FAMILY VOICES®

Washington DC Update

November 16, 2016

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.

And don't forget to check out the Family Voices/NCFPP ACA webpage and the latest Family Voices ACA blog post, "How the ACA is Helping Children with Special Needs and Their Families."

Greetings from Washington! Not surprisingly, the city is abuzz after the presidential election, and those on both sides of the aisle are preparing for major changes to come. This issue of the Washington Update will focus on the possible impact of the election on the Affordable Care Act, Medicaid, and other health care policies of relevance to children and youth with special health care needs and their families.

Please note: The Washington Update will not be issued Thanksgiving week but will resume on Wednesday, November 30.

UPCOMING WEBINARS AND CALLS

PLEASE NOTE: Webinars are listed in chronological order, by the date of the first webinar in the series, where applicable.

Defending Health Care in 2017
Wednesday, November 16, 2:00-3:00 pm ET
Sponsored by Families USA

Caregiving Youth: a Community-Based Framework for Identifying and Supporting a Hidden Population
Wednesday, November 16, 3:00-4:00 pm ET
Sponsored by Family Voices of California

Every Student Succeeds Act (ESSA) – How It Affects Students with Intellectual/Developmental Disabilities
Thursday, November 17, 1:00-2:00 ET
Sponsored by the USC University Center for Excellence in Developmental Disabilities and Children's Hospital Los Angeles

Preventing and Resolving Data-Matching Issues
Thursday, November 17, 2:00-3:00 pm ET
Sponsored by the Center for Budget and Policy Priorities' "Health Care Reform: Beyond the Basics" Project

Stakeholder Listening Sessions on Disability, Independent Living, and Rehabilitation Research
The National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR) will hold a number of listening sessions across the country to help inform future funding priorities and strategic direction. The meetings can be attended in person, or heard via telephone. Comments can be provided via email. Registration is required to attend in person or listen by phone. Registration details can be found here. NIDILRR will accept written comments via email at NIDILRRfuture@acl.hhs.gov through December 12, 2016. The remaining meetings will take place in:

Boston, Nov. 18, 10:00-1:00 pm ET
Dallas, Dec. 5, 10:00-1:00 pm CT

Patient and Family Centered Care: What You Need to Know
Friday, December 2, 1:00-2:00 pm ET
Sponsored by the Johnson Center for Child Health and Development

CONGRESS

Congress reconvened this week and is expected to be in session until mid-December (with a week off for Thanksgiving). Its first order of business will be to fund the departments and agencies of government beyond December 9, when the current funding law (a.k.a., the "continuing resolution" or "CR") expires. At this point it is unclear whether Congress will pass another CR to fund programs until the end of February, so the new president and Congress can make final spending decisions, or will approve legislation during the remainder of this session to fund the government through the end of the fiscal year on September 30.

Aside from spending bills, the "21st Century Cures Act" has been identified by Senate Majority Leader Mitch McConnell (R-KY) as a high priority for the coming month. That bill would promote and increase funding for medical research, and reform regulatory policies at the Food and Drug Administration (FDA). It has been the top priority of the outgoing chairman of the relevant House committee, Rep. Fred Upton (R-MI), who is expected to introduce an amended version during the lame duck session. Given the election outcome, however, it is unclear whether Senate Democrats will be comfortable moving forward with the bill's easing of FDA regulatory processes.

Republican leaders also promised Senate Democrats that a pending water resources bill would include funding to address the problem of lead-contaminated water in Flint, Michigan.

IMPACT OF THE ELECTION ON HEALTH CARE POLICY

The health care world is trying to figure out what exactly what can and will happen during the next two years, when the presidency and both houses of Congress will all be under the control of leaders who have promised to repeal and replace Obamacare (the Affordable Care Act, or ACA) and make

fundamental changes to the Medicaid program. Discussed below are the futures of the ACA, Medicaid, the Children's Health Insurance Program (CHIP), domestic discretionary spending, and prescription drug policies.

THE FUTURE OF THE ACA

The first question on people's minds is the future of the Affordable Care Act (ACA).

