FAMILY VOICES®

Washington DC Update

May 10, 2017

Did you know that ONE in FIVE families has at least one child with special health care needs? Join the Family Voices One-in-Five Awareness Campaign.

Greetings from Washington!

The big news from last week:

- On Friday, by a vote of 217-213, the American Health Care Act (H.R. 1628) was approved by the House of Representatives. The bill includes a number of provisions of concern to families of children and youth with special health care needs (CYSHCN), as well as others - such as caps on federal funding for Medicaid - but it has a long way to go before it could become law.
- Both houses of Congress passed, and the president signed, a bill to fund the government for the remainder of FY 2017 (through September 30, 2017). In general, agencies and programs affecting CYSHCN and their families were either level-funded or received slight funding increases.

In case you missed it: Last week, Jimmy Kimmel (late-night talk show host) presented a heartfelt monologue about his newborn son's unexpected congenital heart defect. He thanked the nurse who suspected a problem and his son's other health care providers, and made a plea that all children be guaranteed health insurance. Senator Cassidy (R-LA) later said he wants to be sure that health care legislation meets the "Jimmy Kimmel test." The Senator, a physician, appeared by video on the Kimmel show last night and had a conversation with the host about health legislation. (This links to the 12-minute monologue; Cassidy first refers to the "Kimmel test" at about minute 6:00 and starts talking with Kimmel at about 6:50.)

UPCOMING WEBINARS AND CALLS

Federal Policy Update and Planning for the Future (about the new federal rule on ACA Marketplaces)
Thursday, May 11, 2:00-3:00 pm ET
Sponsored by Families USA

Meaningfully and Effectively Engaging Families in Pediatric Practices and Systems
Webinar series **s**ponsored by the National Center for Medical Home Implementation

- **Beyond Coexistence: Cultivating Successful Family Partnerships in Clinical Practice**
  Monday, May 15, 2017, 4:00-5:00 pm ET

- **Moving Beyond Cooperation: Engaging Families in Health Care Organizations and Practices**
  Thursday, May 25, 2017, 12:00-1:00 pm ET

- **Achieving True Partnership: Integrating Family Engagement in Systems of Care**
  Date, time, and registration information coming soon!

Working with Adult Allies (for young adults only)
Tuesday, May 16, 7:30-8:30 pm ET
This is the last of a three-part webinar series sponsored by the National Center for Family Professional Partnerships (NCFPP), in collaboration with the Autistic Self-Advocacy Network, Kids As Self-Advocates, and Youth MOVE. ***Completed webinars: Participating in Advisory Groups; Telling Your Story for a Public Policy Purpose.***

Connecting Kids to A+ Health Coverage for Back-to-School Season
Wednesday, May 17, 2:00-3:00 pm ET
Sponsored by InsureKidsNow.gov

Learn how to strategically use both grasstops and grassroots strategies in legislative advocacy
Thursday, May 18, 1:00-2:00 pm ET
Sponsored by Phone2Action

The Hope Squad Program – Addressing Suicide Prevention and Untreated Mental Illness
Thursday, May 18, 3:00-4:00 pm ET
Sponsored by the American Indian and Alaska Native National Partnership for Action to End Health Disparities (NPA) Caucus

CONGRESS

The American Health Care Act

On Thursday, May 4, the House of Representatives passed, 217-213, the American Health Care Act (ACHCA, H.R. 1628), a step toward fulfilling the Republican promise to repeal and replace the Affordable Care Act (ACA). All Democrats and 20 Republicans opposed the legislation, giving it only one more vote than it needed to pass. (See vote tally.)

