American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN®

March 2019

Washington Report

Academic and Subspecialty Advocacy

Executive Summary

The AAP is working to reauthorize loan repayment for pediatric subspecialists in the Title VII Health Professions Programs reauthorization. The Pediatric Subspecialty Loan Repayment Program (PSLRP) would provide pediatric subspecialists $35,000 in loan repayment annually for up to three years in exchange for practicing in an underserved area.

Funding for public health research into firearm-related injury and death is a top AAP priority in the new Congress. The Academy led a sign-on letter of over 160 medical and public health organizations urging Congress to fund this work to identify evidence-based policy interventions to reduce gun violence.

The Children's Hospital Graduate Medical Education (CHGME) program was reauthorized for five years in September. The annual authorization level for CHGME was increased from $300 million to $325 million, ensuring this critical program that funds training for more than half of pediatric residents and fellows can help meet future pediatric workforce needs.

Congress passed the SUPPORT for Patients and Communities Act (H.R. 6) in October, a comprehensive response to the opioid crisis. The AAP is working to ensure the bill's child health provisions are fully funded and appropriately implemented.

The National Institutes of Health (NIH) received a $2 billion funding increase in Fiscal Year (FY) 2019, the fourth consecutive multi-billion-dollar funding increase for the biomedical research funder.

The newly launched Trans-NIH Pediatric Research Consortium (N-PeRC) is working to better coordinate pediatric research across the NIH. N-PeRC is comprised of senior staff from all 27 Institutes and Centers at NIH.

The Department of Health and Human Services (HHS) has approved Medicaid waiver requests from multiple states that include work requirements and other provisions that would limit access to coverage. The AAP is engaged in the regulatory process and supporting ongoing litigation around these waivers to ensure that children and families maintain access to Medicaid coverage.

Federal agencies have advanced several regulations that threaten access to health coverage in the individual market. These regulations are likely to make comprehensive health benefits more difficult to obtain and drive up the cost of health care coverage for individuals with preexisting conditions.

The Centers for Medicare and Medicaid Services (CMS) announced a Final Rule that outlines significant changes to payment policies under the Medicare Physician Fee Schedule for 2019. CMS finalized several items designed to reduce the regulatory burden on physicians, effective January 1, 2019, but other changes to documentation, coding, and payment will be delayed until calendar year 2021.

Following the death of two migrant children in Customs and Border Protection (CBP) custody, the AAP has been leading efforts to ensure migrant children have access to the care they need while in federal custody. The Academy is advocating that CBP and the Department of Homeland Security (DHS) improve pediatric medical screening and referral for appropriate treatment for children.

The AAP led the charge in opposing the Department of Homeland Security's (DHS) policy of separating parents and children at the border. The Academy has provided expert congressional testimony about the harms of separation on child health and development and continues to speak out as news that potentially thousands more children were separated than previously thought.

In a proposal released in October, DHS announced it would change the definition of a "public charge" to make it harder for immigrants to enter the United States and advance through the immigration process. The proposed rule will likely discourage immigrant families from seeking health care for their children through Medicaid and nutrition through the Supplemental Nutrition Assistance Program (SNAP), and may also prevent some non-citizen medical trainees from receiving permanent residency.

Letter from the President

Colleagues:

Since its founding in 1930, advocacy for children has been a core focus of the American Academy of Pediatrics. There is perhaps no better reminder of the critical voice of pediatricians, pediatric medical subspecialists, and pediatric surgical specialists in advocating for every child than the family separation crisis at the border. The pediatric community led the charge in opposing this abhorrent policy, and the public outcry and ongoing advocacy brought it to a swift end.

Advocacy requires sustained effort, and it's important to recognize our successes. We've faced many challenges over the last two years, but we've enjoyed numerous child health victories as well. The recently released *2018 Update: Achievements in Child Health Advocacy* takes stock of all the Academy's recent accomplishments that were made possible by AAP's members working in concert to speak up for children. From the 10-year extension of the Children's Health Insurance Program (CHIP) to the inclusion of children in human subjects research, the document covers the impressive breadth of the AAP's advocacy work, and I encourage you to take a look.

I'm delighted to share with you our latest **AAP Academic and Subspecialty Advocacy Washington Report**. This report details the important advocacy work that the Academy is engaging in and highlights issues of particular importance to our medical and surgical subspecialty members who include many academicians and researchers. It includes updates on AAP advocacy efforts to protect comprehensive health care coverage through Medicaid and the private insurance market, promote pediatric subspecialty workforce issues, protect immigrant children, increase funding for pediatric research, and improve drugs and medical devices for children, among many other issues.

If you have questions or comments about the AAP's advocacy work for subspecialists, please be in touch. And thank you for all you are doing for children and families. The vitality of the Academy depends on your hard work and engagement.

Sincerely,

Kyle Yasuda, MD, FAAP
President

AAP Advocacy for Academic and Subspecialty Pediatrics

The American Academy of Pediatrics is actively engaged in federal advocacy for the needs of academic and subspecialist pediatricians and the children for whom they provide care. Through the AAP Washington Office and dedicated staff for academic and subspecialty issues, the Academy works to promote medical research for children, funding for medical education, child access to needed providers through appropriate payment, and a pediatric workforce able to meet the needs of children across the country.

The AAP has helped lead coalition efforts to pursue this agenda and partners with many pediatric subspecialty organizations. The Academy also works closely with the Pediatric Policy Council, which represents academic pediatric organizations: the Academic Pediatric Association, the American Pediatric Society, the Association of Medical School Pediatric Department Chairs, and the Society for Pediatric Research.

If you have questions, please contact the AAP Washington Office: James Baumberger (jbaumberger@aap.org) or Matt Mariani (mmariani@aap.org).

AAP Subspecialty Advocacy Toolkit

The AAP engages in advocacy across a wide spectrum of child health issues, including a host of issues that impact the care pediatric subspecialists provide, at all levels of government. To help AAP subspecialty members connect with the Academy's many advocacy resources, the **AAP Subspecialty Advocacy Toolkit** is now available.

