

The Advancing Care for Exceptional (ACE) Kids Act Puts Complex Pediatric Cases at the Forefront

Darby O'Donnell, JD, Alliance for Patient Access (AfPA) Government Affairs Team

The Alliance for Patient Access (allianceforpatientaccess.org), founded in 2006, is a national network of physicians dedicated to ensuring patient access to approved therapies and appropriate clinical care. AfPA accomplishes this mission by recruiting, training and mobilizing policy-minded physicians to be effective advocates for patient access.



Earlier this month, the United States Senate passed unanimously a bill that contained a number of Medicaid provisions, including the Advancing Care for Exceptional (ACE) Kids Act of 2019.

The ACE Kids Act is a congressional proposal that would allow state Medicaid programs to improve how care is delivered through a coordinated care model for children with medically complex conditions.

The United States House of Representatives passed the package in the week prior to the Senate's action, so the ACE Kids Act is on its way to the president's desk for his signature.

Why does the ACE Kids Act do?

Under the bill, care can now be provided to patients through a so-called "health home" (i.e., a designated provider or team of health-care professionals). These individuals help navigate care and the health care system across one patient's multiple appointments with potentially multiple providers, much like a case manager. When families get overwhelmed, they have a team of individuals to support them.

Senate Finance Committee Chairman Chuck Grassley (R-Iowa), a co-leader of the legislation on the Senate side, said, following the unanimous passage of the bill:

Thankfully, most children are healthy. But there are some children with medically complex needs that see multiple different doctors

to keep them healthy and out of the hospital. On average, these children can require five to six doctors and as many as 20-30 allied health care professionals. Families of these children are frequently left alone to navigate a complicated health care system. ACE Kids will provide those families with an option to have better care coordination for their children."

" On average, these children can require five to six doctors and as many as 20-30 allied health care professionals. Families of these children are frequently left alone to navigate a complicated health care system. "

Easing access to care across state lines

Another aim of the ACE Kids Act is to resolve discrepancies between state Medicaid programs when a child or infant must be treated across state lines. The policy goal is better coordination reduces health care costs to the Medicaid system because it could mean less emergency room visits and hospitalizations too.

Chairman Grassley also noted that more children are surviving and living their lives despite "life-threatening conditions" in childhood, including prematurity, childhood cancer, and complications associated with Down syndrome. These children have ongoing medical and health needs, though. Their families are often required to seek care for them in another state to find treatment. This travel across states lines for care presents another set of complications for a sick child, particularly when it comes to coverage.

According to a release earlier this year by Senator Grassley's office and other advocates for the ACE Kids Acts:

- Medicaid covers about two-thirds of the three million children with complex medical conditions
- These represent nearly 40 percent of Medicaid costs for children.

Readers can also follow

NEONATOLOGY TODAY

via our Twitter Feed

@NEOTODAY

Opponents & Proponents

Passage of the bill took a multi-year effort and was not without controversy.

Modern Healthcare summarized in an article last year when the bill was considered during the 115th Congress: "Medicaid plans that stand to lose an expensive group of patients remain staunchly opposed, and other non-industry analysts and advocates are lukewarm and still confused about what the legislation will actually do, as well as what the health home model will look like since the legislation is vague about the details." (1)

" Medicaid plans that stand to lose an expensive group of patients remain staunchly opposed, and other non-industry analysts and advocates are lukewarm and still confused about what the legislation will actually do, as well as what the health home model will look like since the legislation is vague about the details."

According to the article, some conservatives criticized the program of changing from fee for service to health home beyond the scope of the original intent of Medicaid.

However, the legislation also had a broad network of supporters. Notably, it was supported by groups such as The American Academy of Pediatrics, The American Board of Pediatrics, The Association of American Medical Colleges, The Children's Hospital Association, The March of Dimes, Moms Rising, and The National Association of Pediatric Nurse Practitioners, to name a few. This list of supporters helped push the bill across the finish line after coming close to completion in previous sessions of Congress.