With respect to ACA repeal, there are several legal questions at issue:

- **What elements of the ACA can be repealed with 60 votes in the Senate?**
- **What elements of the ACA can be repealed with 51 votes in the Senate?**
- **What elements of the ACA can effectively be repealed by the president alone?**

As explained in more detail below –

- The president-elect has said he would like to retain the ACA's ban on pre-existing condition exclusions and its provision allowing children to remain on their parents' health plan until age 26.
- Without legislation, the administration can take action, or refrain from action, to significantly disrupt the implementation of the ACA.
- It will not be easy to get Congress to pass legislation to repeal the above and other consumer protections in the ACA because that would require a 60-vote majority in the Senate and because most members of Congress will not want to take insurance away from their constituents.
- It will be easier for Congress to pass legislation to repeal the law's premium tax credits, cost-sharing reductions, and the individual and employer mandates since that could be done with only 51 votes in the Senate.
- It will be easier for Congress to pass legislation to make fundamental changes to the Medicaid program since that could be done with only 51 votes in the Senate.
- Congress might be able to use appropriations legislation to interfere significantly with ACA implementation.

See ***What Trump Might Really Do With Health Care*.**

ACA Repeal by Law

There are both political and procedural reasons that it will not be easy to pass a law repealing the whole ACA, at least without a viable replacement.

Politically speaking, it will be difficult for most members of Congress and the president to support legislation that would cause constituents to lose their insurance or important consumer protections, such as the ban on pre-existing condition exclusions. In fact, the president-elect recently indicated that he would like to retain the ACA's ban on pre-existing condition exclusions, as well as its provision allowing children to stay on their parents' insurance plans until age 26.

Procedurally speaking, there are Senate rules that would make it difficult to repeal certain elements of the ACA. In the House, most legislation can be passed with a simple majority. In the Senate, however, most legislation needs 60 votes to proceed. An exception is so-called "reconciliation" legislation, which can proceed with only 51 votes. In general terms, all of the provisions in reconciliation bills must have an impact on the federal budget that is more than "merely incidental" to their purpose. But, there are no clear rules about whether the budgetary impact is "merely incidental." The Senate parliamentarian must make these determinations, often without precedents to follow. For this reason, the following statements about what can and cannot be done in a reconciliation bill are conditional.

The consumer protection provisions of the ACA - including the ban on pre-existing condition exclusions, the ban on annual and lifetime dollar limits on coverage, and the "age 26" provision - were not primarily intended to impact the federal budget, so legislation to repeal those provisions *mostly likely* would need 60 votes to proceed in the Senate. In the next Congress, Republicans will have majority of only 51 or 52 out of 100 Senators. (A Louisiana Senator will be determined in a Dec. 10 run-off election.) Therefore, it will be difficult to get the 60 votes (probably) needed to repeal the consumer protection provisions of the ACA.

However, other important elements of the ACA could be repealed with a reconciliation bill, which would require only a simple Senate majority. In fact, in 2015 Congress passed reconciliation legislation to, among other things, repeal the ACA's premium tax credits, cost-sharing reductions, and Medicaid expansion, and to reduce to zero the penalties for failure to comply with the individual or employer mandate. This legislation, which would have become effective two years after enactment, was vetoed by the President, and the House failed to override the veto. Under the new administration and Congress, such legislation could likely become law, although, as before, the effective date could be delayed to give Congress and the administration time to develop a replacement.

Thus, it is possible that the individual mandate will be repealed, while the ban pre-existing condition exclusions and other consumer protections are retained. There is a problem with this scenario, however. It is not feasible to require insurers to cover people with pre-existing conditions without simultaneously requiring all individuals to maintain insurance coverage. Without the latter requirement, healthy people can wait until they get sick to purchase insurance, resulting in a risk pool composed disproportionately of individuals who are likely to draw down insurance payments (i.e., people with health problems), thus leading to higher and higher insurance premiums – a so-called "death spiral" that ultimately makes insurance completely unaffordable.

It should be noted that Congress might also be able to effectively nullify significant parts of the ACA by including a provision in an appropriations bill to prohibit the use of any appropriated funds to implement the law. Appropriations bills generally require 60 votes in the Senate, although there may be scenarios that essential force the Senate to accept the legislation.

Undermining the ACA through Executive Action or Inaction

In writing the ACA, Congress left a lot of policy decisions up to the executive branch (e.g., the details of the law's ten "essential health benefits"), and numerous regulations have been issued to implement the law. The new administration could change these regulatory policies, but it takes a fair amount of time to amend regulations due to applicable legal requirements, such as providing a public comment period.