View the toolkit to learn more about how to engage in federal and state advocacy issues, as well as in advocacy communications. This includes information on opportunities to interact with AAP Advocacy Staff, planning for advocacy specific to your subspecialty, and ways to make your voice heard as a pediatric medical subspecialist or pediatric surgical specialist.

If you have further questions or are looking to connect directly with AAP Advocacy Staff, please reach out to your AAP Subspecialty Section Manager. We hope you find this to be a helpful resource, and we look forward to working with you further to advance child health.

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Access to Care

Medicaid and the Children's Health Insurance Program (CHIP) together provide coverage for approximately 46 million children and are a crucial source of coverage for children with special health care needs and other children cared for by academic and subspecialty pediatricians. The AAP is actively working to preserve and strengthen the Medicaid program.

Medicaid Waivers

The Academy continues to work with AAP chapters to advocate against Section 1115 waivers that would create unnecessary barriers to care in the Medicaid program, often in the form of work requirements for parents and other adults. In late December, CMS approved work requirement waivers for Maine and Michigan, bringing the total number of states with approved work requirement waivers to 7 (IN, KY, AR, NH, WI, ME, MI). CMS is considering work requirement waiver submissions in 11 other states (AL, AZ, KS, MS, NM, OH, OK, SD, TN, UT, VA) while 1 state (SC) has a waiver pending at the state level.

Notably, in June 2018 a federal judge struck down approval of Kentucky's work requirement waiver saying, in part, CMS failed to consider whether the work requirement would result in gaining coverage, a clear objective of the Medicaid program. This prevented the work requirement from being implemented in the state; however, Kentucky subsequently resubmitted a revised waiver application for CMS approval, which was granted in November. Both the AAP and Kentucky AAP Chapter filed comments opposing this subsequent waiver submission. The National Health Law Program (NHeLP) is continuing to litigate the Kentucky work requirement, and the AAP signed-on to an amicus brief with other medical societies on behalf of the plaintiffs in the amended lawsuit.

There has also been a lawsuit filed over the Arkansas work requirement waiver, which remains the only implemented work requirement waiver in the country. To date, the Arkansas waiver has resulted in almost 17,000 state residents losing coverage. Reports continue to demonstrate very little enrollee knowledge of the work requirement in the state, and limited opportunities to report compliance. The lawsuit in the Arkansas case is before the same judge in the US District Court for the District of Columbia who ruled in the Kentucky case.

On March 6, the Academy led a group of more than 50 national organizations in sending a letter to Secretary Azar expressing deep concern about the possibility of CMS approving pending section 1115 waiver requests to impose work-reporting requirements on very low-income parents and caregivers covered by Medicaid. The letter states that approval of these requests would be extremely harmful to very vulnerable children and their families and would directly contradict the objectives of the Medicaid program.

The Academy continues its work with AAP chapters on this critical issue. To date, the AAP has helped AAP chapters in 20 states submit 38 comment letters at the state and federal levels on Medicaid waiver proposals that include work requirements and other harmful provisions.

Children's Health Insurance Program

After months of uncertainty for the nearly 9 million children who rely on the Children's Health Insurance Program (CHIP) and their families, Congress took long-overdue action last winter, ultimately extending funding for the program for ten years. The bill requires states to report on the pediatric core set of quality measures for all children in Medicaid and CHIP beginning in 2024, which had previously been optional.

Regulations that Threaten Access to Coverage and Care

In 2018, the federal government finalized rules to advance the use of short term, limited-duration (STLD) plans and association health plans (AHPs) as alternatives to ACA-compliant coverage. The STLD plan final rule would allow such plans to be offered for up to 12 months and renewed for a period of up to 3 years. The AHP final rule would allow those "in the same trade, industry, line of business or profession" or those businesses that have a principal location within a specific region to band together for the expressed purpose of acting as an employer to offer AHP coverage. Both types of plans would be cheaper and offer less comprehensive coverage and would exclude several of the ACA's critical consumer protections, such as coverage of essential health benefits (EHB) and preexisting conditions. The AAP submitted comments opposing both the STLD and AHP proposed rules.

In October, the administration released new guidance on Section 1332 waivers that could expand the use of STLD plans and AHPs. Section 1332 waivers were created by the ACA and would allow a state to experiment with different coverage schemes, as long as coverage under the waiver was as comprehensive and affordable, did not result in individuals losing coverage, and did not increase the federal deficit. Guidance issued in 2015 under the Obama administration severely limited the use of Section 1332 waivers; to date they have mostly been used to create state reinsurance programs. The new October guidance rescinds and replaces this 2015 guidance.

The new Section 1332 guidance weakens the four statutory guardrails to promote STLD and AHP coverage. A subsequent November CMS fact sheet provides states with model

concepts they might devise under a Section 1332 waiver, which include models that might restructure the ACA's advanced premium tax credits to direct such funds toward STLD or AHP coverage. The AAP drafted and submitted comments with other children's health groups highlighting the potential harms of the revised guidance.

States still have authority to regulate STLD plans and AHP plans. The Academy has prepared an Advocacy Action Guide to assist AAP chapters in their efforts to promote state regulation of these plans and to warn chapters of the potential harms caused by new Section 1332 waivers. The Academy has also worked to assist AAP chapters with new flexibility offered states via final rule in 2018 to make changes to Essential Health Benefits (EHB). While no state used this new flexibility to successfully reduce benefits in 2018, states may revisit the opportunity in 2019. Academy staff will continue to work with AAP chapters on these critical issues.

On March 11, CMS released a Request for Information (RFI) soliciting comments on how to eliminate barriers to and enhance health insurance issuers' ability to sell individual health insurance coverage across state lines, primarily pursuant to Health Care Choice Compacts. This RFI was written in connection with Executive Order 13813, "Promoting Healthcare Choice and Competition Across the United States."

Medical Foods Coverage

The AAP successfully advocated for a provision in the National Defense Authorization Act (NDAA) that would correct the current ambiguous TRICARE coverage policy for nutrition therapy that often results in delayed or denied care for the treatment of children and adults afflicted by digestive and inherited metabolic disorders. TRICARE had routinely been denying coverage of these foods, and families reported being subject to arduous paperwork to get the foods that they needed. As a result of this advocacy, the final NDAA legislation contains language requiring TRICARE to cover medically necessary foods. In November, AAP and the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition submitted comments to the Department of Defense on the implementation of medical foods coverage.

