

# EPICr<sup>d</sup> Act



## FOCUS: Access to Specialized Care Out-of-State Providers and Telehealth

### Congress Must Act Now To Ensure Medicaid Patients With Rare Diseases Can Access Out-Of-State Providers

Patients with rare diseases often require disease management and care coordination from a multi-disciplinary team of medical specialists. Because most of these conditions have limited numbers of clinician experts throughout the country due to low prevalence or complexity of the condition, it is common for rare disease patients to regularly travel long distances to receive infusions or to see the full team of specialists required to manage their condition. Such patients are also increasingly using telehealth for disease management. Inadequate reimbursement and limited telehealth benefits in Medicaid are a barrier to medically necessary disease management and care coordination.

**Rare ACCESS Act will ensure access to physician-administered rare disease therapies in both the inpatient and outpatient setting for Medicaid patients with complex or disabling conditions who must travel out-of-state.**

- ✓ Eligible drugs include those rare disease therapies more readily available for administration outside the state of the Medicaid beneficiary due to the expertise of the provider, complexity of the therapy and its administration, or the complexity of the rare disease or condition.
- ✓ If the rare disease therapy is available within the state of the Medicaid beneficiary, to be eligible for the demonstration project, the out-of-state provider must be located a shorter distance from the primary residence of the Medicaid beneficiary than the in-state provider or be a center of excellence for the rare disease or condition.

**Rare ACCESS Act will improve Medicaid patient outcomes by leveraging telehealth with multidisciplinary care teams to alleviate barriers related to geography and capacity limits at clinics and hospitals.**

- ✓ Eligible telehealth providers include physicians, psychologists, neuropsychologists, genetic counselors, social workers, nurse practitioners, case managers, dietitians, behavior therapists, speech therapists, audiologists, physical therapists, occupational therapists, or any other providers determined by CMS.
- ✓ Eligible telehealth providers will be required to have a full unrestricted license in their primary jurisdiction.
- ✓ Covered telehealth services include:
  - ▶ Diagnosis, treatment, or care management;
  - ▶ Peer-to-peer consult (including such consults commencing following the transmission of patient's medical information, such as an electronic health record, diagnostic image, or provider report, from an originating site to a distant site without the presence of the patient at either site);
  - ▶ Patient education, including REMS (Risk Evaluation and Mitigation Strategies) required education for prescription drug use; and
  - ▶ Patient monitoring, including post-administration of gene therapy.



## Why is telehealth important in caring for patients with rare conditions?

- ✓ Telehealth can facilitate the transition of pediatric patients to adult care, which is becoming increasingly important for patients with metabolic disorders, who are more frequently living into adulthood due to advances in diagnostics, disease management, and therapeutic interventions.
- ✓ Telehealth can eliminate delays in starting a patient on therapy by facilitating REMS compliance.
- ✓ Telehealth can reduce the burden on patients and caregivers participating in requisite monitoring following the administration of a gene therapy.



## Rare ACCESS Act will set up a five-year demonstration project that would reduce additional barriers to patients accessing specialists located at centers of excellence outside of their state - both in person and via telehealth, by furthering the policy goals of the Accelerating Kids' Access to Care Act (H.R. 4758 / S. 2372).

- ✓ CMS would establish a streamlined screening and enrollment process for all out-of-state Medicaid providers.
- ✓ States participating in the demonstration project must provide payment for telehealth (including both providers in a peer-to-peer consult), and drug acquisition and administration at a rate no less than the payment rate of the providers' state.
- ✓ For providers in good standing with their home state medical boards, participating states are required to provide medical licensure reciprocity for providers furnishing a full range of telehealth services to patients outside of the state.
- ✓ A temporary Medicaid reimbursement increase for robust telehealth services and the acquisition and administration of rare disease therapies will make participating states whole for making providers whole.



## Rare ACCESS Act protects state budgets, while eliminating the financial barrier for providers treating out-of-state patients by testing a quarterly furnishing fee paid to the state.

- ✓ The furnishing fee will offset any excess payments made by the state to out-of-state providers for telehealth and drugs (both acquisition and administration costs) furnished under the five-year demonstration project.
- ✓ Upon selection for the demonstration project, a participating state cannot lower its payment rates for telehealth and drugs; if such state has lowered rates in the 12 months prior to selection, the payment rate on which the furnishing fee is based cannot be lower than national three-year average for such items and services.

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.

