



July 5, 2016

TO: Members, Subcommittee on Health
FROM: Committee Majority Staff
RE: Hearing entitled “Examining the Advancing Care for Exceptional Kids Act.”

I. INTRODUCTION

On Thursday, July 7, 2016, at 10:15 a.m. in 2322 Rayburn House Office Building, the Subcommittee on Health will hold a hearing entitled, “Examining the Advancing Care for Exceptional Kids Act.”

II. WITNESSES

- Jay Berry, MD, MPH, Assistant Professor of Pediatrics, Harvard Medical School;
- Matt Salo, Executive Director, National Association of Medicaid Directors;
- Maria Isabel Frangenberg, Project Coordinator, Family Voices;
- Tish West, Parent of a Child with Medically Complex Conditions;
- Steven Koop, MD, Medical Director, Gillette Children’s Specialty Healthcare; and
- Rick Merrill, President and Chief Executive Officer, Cook’s Children’s Health System.

III. BACKGROUND

H.R. 546, the Advancing Care for Exceptional Kids Act of 2015 (ACE Kids), was introduced by Rep. Barton (R-TX), Rep. Castor (D-FL) and colleagues to improve the delivery of care for children with complex medical conditions under Medicaid. The bill seeks to achieve three primary goals:

- 1) to improve coordination of care for children to reduce the burden on families;
- 2) to address problems with potentially fragmented or uncoordinated care children may access, especially challenges accessing care across State lines; and
- 3) to gather national data on conditions to help researchers improve services and treatments for children with complex medical conditions who are covered by Medicaid.

Cosponsors and the Committee have received robust feedback and interest on the introduced legislation (H.R. 546) from a wide variety of Medicaid and health care stakeholders. Based on that feedback, this hearing will be an opportunity to review a revised draft of ACE

Kids. This revised draft, released by the Committee on June 30, is designed to address the goals of the introduced bill in a manner that incorporates and builds upon the diverse range of stakeholder feedback.

Better coordinating care. To achieve the goal of improving coordination of care, the draft legislation would create a new State option to coordinate care for children with medically complex conditions through a health home. This policy would remove federal barriers and give States a new option to target Medicaid resources and expertise to coordinate care for some of the most vulnerable children served in Medicaid.

Under the health home, a provider—such as a pediatrician or pediatric specialist, a children’s hospital, or community health center—or a team of health care professionals would provide comprehensive care management and care coordination services to eligible children, including coordinating access to medical services from out-of-state health care providers as medically necessary. As a condition of participating in the health home option, States would be required to collect data on the characteristics of participating children and providers, as well as applicable quality of care measures.

Improving access to care. To address challenges that families and children with medical complexity may face when accessing care (such as specialty or subspecialty care) across State lines, the draft legislation would require the Department of Health and Human Services to issue guidance to State Medicaid Directors on best practices for providing care to children with medical complexity. That guidance, due within one year of enactment, is to include information on arranging and providing reimbursement for care provided by providers from other States, practices for reducing barriers to such care, and efforts to streamline the process for screening and enrolling out-of-state providers in a State’s Medicaid program.

Targeting Medicaid resources to the most vulnerable. To gather national data to improve treatments for children with medical complexity, the draft legislation would require the Medicaid and CHIP Payment and Access Commission (MACPAC) to collect data and report on children with medical complexity. The MACPAC report, due 18 months after enactment, would include information on the characteristics of children with medical complexity and options for defining the population. The report would also include data on such children enrolled in Medicaid, including the delivery systems and care arrangements in which they are served, the providers that care for these children, and the extent to which those providers are located out-of-state.

IV. POTENTIAL ISSUES FOR DISCUSSION

To help Members better understand the range of children with medical complexity who are accessing care under the Medicaid program today, the following issues may be discussed at the hearing:

- What is medical complexity and how are children with medical complexity identified?
- How many children with medical complexity are enrolled in Medicaid?

- How are children with medical complexity currently served under Medicaid? What programs or services are in place to coordinate their care?
- How do State Medicaid programs and providers handle the provision of care from another State?
- How does the provision of care differ in cases of an acute medical crisis, compared to long-term disease management?
- What barriers, if any, exist for families of children with medical complexity in accessing needed care? What is the role of time and distance in creating barriers for children living in rural areas of the U.S.?
- What potential changes to current Medicaid law and policy could have unintended consequences, disrupting care for children with medical complexity?
- What are States' experiences with health homes and how could the new option created under the discussion draft benefit children with medical complexity?

V. STAFF CONTACTS

If you have any questions regarding this hearing, please contact Josh Trent or Michelle Rosenberg of the Committee staff at (202) 225-2927.