Key provisions. Among other things, the AHCA would (as of various effective dates):

- create per capita caps on federal payments to states for Medicaid and allow states to accept block grants as an alternative to these caps (more below*);
- eliminate the requirement that states provide Medicaid coverage to children ages 6 through 18 in families with incomes between 100 and 133 percent of the federal poverty level;
- phase out the Medicaid expansion for childless individuals with incomes greater than 133 (effectively 138) percent of the federal poverty level;
- allow states to impose work requirements on certain Medicaid beneficiaries (but not pregnant women through 60-days post-partum, children under 19, individuals who are the only parent/caretaker relative in a family with a child under age 6 or a child with disability, and some others);

- reduce and change the formula for providing premium tax credits (basing them primarily on age rather than income and location as under current law), and eliminate cost-sharing subsidies for people purchasing insurance on the individual market;
- increase the ratio of premiums for older individuals in relation to younger individuals from 3:1 (under current law) to 5:1;
- eliminate fines for individuals that do not have insurance coverage and for employers who do not offer insurance coverage, but allow higher premiums to be charged temporarily for individuals who do not have continuous coverage;
- allow states to get waivers to (1) alter the Essential Health Benefits that insurance policies must cover under current law, (2) in states with a high-risk pool or a similar program, allow insurers to charge higher premiums for people with pre-existing conditions who cannot demonstrate that they have had insurance coverage for all but (at most) 63 days in the past 12 months; and /or (3) increase the ratio of premiums that insurers can charge older people compared to younger people;
- eliminate the enhanced match for states to implement home and community-based programs for long-term services and supports ("Community First Choice" option);
- increase the annual tax-free contribution limit for Health Savings Accounts;
- decrease the spending threshold for medical expenses that can be deducted from income tax liability, and broaden the definition of medical expenses;
- prohibit Medicaid and other federal program payments to Planned Parenthood facilities.

***Medicaid caps and block grants**

Since the inception of the Medicaid program in 1965, the federal government has shared the cost of providing care to Medicaid beneficiaries with the states, at varying levels depending on the state's economic circumstances (the state's Federal Matching Assistance Percentage or FMAP). The federal contribution is based on the amount the state spends to provide Medicaid- covered items and services to Medicaid beneficiaries. There is no absolute dollar limit on federal payments. The AHCA would fundamentally change the Medicaid program, in a manner that would make it very difficult to change back in the future.

Per capita caps. Rather than providing an open-ended amount to match state expenditures, the AHCA would determine federal payments to states on a per capita cap basis, beginning in 2020 (unless the state chose a block grant, as described below). Each state's federal allotment would be calculated based on the number of each of five types of Medicaid beneficiaries in the state –

- **elderly** (age 65 or older);
- **blind and disabled** -- whose Medicaid eligibility is based on their being blind or disabled;
- **children under age 19** who are not eligible due to blindness or disability;
- **"expansion enrollees"** not in another category (i.e., childless adults who are eligible because their state took up the ACA's Medicaid expansion); and
- **"other nonelderly, nondisabled, non-expansion adults."**

Roughly speaking (although actually more complicated) the federal payment would be based on number of each type of enrollee multiplied by a certain dollar amount for that type of enrollee. That dollar amount would be based on the amount the state spent for that type of enrollee in FY 2016, trended forward to 2019 by the Medical Consumer Price Index (medical CPI). Beginning in 2020, each

state would have a "**target expenditure"** based on the 2019 per-enrollee amounts for each enrollment group multiplied by the number of enrollees in each group. In each subsequent year, per enrollee amounts would be based on the prior year amounts increased by an inflation adjuster -- medical CPI plus 1 percentage point for the elderly and blind/disabled groups, and medical CPI for children, expansion adults, and other adults. If a state exceeds its target for one year, then its target for the following year would be decreased by that excess amount.

Per capita caps would not apply to individuals. They would be used only to calculate the amount of the state's target expenditures. Once the state's allotment is calculated, the state can allocate its funds in whatever ways it chooses. Thus, a state may decide to provide an optional service to healthy children while reducing reimbursement for nursing homes, even though the per capita base and inflation adjustment would be greater for each "elderly" enrollee than it would for each enrollee in the "children" category.