On the other hand, there are other actions that the president could take, or refrain from taking, almost immediately. Some of these could seriously undermine the operation of the ACA. The simplest of these actions would be to drop the government's appeal of the federal district court decision in House v. Burwell, which found the administration's funding of cost-sharing reductions without an explicit congressional appropriation to be unconstitutional. The cost-sharing reductions at issue reduce copayments and deductibles for more than half of all consumers purchasing health care on the exchanges. Insurers do not impose these charges on the eligible consumers, and the government reimburses the insurers to make up the difference. If the Trump administration drops the appeal, payments to insurers will cease but insurers will still be obliged to reduce costs to consumers. Consequently, insurers may drop out of the exchanges. If this were to happen, consumers would have to find other coverage, as explained in a blog post from the Georgetown Center for Health Insurance Reform.

The administration could also undermine the ACA by not encouraging people to purchase health plans, refraining to enforce the individual or employer mandate, or failing to approve state plan amendments to expand Medicaid.

Replacement of the ACA

While some Members of Congress might be happy to repeal the ACA without a replacement, the president-elect has said he will replace the ACA at the same time it is repealed, providing "great healthcare for much less money." Although Mr. Trump has issued several specific proposals, he has not explained how these will ensure that everyone will have the health care coverage they need. In campaign and post-election documents, he has proposed:

- allowing insurance to be sold across state lines
- facilitating the creation of health savings accounts (HSAs)
- allowing individuals to deduct the cost of health insurance premiums on their taxes
- requiring price transparency from health care providers
- allowing the importation of drugs from overseas
- speeding up the drug approval process
- establishing high-risk pools for individuals with significant medical expenses who have not maintained continuous insurance coverage
- changing Medicaid into a block grant program (i.e., giving a fixed sum to each state rather than matching actual state expenditures)

All of these proposals would probably require acts of Congress, but even Republicans are already in disagreement about how to proceed.

The Future of Medicaid

As an entitlement program, Medicaid can be changed through the reconciliation process (see above), meaning that changes to the program need only 51 votes to pass the Senate, rather than the 60 votes needed for other legislation. As a consequence, it would be relatively easy for the new Congress and administration to significantly alter the program, as discussed below.

The president-elect has proposed turning Medicaid into a "block grant" program rather than an individual entitlement program, meaning states would get a fixed sum of federal funds each year

rather than a federal match for their actual Medicaid expenditures. Federal payments to states would increase over time at a slower rate than would be expected if the current federal matching formula were in place, meaning states would receive less and less federal funding over time. In exchange, states would get more flexibility in running their Medicaid programs. Depending on how the law is amended, states might be able to restrict eligibility and/or reduce benefits in ways they are not permitted to do now. Governors generally like the flexibility a block grant would provide, but will fight to ensure that their states do not lose too much money in the process.

House Speaker Paul Ryan (R-WI), in his "Better Way" proposal, has proposed giving states the option of a Medicaid block grant or per-capita-cap payment system. Under the latter model, states would receive a certain amount of federal funding for each Medicaid enrollee, with different payment rates for different types of enrollees. Ryan has proposed the following enrollee categories: aged, blind and disabled, child, and adult. Senate Finance Committee chairman Orrin Hatch (R-UT), among others, have also proposed funding Medicaid through per capita caps. (The Finance Committee has jurisdiction over the Medicaid program.)

Block-granting Medicaid or turning it into a per-capita-cap program would be designed so that the federal government provides less and less money to states over time, compared to the matching payments that would be made under current law. As a result, states would have difficulty responding to changing circumstances, such as disease outbreaks, economic downturns, or significant increases in health care costs. As they have in the past, advocates will fight hard against such fundamental Medicaid changes. See Changes coming for Medicaid after Trump's election. Will patients lose coverage?.

The Future of CHIP

The president-elect's health care proposal does not mention the Children's Health Insurance Program (CHIP), but funding for the program must to be extended by the end of this federal fiscal year. CHIP has enjoyed bipartisan support in the past, and child health advocates are already mobilized to fight for its extension. In December, the Medicaid and CHIP Payment and Access Commission (MACPAC), a congressional advisory commission, will be making its recommendations on how long to extend CHIP and whether to maintain CHIP-related provisions that were enacted in the ACA. Children's health groups, including Family Voices, are developing comments to MACPAC. CHIP legislation is likely to serve as the legislative vehicle on which various "health extenders," including reauthorization and funding of Family-to-Family Health Information Centers (F2Fs), are attached.

