

ONE HUNDRED FOURTEENTH CONGRESS  
**Congress of the United States**  
**House of Representatives**  
COMMITTEE ON ENERGY AND COMMERCE  
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**MEMORANDUM**

**July 5, 2016**

**To: Subcommittee on Health Democratic Members and Staff**  
**Fr: Committee on Energy and Commerce Democratic Staff**  
**Re: Hearing on “Examining the Advancing Care for Exceptional Kids Act”**

On **Thursday, July 7, at 10:15am, in Room 2322 of the Rayburn House Office Building**, the Subcommittee on Health will hold a legislative hearing on a revised discussion draft of H.R. 546, the “Advancing Care for Exceptional Kids Act.” This legislation, and the revised discussion draft that is the topic of the hearing, aim to address and improve care delivery for medically-complex children in the Medicaid program.

**I. BACKGROUND**

Established along with Medicare by the Social Security Amendment of 1965, Medicaid is a joint federal-state program that finances the delivery of primary and acute medical services, as well as long-term services and supports, for a diverse low-income population, including children, pregnant women, individuals with disabilities, and people age 65 and older.<sup>1</sup> Medicaid is jointly financed by the federal government and states, with states responsible for administering Medicaid. The federal government sets basic requirements for Medicaid, but states have the flexibility to design their own Medicaid programs within the federal framework. As a result, there is significant variation across Medicaid programs.

Similarly, CHIP is a federal-state program that provides health coverage to certain low-income children and some pregnant women in families with annual incomes above Medicaid

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<sup>1</sup> For more information about Medicaid, see Alison Mitchell, *Medicaid: An Overview*, Congressional Research Service (CRS) (R43357).

eligibility levels that have no health insurance.<sup>2</sup> The relationship between the states and the federal government with respect to the CHIP program is similar to Medicaid in that there is significant variation across state CHIP programs within broad basic federal requirements.

Medicaid provides coverage for more than 72 million individuals.<sup>3</sup> Together with the CHIP program, in 2015, Medicaid covered more than 45 million children in the United States.<sup>4</sup>

For further background information on the Medicaid program, please refer to the committee's [memo from July 7, 2015](#).

#### **A. Medically-Complex Children in the Medicaid Program**

Both Medicaid and CHIP cover children with complex medical conditions, which can also be referred to as “children with special health care needs.” The Medicaid program plays a particularly important role for children with complex medical conditions, as the benefits for children in Medicaid are typically more comprehensive than other sources of coverage, particularly for individuals with disabilities.

Specifically, children covered by Medicaid or CHIP- Medicaid expansion programs<sup>5</sup> are required to receive the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit. Under this benefit, states are required to provide services that are determined to be medically necessary, even if the services are not listed as covered in the State Medicaid Plan.<sup>6</sup>

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<sup>2</sup> For more information about CHIP, see Evelyne P. Baumrucker and Alison Mitchell, *State Children's Health Insurance Program: An Overview*, Congressional Research Service (CRS) (R43627).

<sup>3</sup> Department of Health and Human Services (HHS), *Medicaid and CHIP: April Monthly Applications, Eligibility Determinations and Enrollment Report* (June 30, 2016) (online at <https://www.medicaid.gov/medicaid-chip-program-information/program-information/downloads/april-2016-enrollment-report.pdf>).

<sup>4</sup> Center for Medicaid and CHIP Services, *FFY 2015 Number of Children Ever-Enrolled in Medicaid and CHIP* (online at <https://www.medicaid.gov/chip/downloads/fy-2015-childrens-enrollment-report.pdf>).

<sup>5</sup> States may design their CHIP programs in three ways: a CHIP Medicaid expansion, a separate CHIP program, or a combination approach. CHIP benefit coverage and cost-sharing rules depend on program design. CHIP Medicaid expansions must follow the federal Medicaid rules for benefits and cost sharing. For separate CHIP programs, the benefits vary.

<sup>6</sup> More information on the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit is available online at (<https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-and-Periodic-Screening-Diagnostic-and-Treatment.html>).