The AHCA does not define "disabled" or what it means to be "eligible for medical assistance …on the basis of being blind or disabled." One would guess that a child initially enrolled in Medicaid because he or she was receiving Supplemental Security Income (SSI) would fall into the "blind and disabled" category. But would children who were initially enrolled in Medicaid based on family income and then became disabled be excluded from that category? (It would be in the state's interest to make sure children who *could* be eligible based on blindness or disability were counted in that category, since that would give the state a higher target expenditure level.) If the "disability" category is limited to children who receive SSI, then many children with special health care needs will be in the "children" category, even though their expenses may be higher than those of the "average" child. As a result, the state would be getting less than it might actually need to provide services to its child population.

The Congressional Budget Office (CBO) has predicted that the AHCA's per capita cap formula will result in a shortfall of funds for states over the long run, since the inflation adjustments in the bill (medical CPI plus one percentage point and medical CPI) will not keep up with the actual increase in Medicaid costs. In theory, states could make up for this shortfall by increasing state revenue. But CBO predicts (and common sense suggests) that states will likely make cuts in services, eligibility, and/or reimbursement instead of or in addition to raising taxes to pay for Medicaid. For more about per capita caps, see Five Myths about the Medicaid Cap (Georgetown Center for Children and Families blog, May 3, 2017).

Block grants. The AHCA would permit states to choose a "block grant," rather than a per capita cap, for children and non-expansion adults, or for non-expansion adults only. With a block grant, a state could set conditions of eligibility, except that they would be required to cover mandatory pregnant women and children and infants born to eligible pregnant woman for one year. Block grant payments could be used only for "block grant health care assistance," rather than "medical assistance" (current-law Medicaid items and services). States would be required to provide hospital care, surgical care and treatment, medical care and treatment, obstetrical and prenatal care and treatment, prescribed drugs, medicines, and prosthetic devices, other medical supplies and services, and health care for children under 18, but *not* Early, Periodic, Screening, Diagnosis and Treatment services. (For more details, see the Kaiser Family Foundation table for comparing proposals to replace the ACA.)

Medicaid Expansion

In 2020, the legislation would stop providing enhanced matching payments for the "expansion population." Until then, it would provide extra payments to states that did not expand Medicaid, so they are not disadvantaged when the 2016 baseline for per capita caps on federal Medicaid payments is calculated.

Medicaid enrollees and expenditures. The Congressional Budget Office (CBO) has not yet finished "scoring" the cost or effects of the AHCA as it was passed by the House. When CBO analyzed the March version of the bill, it estimated that over the next 10 years, about 14 million fewer people (17 percent fewer) would receive Medicaid benefits under the AHCA as compared to current law. Primarily as a result of these lower enrollment numbers, Medicaid direct spending by the federal government would decrease by about $880 billion over the 2017-2026 period. By 2026, Medicaid spending would be about 25 percent less than what CBO projects it would be under current law. Most of the enrollment and expenditure changes would begin in 2020, when the AHCA would terminate the enhanced federal matching rate for new "expansion" enrollees and would place a per capita cap on federal payments to states.

Insurance requirements; consumer protections

- **Age 26 requirement.** The AHCA would retain the ACA's provision allowing young adults to stay on their parents' insurance policies until age 26.

- **Guaranteed issue/medical underwriting.** In theory, the bill continues the "guaranteed issue" policy in current law, meaning that no one can be denied insurance due to a pre-existing condition. Current law also prohibits insurers from "medical underwriting," meaning they cannot charge more to individuals who have a pre-existing condition. Rather, they must use "community rating" (the same rate for all individuals of the same age). In practice, however, the AHCA could undermine these protections if states choose to get waivers from the "community rating" requirement for people who cannot demonstrate that they have had continuous coverage. Insurers in those states could charge prohibitively high premiums to such individuals. Moreover, in states with waivers of Essential Health Benefits, insurers could sell policies that do not cover the benefits needed by those with common pre-existing conditions. Some policy analysts predict that the AHCA ultimately would eliminate protections for *all* people with pre-existing conditions, not just those who have not maintained continuous coverage. See New amendment to GOP health bill effectively allows full elimination of community rating, exposing sick to higher premiums (Brookings Institution, April 27, 2017); Amendment to House ACA Repeal Bill Guts Protections for People with Pre-Existing Conditions (Center on Budget and Policy Priorities, April 27, 2017).