In the 115th Congress, Senators Chuck Grassley (R-Iowa) and Bob Casey (D-Pa.) and Representatives John Delaney (D-Md.) and Jaime Herrera Beutler (R-Wash.) introduced the Medical Nutrition Equity Act (S. 1194/H.R. 2587), which would provide public and private insurance coverage for medically necessary foods for digestive and inherited metabolic disorders. The legislation closely resembles the TRICARE provision and applies to both federal health programs and private health insurance. This AAP-supported legislation is expected to be reintroduced for the 116th Congress in the coming months.

ACE Kids Act

The Advancing Care for Exceptional (ACE) Kids Act passed the House of Representatives with broad bipartisan support (400-11) last December as part of a larger health care package known as the IMPROVE Act. In order to keep the costs of the legislation down, lawmakers significantly reduced the incentives to states to coordinate care for this population, including decreasing the duration of enhanced federal match from four quarters to two, and revising the across the board 90 percent enhanced matching rate to an increase of 15 percent over a state's normal enhanced rate, not to exceed 90 percent. The bill did not pass the Senate in the 115th Congress.

The ACE Kids Act was reintroduced, with the changes noted above, in the Senate on February 4, 2019 by Senator Chuck Grassley (R-Iowa). The AAP, the American Board of Pediatrics, and the Association of Medical School Pediatric Department Chairs support the legislation.

This legislation seeks to address existing challenges facing children with complex medical conditions by improving the coordination of care across multiple providers and services. The bill allows states to expand access to patient-centered, pediatric-focused coordinated care models tailored for children with medical complexity, which can lead to improved quality of care for this population.

The bill text includes language clarifying that the adoption of the program is voluntary for states, providers, and families.

Academic and Subspecialty Workforce

Shortages and maldistribution among pediatric subspecialists create access problems for children with special health care needs. The Academy strongly advocates for funding programs to improve the subspecialty workforce, including the Children's Hospital Graduate Medical Education Program (CHGME) and the Pediatric Subspecialty Loan Repayment Program.

Support for Pediatric Subspecialists

Congress is working to renew the Title VII Health Professions programs administered by the Health Resources and Services Administration (HRSA), which provide education and training opportunities in high-need disciplines and settings and provide financial aid to health professions students. The Pediatric Subspecialty Loan Repayment Program (PSLRP, Section 775 of the Public Health Service Act) is a Title VII program that would provide $35,000 per year for up to three years in exchange for practicing in an underserved area. This program was originally authorized in 2010 but was never funded by Congress before its authorization lapsed in 2014. The AAP led a coalition sign-on letter of more than 70 organizations, including health care provider groups and patient advocacy organizations, calling on

Congress to reauthorize PSLRP and is actively working to advance this priority in the 116th Congress.

Congress has also considered efforts to allow pediatric subspecialists to qualify for loan repayment through the National Health Service Corps (NHSC) as an additional means to addressing subspecialty workforce shortages. In the last Congress, Sens. Roy Blunt (R-Mo.) and Jack Reed (D-R.I.) and Reps. Billy Long (R-Mo.) and Joe Courtney (D-Conn.) led these efforts, introducing the Ensuring Children's Access to Specialty Care Act of 2017 (H.R. 3767/S. 989). The AAP and subspecialty partners worked with these congressional champions to develop this legislation as part of broader efforts to explore new ways to fund training for subspecialists.

Children's Hospital GME Funding and Reauthorization

On September 18, President Trump signed into law the Dr. Benjy Frances Brooks Children's Hospital GME Support Reauthorization Act of 2018 (H.R. 5385), which provides for a five-year reauthorization of the Children's Hospital Graduate Medical Education (CHGME) program. The program's authorization was set to lapse on September 30. H.R. 5385 increases CHGME's annual authorization from $300 million to $325 million, while making no policy changes to the program. The bill was passed with broad support in both the House and the Senate and came after a House Energy and Commerce Health Subcommittee hearing on the subject in May at which Susan Guralnick, MD, FAAP, chair of the AAP Committee on Pediatric Education, testified about the importance of the federal investment in graduate medical education.

As of October 1, the Department of Health and Human Services (HHS), under which CHGME is administered, is currently operating under the Fiscal Year (FY) 2019 appropriations spending bill signed into law on September 28. CHGME is funded at $325 million for FY 2019, representing a $10 million increase as compared to the FY 2018 enacted level. This is the program's third consecutive funding increase.

CHGME provides funding to free-standing children's hospitals to support pediatric residency and fellowship positions; these institutions are not eligible for GME funded through Medicare because they do not care for Medicare-eligible patients. The AAP has worked to maintain this invaluable funding stream for pediatric residents and fellows, more than half of whom train at CHGME-eligible children's hospitals.

Immigration

Family Separation

In January, the Department of Health and Human Services Office of the Inspector General issued a report investigating the number of children who were separated from their parents at the border. The report found that thousands more children than have been publicly reported were separated from their parents at the border. Many of these separations occurred before the Trump administration's "zero-tolerance" policy was announced. In March, a federal court ruled that the Trump administration must identify these children who were separated outside of the "zero-tolerance" policy.

In February, Julie Linton, MD, FAAP, co-chair of the AAP's Immigrant Health Special Interest Group, testified before the House Energy and Commerce Committee Subcommittee on Oversight and Investigations in a hearing on family separation. Dr. Linton's testimony was covered by PBS Newshour and MedPage Today.

Dr. Linton outlined the child health effects of family separation, both based on scientific literature and what she has witnessed herself caring for her own patients. In particular, she shared the story of one of her young patients who was separated from his pregnant mother in the midst of the zero-tolerance policy. Pediatrician Jack Shonkoff, MD, FAAP, also testified about toxic stress and the consequences of separation for both the child and parent.

Conditions in DHS Custody and the *Flores* Settlement Agreement

After 7-year-old Jakelin Caal Maquin died in the custody of Customs and Border Protection (CBP) in December, AAP led fourteen medical and mental health provider organizations, in sending a letter to CBP and the Department of Homeland Security (DHS) calling for a full, transparent, and public investigation into her death. The Academy's response was widely covered in the news, including CBS News, TIME and in this Washington Post op-ed. AAP Immediate Past President Colleen Kraft, MD, MBA, FAAP, also wrote an op-ed in the Las Cruces Sun-News speaking out against Jakelin's death.