For the services not listed in a state's State Medicaid Plan, the state must contract with an in-state or out-of-state provider who will accept Medicaid payment.<sup>7</sup>

There is not one agreed-upon definition for children with complex medical conditions; recognizing a particular child is medically complex may seem straightforward at the individual level, but characterization is more difficult at a population level.<sup>8</sup> Medical complexity is regarded differently depending on the point of view of consideration, and often, individual level details that are recognizable in a one-on-one encounter do not translate to currently available population-level data sources. However, in general, these children have chronic, multisystem diseases that are expected to last longer than a year, and that are associated with functional limitations, high morbidity and mortality, and high use of health resources.<sup>9</sup>

Both identifying data and quality data on medically complex children in Medicaid is scarce to non-existent. One study estimated that 5.8 percent of the children covered by Medicaid in 2011 were children with complex medical conditions. These children accounted for an estimated 34 percent of all Medicaid spending for children,<sup>10</sup> but the scope of the problem and the quality of care received by such children in Medicaid is virtually impossible to determine on a national basis with available data sources.

In addition to data and quality challenges, families with medically complex children often struggle with significant difficulties coordinating care across state lines with multiple state Medicaid programs. Compounding data and care coordination issues further, Medicaid families can often face additional challenging social and family circumstances that add complexity onto already difficult to manage medically-complex cases.<sup>11</sup>

Family-centered care for this population has been cited by stakeholders as critical to meaningful improvements in care. For instance, Family-to-Family Health Information Centers can be an integral partner to connect families with resources and advocate for and help Medicaid families navigate a health care system that can potentially span many states. Beneficiary stakeholders have cited that any efforts to improve care for this population must involve families in the development of programs, policies and procedures.

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<sup>7</sup> Centers for Medicare & Medicaid Services (CMS), *EPSDT - A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents* (June 2014) (online at [https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Downloads/EPSDT\\_Coverage\\_Guide.pdf](https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Downloads/EPSDT_Coverage_Guide.pdf)).

<sup>8</sup> Jay G. Berry et al., *Ways to Identify Children with Medical Complexity and the Importance of Why*, *Journal of Pediatrics* (Aug. 2015).

<sup>9</sup> Joanna Thompson et al., *Financial and Social Hardships in Families of Children with Medical Complexity*, *Journal of Pediatrics* (May 2016).

<sup>10</sup> Jay G. Berry et al., *Children with Medical Complexity and Medicaid: Spending and Cost Savings*, *Health Affairs* (Dec. 2014).

<sup>11</sup> *Id.*

Care coordination across state lines has also been identified as a significant issue for these children by numerous stakeholders. For example, some pediatricians may be able to care for children with complex medical conditions, but in many cases, pediatric specialists may better manage the care for these children.<sup>12</sup> However, access to care can be an issue; pediatric specialists generally practice at children's hospitals, which are not readily accessible to all children with complex medical conditions.<sup>13</sup> Children with medical complexity often must travel nationwide to find providers to suit their unique care needs. Medicaid's very nature as a state-by-state program can make efficient coordination of care and payment particularly challenging. Stakeholders have cited the conflicting regulations and paperwork requirements that can delay treatment and lead to unnecessary hospitalizations. States are able to contract with out-of-state providers for their Medicaid program, and the state must pay the out-of-state provider to the same extent that it would pay in-state providers for the same services;<sup>14</sup> however, not all specialists accept out-of-state Medicaid payments and providers that do have reported significant delays in payment. Additionally, providers often do not receive reimbursement incentives under standard reimbursement models for the extensive care coordination that is needed for this population.

#### **B. New Delivery System Models in Medicaid and CHIP**

In recent years, states have been implementing new delivery system models for their Medicaid and CHIP programs to increase integration of services and care coordination. For example, at least 18 states have set up accountable care models to improve integration of services, and 13 of these states are using this model for Medicaid and/or CHIP children. At least 18 states have established patient-centered medical homes that are designed to coordinate primary care services. Also, at least 16 states are using the health home option in their Medicaid and/or CHIP program.<sup>15</sup> However, none of these current authorities specifically address medically complex children, and the unique multi-state and/or national care needs of this population.

As part of a first step forward to address this issue, the Center for Medicare & Medicaid Innovation (CMMI), through the Health Care Innovation Awards (HCIA), has awarded several projects that focus on this population. HCIA grants are awarded to organizations that are implementing the most compelling new ideas to deliver better health, improved care and lower costs to people enrolled in Medicare, Medicaid and CHIP, particularly those with the highest health care needs.<sup>16</sup>

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<sup>12</sup> *Id.*

<sup>13</sup> *Id.*

<sup>14</sup> 42 CFR 431.52.