- **Annual and lifetime limits/out-of-pocket maximums.** Under current law, insurers are prohibited from imposing annual or lifetime coverage limits and are required to limit out-of-pocket expenses. These protections apply only with respect to the ACA's ten "Essential Health Benefits" (EHBs). Since the AHCA would allow the Secretary of Health and Human Services (HHS) to let states waive the EHB requirement, these consumer protections would not be effective in those states. (Some analysts think that these waivers eventually could lead to

elimination of lifetime and annual caps for everybody, including people with large-employer-based coverage.)

- **Gender discrimination.** The AHCA states that it shall not be construed to permit basing premiums on the gender of the insured, but other provisions in the bill could undermine this protection. For example, in states with waivers of "community rating" provisions, insurers could charge higher premiums to women with the "pre-existing condition" of pregnancy. If a state had a waiver of the ACA's Essential Health Benefits, it could omit coverage for maternity care, as many pre-ACA plans did.

Next steps. The House-passed the bill must surmount many hurdles before it could become law. First, it must go through the Senate, where it will certainly be amended, perhaps significantly. It will also face procedural obstacles in the Senate. It is considered a "reconciliation bill," which means it can pass the Senate with a simple majority of 51 votes. (Most Senate bills must get 60 votes to advance.) On the other hand, reconciliation bills may include only provisions that have an impact on the federal budget that is not "merely incidental." If the Senate parliamentarian determines that a provision is not appropriate for a reconciliation bill, then it must be removed from the bill unless 60 Senators vote to waive the rule. Some provisions that might be vulnerable to Byrd Rule challenge are those allowing states to waive Essential Health Benefits or protections for people with pre-existing conditions.

It is unclear how long it will take to get a bill through the Senate, although there are various procedural and political pressures to get health care legislation done as soon as possible. Senate leaders will likely bring the bill to a vote if and when they think they can get the 51 votes needed to pass it. Since all Democratic Senators are expected to oppose the bill, and there are only 52 Republican Senators, the bill will fail if three or more Republican Senators oppose it. (If two oppose it, Vice-President Pence can break the tie.) If a version of the AHCA should pass the Senate, then a House-Senate conference committee would be convened to try to craft a compromise between the two bills. The House and Senate would each have to approve the compromise legislation before the bill could be sent to the president.

More Information on the AHCA and related materials

AHCA summaries and analyses:

- Summary of the American Health Care Act as passed by the House May 4, 2015. (Kaiser Family Foundation)
- A tool from the Kaiser Family Foundation provides a side-by-side comparison of current law (ACA) and the AHCA (and other bills).
- Committee Report on the American Health Care Act, H.R. 1628 (Committee on the Budget, 3/20/17; 820 pages; explanation of provisions on Report pp. 370-415)

Resources:

- Digging into the ACHA Provisions on Medicaid Expansion and Capped Funding (State Health Reform Assistance Network, 3/22/17)
- Essential Facts About Health Reform Alternatives: Medicaid Per Capita Caps (The Commonwealth Fund).
- Evaluating Medicaid Block Grant & Per Capita Cap Proposals (National Health Law Program)