In response to AAP's letter to CBP as well as the death of a second child, Felipe Gomez Alonzo, in CBP custody, CBP Commissioner Kevin McAleenan reached out to AAP Immediate Past President Colleen Kraft to discuss the need to improve pediatric medical screening and referral for children in CBP custody. AAP continues to maintain its position that children do not belong in CBP custody but is offering its expertise and resources to assist CBP with improving care for children that are in their care. Following Felipe's death, the

Academy's position continued to be covered in the news, including CNN, NBC News, TIME, PRI's The World and PBS Newshour.

In March, Julie Linton, MD, FAAP, co-chair of the AAP's Immigrant Health Special Interest Group testified before the Senate Judiciary Committee on the conditions in U.S. Customs and Border Protection (CBP) custody. In her testimony, Dr. Linton outlined the Academy's longstanding concerns with the conditions in CBP custody and their impact on children's health. In addition, Dr. Linton emphasized the need for medical professionals with pediatric training at these facilities and along the border.

In February, Sen. Martin Heinrich (D-N.M.) introduced the Remote, Emergency, Medical, Online Training, Telehealth, and EMT (REMOTE) Act. The REMOTE Act works to ensure appropriate medical screening and care is available to all children in CBP custody. It requires all border patrol agents to complete an online training program that meets nationally recognized standards for the medical care of children. It also enhances the level of pediatric training for EMTs and paramedics, requires CBP agents to have minimum supplies like water, and requires 24-hour access to a board-certified physician or mid-level health care provider with pediatric training to consult CBP regarding children's medical needs. AAP sent a letter of support for the bill to Sen. Heinrich upon its introduction.

The Trump Administration has been arguing that the *Flores* Settlement Agreement and a federal law mandating special protections for unaccompanied children be overturned so that more children can be detained for longer periods of time and then deported. The AAP strongly opposes this and previously submitted comments on a proposed rule that would overturn *Flores.* Legal challenges to the regulations are expected. In March, AAP Immediate Past President Colleen Kraft, MD, MBA, FAAP, published an op-ed in USA Today, outlining what she saw during her recent trip to a detention center on the border and the harms of detention on immigrant child health.

Public Charge

In December, AAP submitted comments on a proposed regulation from the Department of Homeland Security (DHS) that would change the definition of "public charge," making it harder for immigrants to enter the United States and advance through the immigration process by counting their use or likely use of public benefits such as Medicaid, SNAP or housing assistance against them when determining whether they are a public charge.

During the comment period, AAP repeatedly engaged members and urged them to take action against the proposal. AAP President Colleen Kraft, MD, MBA, FAAP, sent multiple emails to all AAP members explaining the potential impact of this regulation and detailing how pediatricians can play a critical role in explaining how this proposal is damaging to children's health. AAP also released a Public Charge Advocacy Toolkit with ways to take action and speak out against this rule. More than 400 AAP members submitted comments on the proposal through the AAP's advocacy action website.

The AAP's opposition against the proposal received attention in the media and the broader health care community. When the proposal was released, the Academy immediately issued a press release and joined a statement with other leading physician groups. The AAP's position was covered by news outlets such as CBS, the Los Angeles Times, TIME, and Modern Healthcare, and many pediatricians published opinion pieces in their local newspapers. Dr. Kraft published an op-ed in Newsweek with the presidents of the American College of Physicians and the American College of Obstetricians and Gynecologists. In total, more than 210,000 comments were submitted on the proposal. DHS will now review the submitted comments and issue a final rule that responds to those comments. Litigation is expected to be filed once a final rule is issued.

Physician Payment

Appropriate payment for services provided by all pediatricians is essential to ensuring that all children have access to care. The Academy is continuing to advocate for increased Medicaid payment for pediatricians with the broadest possible applicability to pediatricians and pediatric subspecialists.

Surprise Medical Billing

Surprise medical bills – those from out-of-network physicians that patients had no role in choosing – are not a new phenomenon, but national attention to the issue has grown tremendously in recent years. Surprise bills arise most often during emergency care or during elective care involving ancillary physicians (such as radiologists, anesthesiologists, pathologists) who patients do not actively choose and are not in the insurer's provider network.

Many states have taken steps to mitigate this problem. However, current state laws do not apply to the roughly half of privately-insured Americans enrolled in so-called "self-insured" health plans that are common among large employers, because the Employee Retirement Income Security Act (ERISA) precludes states from regulating these plans. Federal legislation could protect people enrolled in self-insured employer health plans, as well as all privately-insured individuals in the majority of states that have not enacted comprehensive surprise billing legislation.

In February, the AAP signed on to a letter to Congress, led by the American Medical Association (AMA), outlining principles for legislators in developing legislation to address surprise billing. The principles seek to "improve transparency, promote access to appropriate medical care, and avoid creating disincentives for insurers and health care providers to negotiate network participation contracts in good faith."

Medicare Physician Fee Schedule CY 2019

In November, the Centers for Medicare and Medicaid Services (CMS) announced a Final Rule that outlines significant changes to payment policies under the Medicare Physician Fee Schedule for 2019.

While the changes proposed are specific to Medicare, which only includes a few pediatric services, payment policies introduced in Medicare are frequently adopted by Medicaid and private payers and are therefore relevant for pediatricians and the children for whom they care.

The Academy supported the proposed changes to reduce documentation burden on physicians, which allows physicians to choose from the following documentation rubrics:

- document office/outpatient evaluation and management (E&M) visits using either medical decision-making or time
- maintain the option of applying the current 1995 or 1997 E&M documentation guidelines
- focus documentation on what has changed since the last visit

However, the Academy raised concerns with the proposal to blend Medicare payment for the current five-tier E/M system. The Academy believes that blending rates will potentially create disincentives for physicians to confront patient complexity and thus encourage either passing complex patient problems into multiple visits or to referring patients to other settings such as emergency departments. The Academy submitted detailed comments on the proposed rule expressing support for CMS efforts to simplify E&M documentation requirements for office visits. However, AAP believes that CMS can implement many of its documentation revisions separate from its blended rate proposal.

