EPICrd Act

Ensuring Parity through Individualized Care for Rare Disorders

What is EPICrd? A comprehensive legislative approach to ensuring coverage parity for patients with rare genetic conditions in accessing specialists, medicines, and other necessary items and services within Medicaid.

Innovation in treatments, diagnostics, equipment, and other technologies supporting individuals with rare genetic conditions is outpacing Medicaid access. Innovation without fair access, however, will not help patients and their families. Discriminatory anti-innovation policies are preventing those with chronic illnesses and disabilities from obtaining medically necessary interventions - including access to experts in rare disorders.

Access to rare disease therapies must not be hindered

- ✔ Transformative medical breakthroughs satisfy unmet medical needs and advance standards of care
- ✔ Patient access to these therapies must be enhanced; provider burden should be reduced
- ✔ Medicaid prior authorizations and other coverage restrictions deny rare disease patients fair access to qualifying rare disease therapies, further exacerbating socioeconomic disparities in healthcare

Medical necessity determinations must be streamlined

- ✔ Medicaid should not override FDA and providers' authority and expertise
  - FDA approval demonstrates effectiveness
  - A doctor's attestation that a medicine is reasonably likely to work should determine medical necessity

Patients with rare genetic disorders need more than access to medicines

- ✔ Home infusion therapy and services
- ✔ Durable medical equipment, supplies, and foods
- ✔ Home health benefits such as physical and occupational therapies
- ✔ Access to multi-disciplinary teams

Access to specialized care should be easier

- ✔ Telehealth for access to rare disease experts
- ✔ Administration of medicines by out-of-state providers
- ✔ Healthcare navigators

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