

**Opening Statement of Chairman Fred Upton**  
**Health Subcommittee Hearing on “Examining the Advancing Care**  
**for Exceptional Kids Act”**  
**July 7, 2016**

Today, the Medicaid program is an important safety net that provides needed medical care to millions of children in communities across the nation. In FY2013, roughly half of all Medicaid enrollees were children.

Many of these children are healthy, well and primarily just rely on the program for routine medical care, preventative screenings, and other treatments.

However, some of the children served by Medicaid face very serious, debilitating, even life-threatening conditions that make it very difficult for them to perform the activities of daily life. These children are often referred to as “children with medical complexity,” because they may face any number of rare diseases and conditions, which can force them to rely on very specialized care.

I know we all want to ensure that the Medicaid program does right by these kids and the families that depend on the program for care—especially the most vulnerable. So today we are discussing another bipartisan bill introduced by members of this committee. The ACE Kids

Act, led by Chairman Emeritus Barton and Ms. Castor, seeks to improve care for these children.

We first discussed this bill as part of the 21<sup>st</sup> Century Cures initiative. Since then, we've received a lot of feedback from my colleagues, and stakeholders – many of which are in this very room. I'm glad to see such strong interest in working together to get this bill right and better serve the patients in need of our help.

So, in that spirit of cooperation and collaboration, I want to stress we all agree on the goals of the ACE Kids Act – improving care coordination within a state, ensuring access to care across state lines, and ensuring we are leveraging data to target interventions. But each of us also wants to ensure that any targeted improvements actually fix what is broken by building on what is working –without disrupting proven, successful models of care that help kids within the program today.

We want to do everything we can to ensure we enhance care, and protect choices within the program.

That's why we have our witnesses before us today. We need their feedback and insights to better understand the challenges this population of children faces within the Medicaid program today.

We also want to hear from folks not on the panel. Whether it's managed care plans, individual Medicaid directors, physicians, nurses, children's health advocates, or others – we invite them to continue to share their insights and ideas about how we can tailor solutions to improve care for children.

We want to better understand what's working and also what opportunities exist for bipartisan improvements to give beneficiaries, states, plans, and providers more tools to design solutions that best serve these kids.

I yield the balance of my time to the Vice Chairman of the full committee, Ms. Blackburn.