In response to these comments and others, CMS finalized several items designed to reduce the regulatory burden on physicians, effective January 1, 2019, but other changes to documentation, coding, and payment will be delayed until calendar year 2021. Additionally, the final rule collapses E/M office/outpatient visit levels 2 through 4 while maintaining the payment rate for level 5 (the proposed rule collapsed levels 2 through 5).

For more information, see this fact sheet from CMS.

Medicaid Access Rule

On Friday, March 23, 2018, Centers for Medicare and Medicaid Services (CMS) released a proposed rule that would weaken the federal requirements for states to document whether fee-for-service (FFS) Medicaid payments are sufficient to ensure people enrolled in Medicaid have adequate access to care and services. The agency proposes to exempt states from certain access monitoring requirements if the vast majority of people in the state receive services through managed care plans. Additionally, the rule would make it easier for states to cut provider payment rates in FFS in all states, which could lead to less provider participation in the program. In response, the Academy submitted its own comment letter urging CMS to withdraw the proposed rule, and also spearheaded joint comments by the Group of 6 Frontline Physicians as well as comments by prominent national child health advocacy organizations.

On December 12, CMS notified OMB that it would rescind its proposed changes to the Access Rule.

Medicaid Payment Equity

The Medicaid payment equity provision authorized under the Affordable Care Act (ACA) increased Medicaid payment rates for primary care services to at least those paid by Medicare. Currently, Medicaid payment rates are about 70% of Medicare payment rates. However, the ACA provision only applied to calendar years 2013 and 2014.

Several efforts have been made by legislators in previous sessions to restore this Medicaid payment parity provision, including most notably the Ensuring Access to Primary Care for Women & Children Act proposed by Senator Brown (D-Ohio), which extends the primary care payment increase to Medicare levels, as established under the ACA, for two more years and for more primary care providers. This provision was also recently included in the State Public Option Act, bicameral legislation proposed by Senator Schatz (D-Hawaii) and Representative Ben Ray Luján (D-N.M.) to create a Medicaid-based public health care option to strengthen the Affordable Care Act. Representative Kim Schrier, MD, FAAP, a newly elected Democrat from Washington state and the first pediatrician ever elected to Congress, has co-sponsored the bill.

Although there has been a great deal of anecdotal evidence on the importance of payment parity, several new studies help quantify the impact of Medicaid payment equity on access to care. The most recent of these studies was published in the January 2018 edition of *Pediatrics.* This study included new

research showing the Medicaid reimbursement rate increase under the ACA resulted in more doctors participating in the program. The study, "Increased Medicaid Payment and Participation by Office-based Primary Care Pediatricians," looked at a number of dimensions to measure increased participation among pediatricians in the Medicaid program.

Pediatric Drugs and Devices

The Academy is continuing efforts to advocate for policies that promote access to safe and effective drugs and medical and surgical devices for children.

Over-the-Counter Drug Reform

Unfortunately, the Senate did not pass the Over-the-Counter Monograph Safety, Innovation, and Reform Act of 2018 before the end of the 115th Congress. This legislation, a long-time priority of AAP, would make necessary changes to modernize the over-the-counter (OTC) drug approval process at the Food and Drug Administration (FDA). At the end of 2018, the OTC legislation was combined with the Pandemic and All-Hazards Preparedness and Advancing Innovation (PAHPAI) Act in the House and passed overwhelmingly but it failed to pass the Senate due to a hold by a senator unrelated to substance of the bill.

The legislation has been reintroduced in the 116th Congress and passed by the House. AAP continues to advocate for the Senate to take up and pass the legislation quickly.

Drug Shortages

Last May, the Food and Drug Administration (FDA) announced that it will be taking steps to mitigate current drug shortages and prevent future ones from occurring. Commissioner Gottlieb said that FDA is exploring ways to encourage companies to voluntarily share more timely information about potential supply disruptions. FDA is also considering ways to better act upon the information they receive as well as ways to better manage a shortage. FDA will also take steps to bring on new technology that can improve manufacturing, to help reduce the chance that supply disruptions will occur.

On November 27, FDA hosted a public meeting entitled "Identifying the Root Causes of Drug Shortages and Finding Enduring Solutions." The purpose of the meeting was to give stakeholders, including health care providers, patients, manufacturers, wholesalers, pharmacists, pharmacy benefit managers, public and private insurers, researchers, and the public, the opportunity to provide input on the underlying systemic causes of shortages, and make recommendations for actions to prevent or mitigate them.

Drug Pricing

Last May, the Trump Administration released a Blueprint containing dozens of ideas intended to affect drug pricing. The Blueprint reviews the issue of high drug costs, presents actions the Administration has already taken, lists actions that the Administration may undertake or promote going forward, and seeks feedback on potential actions. The Blueprint does not do much to address pricing of pediatric drugs and is mostly focused on changes to Medicare.

The Trump Administration sought comment on the Blueprint which included many questions for policymakers and stakeholders to consider as they develop actions based on the Blueprint. Notably, the questions also ask if and how low prices in Medicaid (and other government programs) may incentivize manufacturers to increase prices for drugs overall to recoup perceived lost profits. The Blueprint also asks about pricing transparency and potential alternative prescription drug payment structures in Medicaid (and Medicare) including: pricing curative drugs to account for the fact that current payers may not realize long-term cost savings from lower treatment costs; pricing drugs based on the indication they are used for and how effective the drug is for that specific indication; and pricing drugs to remove disincentives to provide a drug in a particular setting (e.g., inpatient versus outpatient).

It is unclear what policy actions will ultimately emerge from the Blueprint, and not all proposals in the Blueprint can be implemented through administrative (as opposed to congressional) action. However, the document provides insight into the Administration's areas of interest for lowering drug costs overall. For more information please see these summaries.

With the outcome of the mid-term elections and the fact that so many winning candidates made lowering drug prices a campaign pledge, we expect to see legislative activity on drug pricing in the 116th Congress.

