

# EPICrd Act

## FOCUS: More than Access to Medicines Items and Services

### Congress Must Act Now to Ensure Medicaid Patients with Rare Diseases Can Access Items and Services Critical to Medical Care

Depending on the severity of their condition, some patients with rare diseases need access to various items and supports, including durable medical equipment (DME), bandages and other wound care products, home infusion, and medical foods. In Medicaid, inconsistent coverage policies for optional, but universally offered benefits, like home infusion therapy and DME are impeding access. Additionally, very few states cover medical foods and medical supplies necessary for patients who are severely chronically ill and disabled, which has forced some families to relocate.

The **EPICrd** (Ensuring Parity through Individualized Care for Rare Disorders) Act is a comprehensive approach to ensuring coverage parity for patients with rare genetic conditions in accessing medicines, specialists, and other items and services within Medicaid. The solutions provided by EPICrd are driven by three core principles:

- 1 Access to rare disease therapies must not be hindered; rather, medical necessity determinations must be streamlined.
- 2 Access to specialized care must be easier.
- 3 Patients with rare genetic disorders need more than access to medicines.

**EPICrd Act will balance state flexibility with providing certainty for Medicaid patients with severe, disabling disorders by establishing a uniform Medicaid home infusion benefit that, if a state chooses to offer it, requires payment without delay for home infusion therapy that a prescriber attests to be medically necessary.**

- ✓ Covered home infusion therapy builds off existing Medicare policy to include not only the covered outpatient drug, but also the infusion pump, intravenous pole, intravenous tubing, intravenous catheters, syringes, needles, and intravenous start and dressing change kits, as well as services provided by a trained infusion nurse, including drug administration and patient education, training, and monitoring.



**EPICrd Act will balance state flexibility with providing certainty for Medicaid patients with severe, disabling disorders by establishing a uniform Medicaid DME benefit that, if a state chooses to offer it, requires payment without delay for DME which a prescriber attests to be medically necessary.**

- ✓ Covered DME builds off the existing Medicare policy, which includes iron lungs, oxygen tents, hospital beds, and wheelchairs used in the patient's home, among other items, to also include any other adaptive equipment or medical furniture not described there.



**EPICrD Act would require Medicaid payment without delay for certain medical supplies for wound care and pain management that a prescriber attests to be medically necessary for children with medically complex conditions and qualified severely impaired individuals.**

- ✓ Covered medical supplies include OTC antihistamine, acetaminophen, NSAIDs, antiseptics, zinc oxide, and antibiotic ointment, as well as bandages, gauze, and dressings.



**EPICrD Act would require Medicaid payment for prescribed food medically necessary for the safe and effective dietary management of a Medicaid beneficiary diagnosed with certain digestive, absorption, and inherited metabolic disorders and conditions.**

- ✓ Covered medical foods would exclude weight loss food and supplements, gluten-free food items, and food intended for diabetes.
- ✓ The benefit would be limited to those Medicaid beneficiaries diagnosed with inborn errors of metabolism, malabsorption disorders, gastrointestinal disorders affecting the alimentary tract, and neurological or physiological conditions.

**EPICrD Act would establish the Medicaid Access to Care Demonstration Project – a two-year demonstration project – to test Medicaid payment for a program navigator for certain rare disease patients and caregivers.**

- ✓ A navigator would assist with Medicaid eligibility determination, enrollment, and coordination with schools and social workers, as well as provide support by coordinating with the prescriber in appealing denials of items and services.
- ✓ If a state opts to select a third party to serve as a contract Medicaid navigator, that contractor must have general experience in assisting consumers in health insurance enrollment and appeals, as well as serving consumers with special needs, including limited English language proficiency, low literacy rates, disabilities, and multiple health conditions, including behavioral health.

**EPICrD Act would clarify that Title V Maternal and Child Health (“MCH”) block grants may be used by states to establish state-wide genetic screening programs and to promote life-long disease management for metabolic disorders that directly cause mental health disorders and pregnancy complications if untreated.**

- ✓ The genetic screening effort would focus on the genetic causes of epilepsy, autism spectrum disorders, skeletal dysplasia, and neuromuscular disorders to diagnose children for disorders not adopted for inclusion on state newborn screening panels.
- ✓ Federal funds could be used by states, patient advocacy and research organizations, or other entities to develop training materials and leverage traditional and digital media to educate the public on:
  - ▶ the necessity of lifelong disease management by a multi-disciplinary team of specialists at a metabolic clinic;
  - ▶ the opportunity to use telehealth for such metabolic clinic visits; and
  - ▶ the most recent standard of care, including the availability of and importance of adherence to therapeutic interventions, to prevent progressive cognitive impairment and other neurological and psychological manifestations.

**EPICrD Act**

Developed by Advocacy. Supported by BioMarin



**For more information and legislative text, visit: [EPICrD.org](https://EPICrD.org)**

**Scan to see all provisions of bill.**