

# State moves to address concerns over managed care switch for developmentally disabled

By Addy Baird 5:35 a.m. | May. 25, 2016

Meri Krassner has a 27-year-old son, Daniel, who lives at home. He was born with two holes in his heart, and suffers from developmental disabilities and scoliosis. He can't ever be left alone.

Daniel goes to a day program on weekdays, and on Saturdays, a community habilitation adviser comes to their New York City home to work with him one-on-one. He spends some weekends in an away program to allow his parents time to rest, and he goes to a summer camp for 11 days each year. The facets of Daniel's extensive care program have been stitched together by his family, and all of the services he receives are available through the state's Office for People with Developmental Disabilities.

As part of the state's Medicaid overhaul, the OPWDD, which serves about 130,000 individuals in New York, will soon transition to managed care, and despite efforts from the state to quell anxieties, Krassner and other other parents fear that the shift might mean that the systems they have carefully designed for their children could come apart at the seams.

"If you look at the rollout [of managed care] and how it's happened in other states, there is cause for concern," said Annette Downey, the executive director of Oakland's Community Living Services, a care provider for people with intellectual and developmental disabilities in Michigan.

Michigan made the transition to managed care in 1998, and Downey said hopes that New York will look to the states that have made the transition and learn from them.

New York will become the eighth state to implement managed care for developmentally disabled adults, and while some states, like Michigan, have had great success, others have seen providers go unpaid, insurers lose money, and care delivery lag. In Kansas, there was even concern that insurers would pull out of the market entirely because of problems with managed care, which would have caused extreme delays in care.

The state is not dismissive of the concerns that parents, providers, and advocates have, and officials are taking steps to explain the benefits of managed care to people who are worried that the system won't properly serve the population it is designed to help.

"Sometimes when managed care is being rolled out people feel like it's being hatched in the back room and that there's a lot of secrecy," Downey said, pointing out that the New York OPWDD is taking steps to avoid that perception.

Acting commissioner Kerry Delaney met with representatives from the NYC Family Advocacy Information Resource Friday, a group of parents of and advocates for

developmentally disabled adults, to discuss the transition, and earlier this month Delaney spoke at a conference for providers and parents.

“I know concerns exist on many levels about how you incorporate some of the concepts that exist in the broader world of managed care to the unique needs of the individuals we serve,” Delaney said at the Advance Care Alliance conference, where she spoke about the details of the managed care system and why OPWDD believes it is an important step.

The managed care model relies on contracts between insurers and providers, who set predetermined payments for a care package, and, in some cases, providers take on risk if the cost of care exceeds what was originally agreed on.

The benefit of managed care is that it allows doctors and care providers to look holistically at an individual and their needs, moving away from the fee for service model of the past.

“We believe that in addition to allowing for greater flexibility and offering more options, care management [can] support the creation of new and innovative ways to deliver and fund supports that can meet the needs of people we serve now and into the future,” Delaney said. “We know that we need more flexibility in our system if we’re truly to provide people with the outcomes that they’re looking for.”

Awarding providers based on outcomes incentivizes efficient service, which can be beneficial for a patient recovering from surgery or handling diabetes. But some parents and providers feel that managed care and value-based payments focus on outcomes in ways that just aren’t possible for the developmentally disabled population.

“It’s not like there’s going to be progress,” Krassner said. “There’s no getting better.”

“How can you measure how happy they are?” asked Elly Rufer, whose 34-year-old daughter suffers frequent and debilitating seizures. “How many times they smile in a day?”

Krassner and Rufer want a system that can measure quality of life for their children and maintain a high level of care for the long-term, rather than a system that looks for health outcomes.

Downey, the care provider in Michigan, has heard concerns like this in her state and others.

“Most people who fear managed care fear that the outcomes will only be health-related,” she said, “and that quality of life outcomes and social determinants such as housing support and assistance with employment will not be seen as equally important.”

Downey thinks these concerns are valid, too, because what gets measured is what gets money.

There is no set timeline for OPWDD's transition to managed care, but state officials have said that they are considering keeping some services outside of the managed care plan, like residential services, which could remain within the fee for service model. Even once the OPWDD begins using the model, it will remain voluntary for providers and individuals to opt into, as well as out of if they feel it doesn't work for them. If the program works well, it could eventually be required.

The opt-in system is part of what's making some parents and advocates anxious about the transition. As the proposal stands today, individuals who opt into the managed care program will only be able to visit providers who have also opted into the system, except in the case of care for existing services.

Rufer, whose daughter lives in a group home, is concerned about which doctors will sign on and whether the ones who have been caring for her daughter will be a part of the program. Although the care continuity exception means that Katie will be able to continue to work with her same care providers, Rufer is concerned that if some of Katie's care providers begin to work within the managed care system and others don't, the transition could mean lapses in care for her child.

"The idea is obviously to cut cost," Rufer said, and that makes her feel like whatever her child is getting now is too much. "They still need to convince us that [with managed care] it will be enough."

Providers have voiced concerns as well.

"The transition to anything is going to cause anxiety," said Ravi Dahiya, the associate director of program operations at Innovative Resources for Independence, an OPWDD program that helps adults with developmental disabilities find work, housing, and community support.

Dahiya does think the shift to managed care will be beneficial for the individuals he works with. Managed care will allow providers to focus on the person rather than the program and to develop more specific care plans, he said, rather than trying to work within a one-size-fits-all program.

"If managed care brings about stronger care coordination then I'm all for it," Dahiya said. "There are a lot of people being underserved right now."

But managed care can also require that providers take on some risk.

"There's anxiety there [about taking on risk], absolutely, because that's not how we've worked before," Dahiya said. "The mechanics are still being worked out."

Ultimately, he thinks that providers will adapt, and that care won't suffer in the process.

But Krassner, Daniel's mom, isn't sure.

"You figure out what's best for your kid," she said.

Much of the discussion Krassner has heard about managed care has been about medical care, which she said is only a tiny part of the care her son receives and needs. Most of his care is habilitative — occupational therapy, day programs with other adults with developmental disabilities — and she isn't sure how managed care will work in that system.

“We're afraid,” Rufer said, “and no one is against saving money and no one is against the concept — if it works.”