Opioids and Children

In October, Congress passed comprehensive opioids legislation to address the ongoing opioid crisis. The bill, known as the Substance Use-Disorder Prevention that Promotes Opioid Recovery and Treatment (SUPPORT) for Patients and Communities Act (H.R. 6), contained numerous provisions to address the multifaceted impacts of opioids on families and communities, and the AAP worked extensively throughout the development of the bill to secure and shape these provisions.

The sweeping legislation contains a host of measures aimed at preventing, treating, and recovering from opioid dependence, including provisions that expand access to medication-assisted

treatment (MAT) for adolescents, improve access to care for children and families, and support children and families affected by parental substance use. The AAP is now working to secure funding for newly created pediatric-focused programs and ensure effective implementation of the law.

Pediatric Research

The Academy continues to advocate for basic and translational pediatric research funding, as well as the importance of including children in clinical research. The AAP closely tracks the Environmental influences on Child Health Outcomes (ECHO) program and the basic and translational research activities at the National Institutes of Health.

Trans-NIH Pediatric Research Consortium

In June, the National Institutes of Health (NIH) launched the Trans-NIH Pediatric Research Consortium (N-PeRC), a new initiative to better coordinate pediatric research across the NIH. N-PeRC will harmonize efforts in child health research across the 27 Institutes and Centers at NIH and identify gaps and opportunities for collaboration. The effort will also serve to enhance communication between NIH, advocacy groups, and Capitol Hill, encourage pediatric researchers to serve on review panels, and work across NIH to support training to grow the pediatric workforce. Senior staff from all 27 Institutes and Centers have already been selected to serve on the consortium, and the group has met several times to date.

The initiative comes as members of Congress have shown increasing interest in ensuring pediatric research is coordinated across NIH; while NICHD is the single largest funder of pediatric research at NIH, the Institute funds only about 18 percent of the child health research at NIH.

Task Force on Research Specific to Pregnant and Lactating Women

The Safe Medications for Moms and Babies Act was included in the large *21st Century Cures Act* that was signed by the President in December of 2016. The legislation established an interagency task force to advise the HHS Secretary related to identifying and addressing gaps in research on safe and effective therapies for pregnant and lactating women. In addition, the legislation requires that the task force submit a report to Congress on research gaps for this population as well as the ethical issues of including pregnant and lactating women in clinical research. AAP Committee on Drugs Chair Bridgette Jones, MD, FAAP, serves on the Task Force.

The Task Force released their report in September. The report outlines the gaps in knowledge and research regarding safe and effective therapies for pregnant and lactating women, and issues 15 recommendations to improve the safety and availability of such therapies.

Inclusion of Children in NIH-Funded Research

In December 2017, the National Institutes of Health (NIH) released an updated policy on the inclusion of individuals across the lifespan in human subjects research. The updated policy requires for the first time that NIH-funded researchers submit data on the age of study participants at enrollment. Researchers will be required to submit de-identified individual-level participant data on age at enrollment, in addition to sex, race, and ethnicity. The updated policy continues to require that research proposals include a rationale for why a specific age group will be excluded and now extends to older adults. It went into effect beginning in January 2019, and the AAP will continue to work with NIH to ensure that the data collected is used most effectively to advance pediatric research.

Since 1998, NIH has required that children be included in government-funded biomedical research where appropriate and relevant to the pediatric population. However, NIH never collected or systematically tracked data on the age of research participants, making the pediatric inclusion requirement impossible to enforce. The policy change comes in response to a requirement in the 21st Century Cures Act, which required the NIH to publish data on the "relevant age categories, including pediatric subgroups" included in its clinical research and to hold a workshop of experts in pediatrics and older populations to provide input on criteria for appropriate age groups to be included in NIH research studies. The AAP championed this provision in the 21st Century Cures Act and worked with the NIH throughout its implementation. The AAP Committee on Pediatric Research has advocated that children be included in NIH-funded research for over two decades and was instrumental in securing this policy change.

National Institutes of Health Appropriations

The Department of Health and Human Services is currently operating under the Fiscal Year (FY) 2019 full-year spending bill. The NIH received a $2 billion funding increase over FY 2018 for a total of $39.1 billion in spending authority. This funding boost marks the fourth multi-billion-dollar funding increase for NIH in recent years, for a total of $9 billion in funding increases for the NIH. NIH remains highly popular with legislators on both sides of the aisle, and the Bipartisan Budget Act, which was signed into law early last year, allowed Congress to increase spending on NIH above what was initially expected.

Within the NIH, the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) was appropriated $1.5 billion. The Environmental influences on

Child Health Outcomes (ECHO) program received flat funding of $165 million as compared to FY 2018, while the All of Us Research Program (formerly known as the Precision Medicine Initiative Cohort Program) received funding of $376 million, or an $86 million increase.

Gun Violence Research and Prevention

The 2018 midterm elections featured a number of candidates campaigning on a promise to do more to reduce gun violence related deaths and injuries. With the change in leadership in the House, the AAP and its partners have begun strategizing on ways to advance gun violence prevention (GVP) legislation in the 116th Congress. To build upon our work in 2018, the AAP is again leading the medical and public health community in advocating for $50 million in federal GVP research funding for the Centers for Disease Control and Prevention (CDC). This advocacy ask, based on the expert input of key pediatrician research leaders, garnered the support of 166 medical and public health groups in a letter to Congress. AAP recently worked with Academy members to place op-eds in the Post & Courier in South Carolina and the Philadelphia Inquirer in Pennsylvania, two key states for outreach. In early March, the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies held its first hearing in over two decades on addressing the public health emergency of gun violence with CDC research funding.

AAP also continues to advocate for universal background checks for firearms sales and transfers. Led by Representatives Peter King (R-NY) and Mike Thompson (D-CA), a group of 10 bipartisan House members introduced a bill on Jan. 8th that would expand federal background checks to apply to all firearm sales and most firearm transfers, the *Bipartisan Background Checks Act of 2019*. The Academy endorsed the bill, issued a press statement, and had a presence at a press event unveiling the bill with House Speaker Nancy Pelosi, other members of Congress, and former Congresswoman Gabrielle Giffords. In March, the U.S. House passed the bill by a vote of 240-190. The Academy issued this press statement applauding the first gun violence prevention measure to pass the House in decades. AAP continues to support progress on this critical issue, including advocating for enactment of the Senate's companion legislation, the Background Check Expansion Act (S. 42), led by Senator Chris Murphy (D-CT). While the bill faces challenging political dynamics in the Senate, this is a significant development of bipartisan commitment on this AAP priority.

