

## **Domain 6 Findings - Barriers and Challenges Federal Policymakers Could Address**

Respondents identified potential actions CMS or Congress could take to modify federal policies, requirements, or rules in a targeted and thoughtful manner that would remove barriers to challenges state Medicaid directors face in ensuring Medicaid beneficiaries living with SCD have consistent high-quality, timely access to comprehensive care and treatment. Responses are summarized below.

- **Multiple respondents identified affordability as something Congress or CMS could take actions to address to improve accessibility.** Respondents noted:
  - Medicaid programs face challenges in paying for treatments and services when an individual loses coverage but still needs care; continuous eligibility for a certain time period was one identified solution to this concern.
  - CMS should continue to pursue the “Cell and Gene Therapy Access Model,” especially to the degree that the state share of the risk involved in paying for these therapies may be mitigated.
  - Federal policymakers should consider creating new pathways to allow states additional flexibility to manage Medicaid costs, specifically those related to prescription drugs, if such flexibility could be demonstrated as improving access.
  
- **Respondents identified specific ways federal policymakers could help states in their efforts to ensure that individuals with SCD have timely access to high-quality care, such as:**
  - Explicitly add SCD as a qualifying condition for Medicaid Health Homes under Section 1945 of the *Social Security Act*.
  - Specifically allow directed payments for SCD treatment that could be easily added to an MCO capitation payment without additional burdensome review by CMS Center for Medicaid and CHIP Services or CMS Office of the Actuary.
  - CMS could publicize preapproved model contract language that states could adopt under MCO contracts.
  - CMS could promulgate a State Medicaid Director Letter or Informational Bulletin that outlines actions states could take to support SCD therapy (similar to past State Medicaid Director Letters on duals integration, value-based payment, and Home and Community Based Services).
  - CMS could improve education for medical providers about SCD, racial bias, and bias in health care delivery.

- For states with fee-for-service delivery systems, create a mechanism for a per-member, per-month (PMPM) payment outside of complicated primary care case management (PCCM) structures.
- Provide greater clarity on coverage, payment, and delivery regarding gene therapies, state Medicaid coverage of experimental therapies, and “Right to Try” products.
- Create exceptions to the SUPPORT Act requirements for opioid management for children with SCD.

