



Legislative Ask #2

The Genomic Answers for Children's Health Act (H.R. 7118)

Bipartisan Legislation Improves the Diagnosis & Treatment of Kids on Medicaid



Problems Facing Certain Children on Medicaid

- Children with rare diseases and/or genetic disorders can face years of delays in getting to a correct diagnosis. This can involve numerous visits with different doctors to get a diagnosis, during which they often undergo unnecessary tests and procedures, receive incorrect diagnoses, and experience delays in getting effective care.
- Not all state Medicaid programs cover needed genomic tests for children, but may restrict coverage based on test, care setting, or age. Tragically, too many children with rare diseases experience irreversible damage as the disease progresses during this "diagnostic odyssey" – the period in which families and clinicians are searching for a diagnosis.

How This Legislation Helps Children on Medicaid

H.R. 7118, introduced in by Representatives Scott Peters (D-CA) and Gus Bilirakis (R-FL), along with Representatives Marc Veasey (D-TX), Troy Balderson (R-OH), Kevin Mullin (D-CA), Mike Carey (R-OH), Chrissy Houlahan (D-PA), and Maria Salazar (R-FL), clarifies Medicaid's coverage requirements and makes related changes. Specifically, it:

- Clarifies Medicaid Coverage of Genomic Sequencing: Makes clear that whole genome sequencing and whole exome sequencing (genomic sequencing) is a covered Medicaid service under Medicaid's required early and periodic screening, diagnostic, and treatment services for children with certain clinical criteria; adds a DRG add-on payment for inpatient sequencing services.
- Promotes Awareness Among Stakeholders: Requires CMS to convene national stakeholders and convey information to make key stakeholders aware of new policy adopted in the bill.
- Report to Congress on Barriers to Care: Directs GAO to publish a report within 24 months examining state reimbursement rates and health outcomes of children receiving genomic sequencing under Medicaid, as well as to assess implementation challenges, evaluate barriers to care, and provide recommendations for improvement.

Why Genomic Sequencing Helps Children on Medicaid

- Genomic sequencing is comprehensive: Research shows genomic testing has a higher diagnostic yield than other tests that only look at one gene or a series of genes. It is a comprehensive analysis of a person's DNA.
- Genomic sequencing is clinically effective and economical: Abundant peer-reviewed research demonstrates the clinical and diagnostic efficacy of whole genome sequencing and whole exome sequencing. Research shows genomic sequencing testing has proven to be cost-effective—and even cost-saving in some circumstances, particularly in the inpatient setting.
- Genomic sequencing improves diagnosis and care: The results from genomic sequencing can significantly shorten the time to diagnosis for pediatric patients, identifying the cause of an undiagnosed condition and enabling targeted care and treatment.