Pediatric subspecialists and pediatric surgical specialists in particular have been outspoken in the need for gun violence prevention measures in the wake of school shootings. Pediatric surgeons are the physicians who treat school-age victims of gun violence. As such, they have a powerful voice in articulating to the public the devastation caused by gun violence and guiding the policy discussion with relevant clinical expertise.

Pediatric Emergency Medicine and Disaster Preparedness

Emergency Medical Services for Children Program

Although passed by the Senate in December, the House was unable to pass legislation reauthorizing the Emergency Medical Services for Children (EMSC) program before the end of the year. EMSC helps states expand and improve their capacity to reduce and respond to pediatric emergencies. The legislation was introduced by Peter King (R-NY), Kathy Castor (D-FL), Chris Stewart (R-UT), and G.K. Butterfield (D-NC) in the House and by Senators Orrin Hatch (R-UT), Bob Casey (D-PA), Brian Schatz (D-HI) in the Senate. Since Senator Hatch has now retired, we are working to cultivate a new republican Senate bill champion and reintroduce the legislation in the 116th Congress.

This bill makes no changes to the EMSC program and extends the existing authorization from FY 2020 through FY 2024 at the most recently appropriated level of $22.334 million for each fiscal year. AAP led a group of 30 organizations in sending a letter supporting the legislation. EMSC is set to expire on September 30, 2019 and AAP will continue to advocate for its reauthorization early this year.

Federal Aviation Administration Emergency Medical Kits

In October, President Trump signed a package into law that contained the AAP-championed Airplane Kids in Transit Safety (KiTS) Act. This provision requires the Federal Aviation Administration (FAA) to review and update the contents of the emergency medical kits on commercial airplanes. Currently, these kits are not required to contain equipment and medication that is appropriately dosed and sized to treat children. Upon passage of this long-time AAP priority, AAP President Colleen Kraft, MD, MBA, FAAP, issued this press statement.

The FAA now has one year to begin a rulemaking process to update the kits. AAP has been in contact with the FAA and is providing them with expertise about what pediatric-appropriate equipment and medication should be included in the kits.

Pandemic and All-Hazards Preparedness Act

Before the end of the 115th Congress, the Pandemic and All-Hazards Preparedness and Advancing Innovation (PAHPAI) Act passed overwhelmingly in the House but failed to pass the Senate due to a hold by a senator unrelated to substance of the bill. PAHPAI is responsible for many important provisions related to preparedness and response for children, including the Hospital Preparedness Program (HPP), the Public Health Emergency Preparedness (PHEP) program, the National Advisory Committee on Children and Disasters (NACCD), the National Preparedness and Response Science Board (NPRSB), and measures related to medical countermeasures.

Among other key provisions, PAHPAI contains two AAP priorities—authorizing the Children's Preparedness Unit at the CDC and reauthorizing and strengthening the NACCD which expired on September 30, 2018. On January 10th, the House again passed this combined bill and sent it to the Senate where we expect Senator Burr to continue his hold. AAP will continue to advocate for the swift passage of this important legislation.

Child and Family Well-Being

Family First Prevention Services Act

The AAP was integrally involved in leading advocacy efforts to successfully enact the Family First Prevention Services Act in the 115th Congress. This landmark law will effect critical reforms in the U.S. child welfare system to improve the health and well-being of children. The law's two key pillars are: 1) allowing states to use funds previously limited to foster care placements for evidence-based services for children and their caregivers that prevent the need for foster care; and 2) ensuring children are placed in a non-family setting only if necessary to meet their needs, and that such settings are accredited and have licensed clinical and nursing staff.

AAP is now among a small group of organizations leading efforts to ensure the effective implementation of Family First through extensive engagement with policymakers and other stakeholders. AAP is also working on a grant-supported project with advocacy partners to develop a comprehensive guide for states on implementing Family First. The largest provisions of Family First take effect starting October 1, 2019, and AAP is working closely with its chapters to support their advocacy for the law's implementation in their state. In addition, the AAP recently worked with pediatricians to place op-eds in the Arizona Daily Star and the Wichita Eagle. Through that work, AAP has begun engaging in targeted projects with AAP chapters to support state implementation of Family First, most recently through a partnership with the Kansas Chapter of AAP and Casey Family Programs. That project entailed briefings for state legislators on how Family First would benefit Kansas, a private meeting with the governor to discuss the policy and opportunities for the state, and an advocacy day with 40 pediatricians at the state capitol.

AAP is also seeking additional outside resources from philanthropy partners to expand its work supporting Family First implementation and will continue pursuing opportunities to work closely with AAP chapters on this law. AAP staff will present on Family First at the Annual Leadership Forum, which will include the launch of a Family First advocacy toolkit.

Immunizations

On March 4, AAP President Kyle Yasuda, MD, FAAP, sent letters to the CEOs of three major technology companies - Google, Facebook and Pinterest - highlighting the growing threat that online vaccine misinformation poses to children's health. In the letters, Dr. Yasuda requests to meet and discuss ways the AAP and the technology companies can work together. This AAP News story has more.

"Pediatricians are working in our clinics and our communities, talking with families one-on-one about how important vaccines are to protect their children's health. But it's no longer enough," said Dr. Yasuda in a press release. "Our worst fears are being realized as measles outbreaks spread across the country." The letters were picked up by several news outlets, including the New York Times.

On March 5, the Senate Committee on Health, Education, Labor, and Pensions held a hearing to demonstrate strong bipartisan support for vaccinations in the midst of ongoing measles outbreaks across the country.

Jonathan McCullers, MD, chair of the Department of Pediatrics at the University of Tennessee Health Science Center and pediatrician-in-chief at Le Bonheur Children's Hospital in Memphis, Tenn., testified during the hearing. He highlighted a pediatrician's role in talking with families about the importance of vaccines, especially in light of the spread of misinformation on social media. Dr. McCullers noted that vaccine refusal is one of the greatest public health threats at this time. Other witnesses included an Ohio high school student who chose to get vaccinated despite his mother's anti-vaccine beliefs and an official from the Washington State Department of Health.