Beyond Medicaid policy ...

Jim Kaufman, vice president of public policy at the Children's Hospital Association, believes one of the other significant pieces - beyond cost reductions for the Medicaid system and improved health outcomes - is that it sets a "national definition" of kids with medical complexity. It codifies in statute the need to "shrink the burden on the kids' families as well as treatment costs." (1, 2)

Once signed into law, the ACE Kids Act will hopefully be a pathway to better treat pediatric patients with complex medical conditions, helping them and their families get the care and support they need.

References:

1. [Health Homes For Chronically Ill Kids Spark Lame-duck Battle.](https://www.modernhealthcare.com/article/20181128/NEWS/181129936/health-homes-fo) <https://www.modernhealthcare.com/article/20181128/NEWS/181129936/health-homes-fo> (accessed April 08, 2019).

Still a Premie?

Some preemies are born months early, at extremely low birthweights. They fight for each breath and face nearly insurmountable health obstacles.

But that's not every preemie's story.

Born between 34 and 36 weeks' gestation?

STILL A PREMIE

Just like preemies born much earlier, these "late preterm" infants can face:

- Jaundice
- Feeding issues
- Respiratory problems

And their parents, like all parents of preemies, are at **risk for postpartum depression and PTSD.**

Born preterm at a "normal" weight?

STILL A PREMIE

Though these babies look healthy, they can still have complications and require NICU care.

But because some health plans determine coverage based on a preemie's weight, **families of babies that weigh more may face access barriers and unmanageable medical bills.**

Born preterm but not admitted to the NICU?

STILL A PREMIE

Even if preterm babies don't require NICU care, they can still face health challenges.

Those challenges can extend through childhood, adolescence and even into adulthood.

Some Premies	All Premies
Will spend weeks in the hospital	Face health risks
Will have lifelong health problems	Deserve appropriate health coverage
Are disadvantaged from birth	Need access to proper health care

NCJIH National Coalition for Infant Health
Protecting Access for Premature Infants through Age Two
www.infanthealth.org

2. [Lawmakers Look To Improve Care For Kids With Complex ...](https://www.disabilityscoop.com/2018/10/01/lawmakers-complex-conditions/25548/) <https://www.disabilityscoop.com/2018/10/01/lawmakers-complex-conditions/25548/> (accessed April 08, 2019).

The author has not indicated any disclosures.

NT

Corresponding Author



Darby O'Donnell, JD
Alliance for Patient Access (AfPA) Government Affairs Team
1275 Pennsylvania Ave. NW, Suite 1100A Washington, DC
20004-2417
202-499-4114
info@allianceforpatientaccess.org



OPIOIDS and NAS

When reporting on mothers, babies, and substance use

LANGUAGE MATTERS



I am not an addict.

I was exposed to substances in utero. I am not addicted. Addiction is a set of behaviors associated with having a Substance Use Disorder (SUD).



I was exposed to opioids.

While I was in the womb my mother and I shared a blood supply. I was exposed to the medications and substances she used. I may have become physiologically dependent on some of those substances.



NAS is a temporary and treatable condition.

There are evidence-based pharmacological and non-pharmacological treatments for Neonatal Abstinence Syndrome.



My mother may have a SUD.

She might be receiving Medication-Assisted Treatment (MAT). My NAS may be a side effect of her appropriate medical care. It is not evidence of abuse or mistreatment.



My potential is limitless.

I am so much more than my NAS diagnosis. My drug exposure will not determine my long-term outcomes. But how you treat me will. When you invest in my family's health and wellbeing by supporting Medicaid and Early Childhood Education you can expect that I will do as well as any of my peers!

Learn more about
Neonatal Abstinence Syndrome
at www.nationalperinatal.org



Patient Safety
MOVEMENT

Patient Safety Movement Foundation
2019 Midyear Planning Meeting

CO-CONVENER:

UCI Health

FOUNDER:



BENEFACTOR:

Medtronic

INVITATION REQUEST