



Advocates: Medicaid's autism coverage plan would keep kids from services

By: ARIELLE LEVIN BECKER | February 11, 2015

Following federal requirements, Connecticut's Medicaid program is expanding coverage of services for young people with autism spectrum disorders.

But advocates say the proposed rules for that coverage contain so many potential barriers that many children would be unlikely to get treatment.

Some provisions of the proposed regulations are unlike those any other state has imposed, according to the national advocacy group Autism Speaks. One requirement – that a caregiver be present or available at all times while treatment is being provided – would discriminate against children of working, single or disabled parents, the group said. And it warned that another provision related to provider qualifications “threatens to virtually gut coverage in Connecticut and deprive Medicaid-eligible children under 21 of medically necessary care in direct violation” of federal obligations.

“There are so many roadblocks here that it’s unlikely for this to allow for the demand to be met,” said Jay Sicklick, deputy director of the Center for Children’s Advocacy, which is affiliated with the UConn School of Law.

At issue is how Medicaid will handle coverage of services for autism spectrum disorders, particularly applied behavior analysis, a treatment that is considered effective but is also intensive – providers often recommend 30 to 40 hours of therapy per week – and costly. In the past, the state Department of Social Services denied Medicaid coverage of applied behavior analysis to families seeking it for their children. But last summer, the federal government made clear that state Medicaid programs must cover medically necessary services for clients under 21 with autism spectrum disorders.

DSS has projected that the coverage would cost \$28.1 million in the next fiscal year, half of which would be reimbursed by the federal government. Although the regulations are not finalized, the coverage took effect Jan. 1.

Unique requirements

About one in four children in Connecticut are covered by Medicaid. And advocates say the proposed regulations would impose restrictions that go beyond what’s required for commercial insurance coverage and could limit access to care. Among the requirements:

To receive approval for coverage, a child would need to receive a comprehensive diagnostic evaluation, followed by a behavior assessment and a care plan. All autism spectrum disorder services must be authorized before being delivered. The providers who complete the behavior assessments, develop plans of care and deliver the services must be either licensed practitioners or board-certified behavior analysts with two years of experience treating people with autism after receiving a degree or certification. Advocates say the two-year requirement is stricter than what other states require and would reduce an already limited pool of providers who focus on autism.

Providers must also have completed college courses in topics including child development, psychopathology, family systems, and multicultural diversity and care, or have at least one year of supervision by a licensed practitioner. Advocates say most professionals who provide applied behavior analysis are unlikely to meet these requirements since the courses are not part of their usual training and Connecticut does not license those providers.

Medicaid would cover no more than 25 hours of autism spectrum disorder treatment per week. People could receive approval for more hours if they are deemed medically necessary based on standards set by DSS.

Caregivers of the youth receiving treatment must participate in at least 50 percent of the sessions. That could be reduced based on unique circumstances. Caregivers must be present or available in the setting where services are provided at all times to ensure that treatment is occurring, rather than child care or other services that are not covered by Medicaid.

DSS spokesman David Dearborn declined to comment on specific aspects of the proposed regulations because they are not finalized and could be revised based on public comments. They will eventually be submitted for final approval to the legislature's Regulations Review Committee.

"Those rules make sure these services are of high quality, are medically necessary and are carefully tailored to each Medicaid member's unique needs," he said, adding that the provider qualifications were based on accepted credentials.

But Robert Ross, senior vice president of Beacon ABA Services, which provides autism treatment in Connecticut and Massachusetts, said the proposed regulations would create potential barriers that don't exist for those with private insurance, setting up a "separate but unequal" system that leaves children who are poor and disabled at further disadvantage.

"There will be no access to those services, which if you're trying to protect the budget is a really effective mechanism," Ross said. "But if you're actually trying to provide the services, these regulations will simply not do that."

Concerns about caregiver, provider rules

Advocates said the requirements related to caregivers are unrealistic. While it can be helpful for family members to participate in therapy, they said, mandating a level of participation ignores both the judgment of providers and potential barriers parents face, such as jobs or obligations to other children.

"Personal limitations based on a parent or guardian's particular social or economic situation cannot serve as a basis for refusing to provide medically necessary treatment to the child," Daniel Unumb, executive director of the Autism Speaks Legal Resource Center, wrote in comments to DSS.

He and others also raised concerns about the requirements for providers. Suzanne Letso, CEO of the Connecticut Center for Child Development in Milford, has been providing autism services in the state for two decades and sits on the board that certifies behavior analysts. But she said she wouldn't meet the DSS criteria to provide services to Medicaid clients, nor would the dozens of people her organization has trained.

Similarly, Ross said the majority of his staff, who serve 1,200 families, would not be considered qualified under the proposed Medicaid rules.

"While I think the intention [to cover autism services] is a good one, the way the regulations are currently written...no one's going to be able to access services," Letso said. "No one's going to be able to provide services."

Advocates have also taken issue with the requirements for having services covered. It can take months to receive a comprehensive diagnostic evaluation, which they noted would be only the first step to getting services approved, potentially delaying treatment that is best provided as early as possible.

They noted that the American Academy of Pediatrics recommends that children receive intervention as soon as an autism diagnosis is seriously considered, rather than waiting for a formal diagnosis to be made.

"Given the critical importance of providing [autism spectrum disorder] treatment early, these multiple hoops will cause irreparable harm for many children whose families and providers are unable to timely navigate them," Sicklick and other advocates wrote to DSS.

Dearborn said the department is "carefully monitoring access to these services" to make sure the system works properly and children and young adults receive the services they need. He noted that DSS, the Department of Developmental Services and the organization that handles the agencies' behavioral health services are providing care coordination to Medicaid members with autism, "to help them navigate a complex service system."

"DSS and DDS will review all comments carefully in collaboration with the state agency partners," he said. "Proposed regulations are often revised based on public comments."

Dearborn added that the state has been in consultation with federal officials, and that its approach to handling the implementation has been in accordance with federal requirements.