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Minnesota Bill Could Expedite Medicaid Coverage for Newborns Based on Disease Screening Results

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NEW YORK – As Republican legislators in the US Congress look to slash Medicaid, the Rare Disease Advisory Council (RDAC) of Minnesota thinks that it has found a way to improve Medicaid access for newborns with rare diseases.

Along with several collaborators, the Minnesota RDAC has proposed a bill, SF 1175, that would make children automatically — or presumptively, in legal phrasing — eligible for Medicaid disability coverage based on the results of newborn screening (NBS).

In Minnesota's NBS program, providers send blood spots obtained from heel pricks to labs for a battery of biochemical tests, including immunohistochemistry, isoelectric focusing, and nuclear magnetic resonance assays. Labs look for signs such as abnormal enzyme activity or unusual levels of compounds such as sulfatide, which might indicate underlying health issues — often rare diseases. Newborns with positive results then get referred for confirmatory diagnostic testing via next-generation sequencing.

One of the disorders screened for, for example, is galactosemia, a rare inherited disorder in which an individual fails to properly process the sugar galactose, which builds up in the body and causes a range of symptoms, including developmental delays such as speech difficulties and intellectual disabilities. Abnormal GALT enzyme activity detected via fluorometric assays on a newborn's blood spot in Minnesota's program would trigger reflex genetic testing for mutations in one of the genes underlying this disorder. Early treatment with a low-galactose diet can avoid most symptoms and enable normal development.

Disability determination in Minnesota currently requires that an individual show symptoms of a disease, even if they have a diagnosis of a debilitating illness, before they can be considered for the disability process. Erica Barnes, executive director of the Minnesota RDAC and one of the bill's primary authors, called this a "reactive" policy that makes little sense in light of recent advances in gene therapies, which often have the best chance of benefiting patients with inherited rare disease before symptoms manifest.

The presumptive eligibility afforded by SF 1175 would last until the last day of the month following the month in which the newborn's presumptive eligibility begins or until a long-term disability determination could be made through Minnesota's State Medical Review Team (SMRT) process, should a family apply for one.

Infants with rare neurodegenerative diseases, for example, must receive gene therapies very early after diagnosis to benefit from them, and "the cruel irony is [that] as soon as that child starts to show symptoms of a disease, they are disqualified from the treatment."

Spinal muscular atrophy (SMA), for instance, almost always manifests at birth and is caused by mutations in the SMN1 gene. It causes progressive muscle weakness and atrophy, affecting motor function, as well as impacting speaking, swallowing, and breathing, along with other symptoms.

If treated early enough, typically either as soon as possible from birth to up to 2 years of age, disease modifying therapies such as Roche and Genentech's Evrysdi (risdiplam), Biogen's Spinraza (nusinersen), and Novartis' Zolgensma (onasemnogene abeparvovec), can sustainably help infants achieve otherwise unattainable motor skill development milestones.

Despite the increasing availability of such therapies, Barnes said that families whose children test positive during NBS occasionally don't follow up with confirmatory diagnostic testing due to uncertainty about coverage and the fear of having to pay high out-of-pocket prices.

"Identification by newborn screening is super great," she said, "but what good is it if there's not good follow-up care for these kids?"

Because confirmatory testing, as well as additional therapies, would be covered by Medicaid, the Minnesota RDAC and its collaborators took care to craft their bill in such a way that it does not expand Medicaid to a never-before-covered patient population, such as would occur through a change in income level, but rather provides access sooner to children who will eventually qualify anyway, based on the natural history of their disease.

"In response to a state legislature with limited interest in pursuing Medicaid expansion, several states have successfully pursued ballot initiatives to expand Medicaid eligibility," Allison Herrity, a senior policy analyst for the National Organization for Rare Disorders (NORD), said in an email.

Even so, she said, there are also examples of states where, despite strong public support for expanding Medicaid, policymakers still oppose implementing it and have therefore crafted restrictive rules around increasing access.

Sue Berry, a professor of genetics and metabolism at the University of Minnesota, whose work often focuses on rare metabolic diseases, said that while the presumptive eligibility of SF 1175 appears to be unique among legislative proposals to expand Medicaid eligibility for newborns with rare disorders, the Minnesota RDAC may be better positioned than most to push such legislation through.

Although RDACs are generally formed to advise governments at the state level, Minnesota's appears to be the only one that is actually a part of its state government. It was founded in 2019 and folded into the executive branch in 2022.

"Being a state agency has the advantage of a closer working relationship with the other state agencies," Barnes said, "which gives us some insight into policy and more credibility when we craft policy."

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