<sup>15</sup> CMS, *Making Connections: Strengthening Care Coordination in the Medicaid Benefit for Children & Adolescents* (Sept. 2014).

<sup>16</sup> More information on the Health Care Innovation Awards can be found online at (<https://innovation.cms.gov/initiatives/Health-Care-Innovation-Awards/>).

The most notable HCIA projects focusing on the medically-complex pediatric population include:

- *Coordinating All Resources Effectively (CARE) for Children with Medical Complexity, CA, CO, FL, MO, PA, TX.* The National Association of Children’s Hospitals and Related Institutions is receiving an award to test Coordinating All Resources Effectively (CARE) for children with medical complexity (CMC), which aims to inform sustainable change in health care delivery through new payment models supporting improved care and reduced costs across multiple states and payers.
- *Massachusetts Alliance for Complex Care (MACC), Boston, MA.* The Boston Medical Center project will test a Collaborative Care Coordination and Consultative Model for Complex Kids (the 4C, or "Foresee" Program) which pairs Complex Care Nurse Care Coordinators and Pediatricians at MACC sites in Boston and Springfield with pediatricians in the community to enhance and improve the care delivered to children with medical complexity in local medical home-like settings.
- *Special Needs Program for Children with Medical Complexity, Madison, WI.* The Wisconsin Department of Health Services project will test an intervention that aims to enhance and expand the Special Needs Program (SNP) model that is currently in place at Children's Hospital of Wisconsin (CHW).

## **II. DISCUSSION DRAFT OF H.R. 546, THE “ADVANCING CARE FOR EXCEPTIONAL KIDS ACT”**

The discussion draft under consideration is based on H.R. 546, the “Advancing Care for Exceptional Kids Act of 2015 (ACE Kids Act)”, introduced by Reps. Barton (R-TX) and Castor (D-FL). The legislation is cosponsored by 208 bipartisan Members of the House. Below is an outline of the discussion draft:

### **A. Sec. 1 - Short Title**

This section cites the title of the bill as the “Advancing Care for Exceptional Kids Act” or the “ACE Kids Act.”

### **B. Sec. 2 - State Option to Provide Coordinated Care Through a Health Home for Children With Complex Medical Conditions**

This section establishes a new care delivery model option for state Medicaid programs—a health home for children with complex medical conditions. The legislation offers two years of enhanced matching payments to establish medical homes and gives states the option to use innovative payment models, like shared savings or other pay-for-performance models. States, under this option, must educate providers about the availability of such services for children, and may also include hospital referral procedures for medically-complex children. Under this new health home option, a state must further provide guidance, consistent with guidance issued by the Centers for Medicare and Medicaid Services (CMS) on payment for multi-state Medicaid payments, taking into consideration guidance issued by CMS regarding best practices for out-of-state payments.

The new health home model contemplated under this section would also require quality reporting to the state's Medicaid program on quality metrics specified by CMS. The state, in turn, would report such data on quality as well as other data points on usage and characteristics of a state's medical home for complex kids to CMS. This section also defines children with medically complex conditions, a health home, and designated provider for purposes of the health home.

**C. Sec. 3 - Rule of Construction on Freedom of Choice**

This section is a rule of construction regarding choice of providers for children defined as medically complex for purposes of the medical home option contemplated above.

**D. Sec. 4 - Guidance on Coordinating Care From Out-of-State Providers**

This section requires CMS to issue guidance, within one year of enactment, to all states on best practices for payment across state lines.

**E. Sec. 5 - MACPAC Report**

This section requires a Medicaid and CHIP Payment and Access Commission (MACPAC) report on medically-complex children.

**III. WITNESSES**

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Executive Director  
National Association of Medicaid Directors

**Jay Berry, M.D.**

Assistant Professor of Pediatrics  
Harvard Medical School

**Tish West**

Parent of a child with complex medical needs

**Rick Merrill**

President and CEO  
Cook's Children's Health System

**Maria Isabel Frangenberg**

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**Steven Koop, M.D.**

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