ceiling for medical spending, not the floor it should be. Profit

incentives and weak oversight by the state skew decisions toward cutting care, they say.

'Deal with it'

Josh Gargano says he’s a prime example. His family appealed United Healthcare's decision last year, submitting letters from his primary care doctor and his visiting nurse.

His doctor called the therapy “medically necessary,” warning that without it, Gargano would experience “decline, immobility and loss of independence.” His nurse noted that the therapy was critical to preventing injury, managing muscle tone and pain and keeping him out of a group home, according to documents reviewed by The Record and NorthJersey.com.

Still, the company upheld the denial.

In a letter, a United Healthcare medical director — a doctor who had never met Gargano — wrote: “You have weakness. You have problems with coordination. This is due to cerebral palsy. … The notes did not show that more visits are medically necessary at this time. … You should be trained in a home exercise program.”

“That’s not the same,” Gargano said. “That’s just telling me to deal with it.”

United Healthcare initially declined to comment on Gargano’s case or the broader managed-care system for this article. Later, the company said it would comment only if Gargano signed a waiver of privacy protections, which he had not done as of press time.

Gargano's mother, Denise, a nurse who worked for numerous MCOs herself, was stunned when her son's hours were cut back.

“There was no reference to his doctor’s letter, no reference to the nurse’s documentation. It was generic. It didn’t justify the decision,” she said.

During the four months the family negotiated, her son developed "a serious abscess" from lying still on his side, she said. Things continued to worsen through multiple appeals, as his neck muscles stiffened and locked up.

“We sent them photos," said Denise Gargano. "How was he supposed to eat and drink? He has a swallowing problem. He can’t feed himself, and he couldn’t hold his head up."

Appealing denials isn't easy

Kim Wright, a mother in Union County, faced a similar trial. Her 21-year-old son, Kalvin Christie, has cerebral palsy and needs a feeding tube. He's also unable to swallow saliva, has a gastric ulcer and has trouble identifying when he's in danger.

For years, Christie had nursing care 16 hours a day. But in 2023, Horizon Blue Cross Blue Shield told Wright it would reduce that to eight hours.

She appealed the decision at every level. There was an internal appeal, an external review and a court hearing. She lost at each step.

A judge eventually ruled in Horizon’s favor. But that ruling was later invalidated by the state after it found the judge's reasoning incomplete, according to a letter from the state Department of Human Services.

Horizon “never addressed what changed in his care,” Wright said. “They never even discussed the four doctors’ letters I submitted showing why he still needed nursing.”

Wright's case was ultimately settled out of court on Oct. 21. She was granted 12 hours a day for six months, at which point the authorization process will start again. It was a deal she wasn't happy with, brokered by a nonprofit lawyer she wished had fought harder.

"I'm going to have to go through this whole thing again in six months," she said**.** “They’re hoping you’ll just give up. This isn’t about Kalvin getting better. It’s about their budget.”

Patients and their loved ones often feel that the appeals process is stacked against them. While managed-care insurers, by law, must provide a formal process to challenge denials, families often find themselves battling insurance company lawyers on their own, even as they continue to care for children with complex medical needs.

“Even when families win an appeal, the decisions aren’t binding,” noted Aronsohn, the disability ombudsman. “It’s not a fair fight.”

Since his appointment in 2018, his office has tallied numerous complaints from families like the Garganos and Wrights who say their Medicaid-funded care, such as private duty nursing or personal care assistants, was cut or denied without clear justification. MCOs use assessment tools that aren’t publicly available, even to his office, Aronsohn said.

“Families have no idea what criteria are being used,” he added.

Insurers determine 'medical necessity'

Horizon, the state's largest MCO, currently serves over 1 million Medicaid members. Of those, about 115,000 are “eligible as aged, blind or disabled,” the company said in a written statement for this story.

The insurer said it determines in-home nursing hours based on medical necessity and each member’s unique circumstances, following state Medicaid rules that require regular reassessments.

“Reductions in skilled nursing care can occur when an individual’s medical conditions improve or medical needs otherwise decrease,” the company said in a statement. “Our goal is to provide the right supports to enable members [to] live safely at home when possible.”

The company’s policies to determine whether prescribed care is a medical necessity are set by its internal team of doctors and nurses, spokesman Tom Wilson added. They are grounded in research and “generally accepted standards of care established by the relevant specialty physician organizations,” he said. Policies are provided to state regulators for review, Wilson said.

Asked whether Horizon Blue Cross Blue Shield tracks what happens to members after medical care is reduced or denied, Wilson said long-term outcome tracking is not required by the state and is difficult to conduct because Medicaid members are allowed to change MCOs at will. Horizon does conduct its own customer satisfaction surveys, he said.

Managed-care companies and state regulators both emphasize New Jersey's requirement that 85% of premiums be spent on patient services. If

MCOs don't reach that level, money must be returned to the state.

In 2024, United Healthcare repaid about $12 million and Aetna about $2 million for missing the benchmark, said Department of Human Services spokesman Tom Hester.

The state tracks rates of internal appeals and hearing requests “as part of its ongoing review of MCO performance,” Hester said in an email. But it does not “generally track what percentage of cases are overturned at various stages of review.”

State orders changes

Some progress has been made. In May, the department issued new guidance to all MCOs aimed at strengthening transparency and fairness. The directive, signed by state Medicaid Director Greg Woods, requires that any letter reducing or terminating services must clearly explain the insurer's reasoning and cite the conditions that merit the decision.

Referring to an internal assessment is no longer acceptable, according to the memo, which said “a number of cases” reviewed by the state “failed to clearly explain the reason for the reduction or termination.”

“Of particular concern were cases where there was no clear indication of a change in the members’ condition to justify the change in approved hours/units,” it said.

More: In NJ, people with disabilities face indignity, missed diagnoses, barriers to health care

The state ordered numerous changes to the appeal process. Among other steps, MCOs must now include contact information with denial letters; allow appeals by phone, mail and online portals; and provide documents requested for a hearing within five days. The department said the changes were essential for "fundamental fairness" and that they would be fully implemented by Jan. 1.

Aronsohn welcomed the moves, but warned that transparency and accountability remain weak systemwide. He still hears from people whose nursing hours have been cut or eliminated, often without clear explanations.

“It’s not enough to change policy,” he said. “We need transparency and oversight to make sure these companies actually follow it.”

His best advocate

Josh Gargano's in-home nursing was reinstated after a meeting with United Healthcare executives and state officials. He still needs to go through a pre-authorization process for the care every 60 days, his mother said.

Though his case is technically resolved, the underlying problems in the Medicaid managed-care system remain, said Josh Gargano. His mother died suddenly in August at age 65. Her son expects to keep advocating for himself — and others.

“I'm not only doing this for me. I'm doing this for the people who can't do it for themselves," he said. "If this can happen to me, what happens to people in group homes, people who can’t speak, who can’t fight?”