Discretionary Spending

Non-Defense Discretionary (NDD) spending refers to the appropriations for domestic programs (as opposed to defense and homeland security-related programs), including medical research, most health-related grant programs, education, disability programs, housing, and transportation, among others. Advocates for these programs are concerned that the president-elect and Republican Congress will seek to eliminate the budget caps and automatic spending cuts (sequester) that apply to both defense and NDD programs under current law, and make up the difference through deeper cuts in NDD funding. The president-elect has also proposed a plan that cuts NDD spending by one-percent a year, each year, for the next ten years.

Prescription Drug Costs

With the controversy surrounding the dramatic cost increase for the EpiPen, Congress has sharpened its focus on the cost of prescription drugs. The president-elect has also focused on this issue. His transition website's health reform page includes the item "Reform the Food and Drug Administration, to put greater focus on the need of patients for new and innovative medical products." His campaign website includes the following health reform proposal: "Remove barriers to entry into free markets for drug providers that offer safe, reliable and cheaper products. Congress will need the courage to step away from the special interests and do what is right for America. Though the pharmaceutical industry is in the private sector, drug companies provide a public service. Allowing consumers access to imported, safe and dependable drugs from overseas will bring more options to consumers."

No legislative action is expected on drug prices during the lame-duck session of Congress, but it is likely to be a topic considered by the next Congress and new administration.

HHS SECRETARY

There is much speculation about Trump cabinet appointments. Those mentioned as possible Secretary of the Department of Health and Human Services include:

- **Dr. Ben Carson,** former neurosurgeon and 2016 presidential candidate
- **Mike Huckabee,** former Arkansas governor and 2016 presidential candidate
- **Bobby Jindal**, former Louisiana governor who served as secretary of the Louisiana Department of Health and Hospitals
- **Rick Scott,** Florida governor and former chief executive of a large hospital chain
- **Newt Gingrich**, former Speaker of the House during the Clinton administration
- **Rick Bagger**, Trump transition team advisor and former pharmaceutical company executive

See A quick guide to the allies Trump might pick to lead HHS

OPPORTUNITIES FOR ADVOCATES

National health, disability, and children's advocacy groups, including Family Voices, are making plans to educate the new administration and Congress about the needs of their constituencies and to defend the ACA, Medicaid, and other important programs that new leaders may seek to weaken in the next few years. Family Voices will be reaching out to newly appointed White House and HHS officials to educate them about the needs of children/youth with special health care needs and/or disabilities. The Family Voices-endorsed Blueprint for Children, developed by the American Academy of Pediatrics, will go to the presidential transition team and congressional leaders. Among other recommendations, the Blueprint recommends that funding be extended for Family-to-Family Health Information Centers.

State-based advocates for children with special health care needs and their families should also seek to educate both their newly elected and incumbent U.S. Senators and Representatives, along with their state legislators, governors and local elected officials.

MEDICAID/CHIP NEWS, INFORMATION, RESOURCES

CMS FAQs on Medicaid and CHIP Managed Care Final Rule

On November 10, the Centers for Medicare & Medicaid Services (CMS) released the first set of frequently asked questions (FAQs) for the Medicaid and CHIP Managed Care Final Rule, The Final Rule was published in the Federal Register on May 6, 2016, with an effective date of July 5, 2016. This first set of FAQs addresses common questions related to the Final Rule. States, managed care plans, and other stakeholders are encouraged to submit questions to ManagedCareRule@cms.hhs.gov to inform future guidance and FAQs.

Medicaid Managed Care: Challenges and Opportunities for Pediatric Medical Home Implementation and CYSHCN

The National Center for Medical Home Implementation, in collaboration with the National Academy for State Health Policy, created a fact sheet that discusses challenges and opportunities to provision of care for children and youth with special health care needs (CYSHCN) enrolled in Medicaid managed care. The fact sheet identifies states that leverage Medicaid managed care to advance the pediatric medical home model through payment incentives, technical assistance, and care coordination services.

ACA NEWS, INFORMATION, RESOURCES

Fact Sheet on Effect of Election

The Georgetown Center for Health Insurance Reforms (CHIR) has published a fact sheet about the effect of the election on consumers purchasing coverage through the ACA Marketplace . Plans purchased for 2017 will remain in effect even if the ACA is repealed before the end of the year, although decisions by the new administration or the courts may cause enrollees to lose cost-sharing reductions during the year.

The election will have no impact on the open enrollment period ("OE4") for the purchase pf health plans on the individual market, which runs through January 31, 2017. People who want their coverage to begin on January 1st must enroll in a plan by December 15. (See key dates and deadlines.)

==========

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

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number U40MC00149. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.