**ensuring parity for individualized care for rare disorders (EPICrd)**

**EPICrd Act: Frequently Asked Questions**

1. ***What does EPICrd Act do?*** Thedraft legislation would make improvements to the Medicaid statute to help ensure Medicaid beneficiaries who are diagnosed with rare disorders can better access various items and services without delays or denials.
2. ***What Medicaid items and services does the EPICrd Act cover?*** The draft legislation provides policy improvements that will ensure the coverage of and payment for *medically necessary*:

* prescription drugs dispensed or administered in the outpatient setting,
* medical supplies (including over-the-counter wound care and pain management),
* home infusion therapy,
* durable medical equipment,
* medical food,
* telehealth across state lines,
* physical therapy,
* occupational therapy, and
* speech pathology and audiology services.

1. ***Why is EPICrd Act necessary?*** Ambiguities in the federal Medicaid statute have allowed inconsistentstate by statecoverage policies which have negatively impacted rare disease patients more than other populations. As a state-federal partnership, it is necessary to strike a balance that allows states to design their programs with flexibility while ensuring minimum coverage standards for medically necessary items and services.
2. ***How does EPICrd Act improve prescription drug coverage for Medicaid beneficiaries?*** The draft legislation streamlines the prior authorization process and requires patient and clinician input when Drug Utilization Review boards and Pharmacy & Therapeutics committees develop drug coverage criteria. If enacted, state Medicaid programs would no longer be permitted to restrict access to medications for individuals with rare disorders.
   * EPICrd ensures Medicaid beneficiary treatment decisions are made by health care providers through prescriber attestation, rather than state bureaucratic policies.
   * EPICrd ensures Medicaid include perspectives of patients and providers with expertise in rare disorders when establishing coverage criteria.
3. ***How does EPICrd Act require inclusion of the patient voice?*** EPICrd establishes a uniform process for DUR Boards and P&T Committees receive live or written testimony from local rare disease Medicaid patients, their caregivers or representatives, and use these testimonies to inform related coverage policy decisions. This process ensures the burden of illness is considered and mitigates an exacerbation of healthcare disparities.
4. ***Doesn’t Medicaid already cover durable medical equipment (DME)?*** EPICrd ensures minimum coverage standards for medically necessary DME to assist with basic activities of daily living, care, and basic health and safety-related activities is a required Medicaid benefit.
5. ***Why doesn’t Medicaid consistently cover over-the-counter (OTC) medically necessary supplies?***  State by state consistency in Medicaid coverage is critical for medically necessary OTC products which may include, but are not limited to, wound care and pain management products for children with medically complex conditions. To receive appropriate Medicaid coverage of these medically necessary supplies, some families have been forced to abandon family, friends, and support systems to relocate to a state that provides this Medicaid benefit.
6. ***How does EPICrd Act affect home infusion for Medicaid patients?*** EPICrd provides a uniform standard for home infusion therapy for not only the drug, but also the required supplies, equipment, necessary nursing services, and prior authorization processes. EPICrd brings Medicaid in alignment with the recently enacted home infusion law which is limited to Medicare.
7. ***How does EPICrd Act address disparities in telehealth coverage for patients with rare diseases?*** Those living with rare diseases have limited numbers of centers of excellence and experts thereby making medically appropriate cross-state telehealth a necessity to access specialists with experience in their rare disorder. The COVID pandemic and its related policies highlighted the benefits of telehealth services. EPICrd establishes a uniform telehealth benefit improving access to care and leading to better cost-effective outcomes for Medicaid beneficiaries with rare diseases.
8. ***Why does EPICrd Act include coverage of medical foods in Medicaid when there are broader medical foods legislation pending?*** EPICrd focuses on coverage of prescribed medical foods for Medicaid patients with rare disorders for safe and effective dietary management. EPICrd would help overcome some of the political hurdles that have prevented enactment of the broader policy for medical foods access such as the Medical Nutrition Equity Act (H.R. 3783, S. 2013).
9. ***Aren’t physical therapy (PT), occupational therapy (OT), speech, and audiology covered under the Medicaid home health benefit?*** EPICrd will require minimum coverage standards for PT, OT, speech, and audiology that are not provided under their school’s Individualized Educational Plan. Inconsistencies in coverage coordination have led to gaps for these vital services. EPICrd requires that payment for such services under the Medicaid home health benefit no longer be considered optional.