- Data Points to Consider When Assessing Proposals to Cap Federal Medicaid Funding: A Toolkit for States (Robert Wood Johnson Foundation State Health Reform Assistance Network)
- State Snapshots of Children's Health Coverage (Georgetown Center for Children and Families and the American Academy of Pediatrics)
- 2017 State Medicaid Fact Sheets (Children's Hospital Association and the American Academy of Pediatrics; data about the importance of the Medicaid program to children, pediatricians and children's hospitals)
- Multiple fact sheets on kids and Medicaid, including EPSDT (Georgetown Center for Children and Families)

Articles:

- Yes, It Is Definitely Possible For The House And Senate To Agree On Health Care (Huffington Post, 5/5/17)
- Senate GOP rejects House Obamacare bill (Politico, 5/4/17)
- Why the Medicaid Cap Can't be Fixed (Georgetown Center for Children and Families blog, 3/22/17)
- Nation's Progress on Children's Health Coverage Imperiled (Georgetown Center for Children and Families blog, 5/5/17)
- Little-Noticed Medicaid Changes in House Plan Would Worsen Coverage for Children, Seniors, and People with Disabilities and Increase Uncompensated Care (Center on Budget and Policy Priorities , 3/15/17; miscellaneous Medicaid provisions)
- Commentary: The Senate Health Bill Must Meet At Least Four Requirements to Pass the "Kimmel Test" (Center on Budget and Policy Priorities, 5/8/17)

Budget/Appropriations

Last week, as expected, the House and Senate both passed a bill (H.R. 244) to fund government agencies and programs through the end of FY 2017, which ends on September 30. The President signed the bill on May 5. As reported last week, the law actually increases funding for some of the programs that the administration had proposed cutting. For example, it increases funding for the National Institutes of Health by about $2 billion. The law also provides increases in funding for HRSA; the Maternal and Child Health Block Grant, including an increase in funding for SPRANS (Special Projects of Regional and National Significance); the Healthy State Initiative; efforts to combat opioid abuse; Alzheimer's research; the Precision Medicine Initiative; the BRAIN Initiative (mapping the brain); and the National Center on Birth Defects and Developmental Disabilities Center (NCBDDD) at the Centers for Disease Control and Prevention (CDC). The law provides level funding for the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs. In addition, it also includes a permanent extension of health insurance for coal miners. (Note: Funding for Family-to-Family Health Information Centers is not made through appropriations legislation like this spending package; rather it is funded directly once the program is reauthorized.) The law does not "defund" Planned Parenthood.

Notably, the law does *not* include funding for cost-sharing reduction payments to insurers under the ACA, but the Trump administration has said that it will keep making these payments "for now." (Cost-sharing reductions reduce out-of-pocket expenses for lower-income consumers who purchase individual insurance policies through the ACA Exchanges.)

Here are the Republican summary and Democratic summary of the spending package.

OTHER NEWS, INFORMATION, RESOURCES

WORTH REPEATING: **Updated Publication: Breaking the Link between Special Health Care Needs and Financial Hardship**
This resource from the Catalyst Center has been updated to reflect developments in health insurance coverage for children since the publication's initial publication in 2009. It includes compelling family stories about the challenges faced by families in financing care for children and youth with special health care needs.

YOUR INPUT SOUGHT

Youth Voice Agency-Level Evaluation Study

Do you work for or with an organization that wants to include youth and young adult voice in agency decision-making? Then you're invited to take part in a study that is testing a new assessment survey of youth and young adult voice at the agency level. The survey will measure organizational support for the meaningful participation of youth in agency-level advising and decision-making. In partnership with researchers at Portland State University, this study will determine whether the survey is accurate for agencies to use. If you're interested in either of these opportunities, contact Kristin Thorp at kthorp@youthmovenational.org for more info.

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We would love to hear any suggestions you might have about how to make the Update more useful to you. Does it provide the right amount of information? What parts are helpful and not so helpful? Please let us know!

And, as always, please feel free to contact us with any questions. Comments and questions can be directed to jguerney@familyvoices.org.

Yours truly,
The Family Voices Policy Team

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