Child Nutrition

Farm Bill

The House and Senate were able to come to agreement and send a final Farm Bill to the President for his signature in December. The Farm Bill is responsible for many food and

agriculture programs, including the Supplemental Nutrition Assistance Program (SNAP). Although the House-passed legislation would have made harmful changes to SNAP, thanks to the advocacy of pediatricians and others, the final bill does not cut SNAP benefits or change eligibility for the program in any significant way.

SNAP

In February, the US Department of Agriculture announced a proposed rule that would strictly limit the ability of adult SNAP participants to obtain food assistance. Currently, the law stipulates that able-bodied adults without dependents who work less than 80 hours per month can receive no more than three months of benefits in any three-year period. However, states have the ability to waive this requirement for certain adult SNAP participants without dependents who are unable to find sufficient employment to meet the program's existing work requirements. The area waivers are limited to regions where there is high unemployment or a lack of available jobs.

The proposed rule sets stricter standards for area waivers, which would have the effect of removing 750,000 people from SNAP. While this proposal is targeted at adults without dependents, it would still likely impact children as families often pool resources to feed children. Notably, Congress declined to include a similar proposal in the Farm Bill.

Budget and Appropriations

The AAP is working hard to support funding for important child health programs that are particularly vulnerable to cuts as a result of the strict discretionary budget caps set forth in the Budget Control Act of 2011, which continue to constrain federal funding on non-entitlement spending.

Fiscal Year 2019 Appropriations

On Friday, Feb. 15, President Trump signed a $333 billion spending package that completed the appropriations process for Fiscal Year 2019. The compromise legislation appropriates funding to the federal departments and agencies whose spending bills were not completed last fall, including the Department of Homeland Security, the Department of Interior, the Department of Agriculture and the Food and Drug Administration. As a reminder, the funding bill for the Department of Health and Human Services and its related agencies was completed on September 30, 2018.

Of note, the spending bill signed last month includes nearly $1.4 billion for barriers along the southern border in the Rio Grande Valley of Texas. It also includes funding for improving Customs and Border Protection (CBP) processing centers and for finding alternatives to detention. And, it includes funding for CBP to contract with medical professionals as well as funds for supplies like water, nutrition, and diapers for those in temporary CBP custody.

The spending package also includes the following funding for other important programs:

- $6.075 billion for the WIC program
- $73.477 for SNAP
- $23.141 billion for the Child Nutrition Program
- $5.8 billion for the Indian Health Service, an increase of $266 million from FY 2018
- $8.8 billion for the Environmental Protection Agency, an increase of $25 million from FY 2018
- $5.7 billion for PEPFER, an increase of $50 million from FY 2018
- $3.1 billion for USAID global health programs, an increase of $97 million from FY 2018, including funding for the following accounts:
- $575 million for family planning programs
- $302 million to fight tuberculosis
- $145 million for nutrition programs
- $755 million to combat malaria
- $290 million for GAVI

With the appropriations process complete for FY 2019, Congress' attention now shifts to starting the appropriations process for FY 2020. One important issue that Congress must address is the spending caps for both defense and non-defense discretionary (NDD) spending that was set in place in the Congressional Budget Act of 2011 (CBA). Every year since 2012, the House and Senate has come to an agreement that raises the spending level outlined in the BCA. Each agreement has been a two-year deal, and the last one expired with FY 2019. If no agreement is reached to raise the spending caps, Congress will need to cut almost $55 billion in NDD funding in FY 2020. The AAP is joining with the NDD community to encourage Congress to come together and approve another budget agreement that lifts the caps for FY 2020 and FY 2021.

Blueprint for Children Update

Two years ago, the Academy published the *Blueprint for Children: How the Next President Can Build a Foundation for a Healthy Future*, outlining its priorities for the 45th presidential administration.

In advance of the national midterm elections in November 2018, the AAP unveiled two new documents: *2018 Update: Achievements in Child Health Advocacy* and the *2018 Update: What's Next in Child Health Advocacy*. Together, these documents outline the AAP's federal policy accomplishments for children's health and map out its priorities for the years ahead.

Please visit aap.org/blueprint for more information on the new resources.

Grassroots Advocacy: AAP Key Contact Program

Key Contacts are AAP members who are interested in receiving advocacy opportunities and timely policy updates from the AAP Washington Office on federal legislation and other issues important to the Academy.

Through regular e-mail communication with specific requests for action, the Washington Office keeps Key Contacts informed of the latest legislative developments affecting children and pediatricians.

How to Become a Key Contact

E-mail kids1st@aap.org with your name, AAP ID if known, and your preferred e-mail address. If you have questions about federal advocacy, contact the AAP Washington Office at 202-347-8600.

FederalAdvocacy.aap.org: AAP Federal Affairs Online Resource Center

Visit the AAP Federal Advocacy website at FederalAdvocacy.aap.org to find federal advocacy resources and tools, including:

- An Action Center where you can e-mail federal legislators directly on current federal child health policy priorities.
- A media center where you can read recent opinion pieces written by pediatricians.
- Background information on current AAP federal child health issues advancing in Congress.
- Highlight the importance of pediatric research with a thank you note to your members of Congress each time you are awarded a federal grant.

Engage with AAP on Social Media

Twitter is a powerful tool that allows individuals and organizations to amplify messages, connect with new and diverse networks, and gain access to local-, state- and federal-level decision-makers. As a pediatrician, Twitter also offers you the opportunity to be part of a community that encourages the exchanging of ideas around child health, while not being constrained by time or geography.

To stay up-to-date on child health news, follow and engage with AAP on social media via @AmerAcadPeds, @AAPPres, @AAPNews, and @healthychildren. You also can subscribe to AAP's official #tweetiatrician list on Twitter by visiting https://twitter.com/AmerAcadPeds/lists/tweetiatricians. Request to be added to the list by emailing AAP's social media community manager, Helene Holstein, at hholstein@aap.org.

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