



# FAMILY VOICES<sup>®</sup>

Washington DC Update  
August 2, 2018

## Greetings from Washington!

It was an eventful week in the child health and welfare policy world. The administration released its final rule on “short-term, limited-duration” insurance plans and re-instituted risk-adjustment payments to insurers. The deadline for reunification of immigrant families came and went; the Senate Judiciary Committee held a hearing on the family reunification issue; several useful Medicaid resources were published; and the Department of Education issued its annual report on state compliance with IDEA. On top of that...

- July 26 was the 26<sup>th</sup> birthday of the Americans with Disabilities Act (ADA) (read the [president's proclamation](#) marking the occasion), and
- July 30 was the 53<sup>rd</sup> birthday of the Medicaid program. Watch this [video](#) about the importance of Medicaid to the families of children with medically complex conditions, from the Georgetown Center on Children and Families (about 13 minutes).

Read about these issues and more in this week's Update.

## UPCOMING WEBINARS AND CALLS

(All topics; in chronological order, by first webinar in a series where applicable.)

### [What Families, Family-based Support Organizations and EHD Programs Want: Findings from a National Needs Assessment](#)

Thursday, August 2, 1:00-2:00 pm ET

*Hands & Voices™*

### [Igniting Change from the Ground Up: Uplifting Best Practices for Community Organizing and Leadership Engagement](#)

Tuesday, August 7, 2:00-3:00 pm ET

*Prevention Institute*

### [Demonstrating Medicaid's Value through Storytelling](#)

Wednesday, August 8, 3:00 pm ET

*Georgetown Center on Children and Families*

### **NEW** [Emerging Best Practices for People with an Intellectual/Developmental Disability Co-Occurring with Serious Mental Illness](#)

Thursday, August 9, 1:30-2:30 pm ET

*Substance Abuse and Mental Health Services Administration*

**NEW Body Image Issues across the Lifespan**

Thursday, August 9, 3:00-4:00 pm ET

*Idaho Federation of Families for Children's Mental Health*

**ACEs: The Role of Life Experiences in Shaping Brain Development**

Thursday, August 9, 12:00-1:00 pm ET

*HHS Partnership Summer Webinar Series*

**NEW Vital Signs Town Hall – Zika in Babies: Opportunities for Monitoring Health and Development**

Tuesday, August 14, 2:00 pm ET

*Centers for Disease Control and Prevention*

Conference Line (US only): 1-800-857-0764

Passcode: 795-4413

**NEW “Money Follows the Person” Sustainability Planning: Meeting the Challenges**

Wednesday, August 15, 2:30-3:30 pm ET

*Mercer*

(This webinar is ideal for MFP Project Directors and Staff, Medicaid Policy Staff, and Partner Agencies.)

**NEW Prevention in Practice: Building Communities that Strengthen the Resiliency of Future Generations** (to prevent drug and alcohol addiction)

Wednesday, August 15, 12:00-1:00 pm ET

*HHS Partnership Center*

**NEW REACH Train-the-Trainer Series: Facing the Future: Transition Tools to Help...**

Tuesday, August 21, 12:00-1:00 pm ET

*SPAN Parent Advocacy Network*

**NEW Childhood Hearing Loss: Intervention and Parent Choice**

Tuesday, August 21, 2:00 pm ET

*National Center for Hearing Assessment and Management at Utah State University*

(Note that one of the presenters will be Rene Averitt-Sanzone, the Executive Director of Parents' Place of Maryland, the state's Family-to-Family Health Information Center.)

**NEW A Conversation on Supporting Self-Management in Children and Adolescents with Complex Chronic Conditions**

Wednesday, August 22, 1:00-2:00 pm ET

*Lucile Packard Foundation for Children's Health*

## THE COURTS

### Supreme Court Confirmation Hearing

On August 1, Senate Judiciary Chairman Chuck Grassley (R-IA), said that the committee would hold confirmation hearings on Supreme Court nominee Brett Kavanaugh in September, and that a Senate confirmation vote could take place as early as October 1. See [Judiciary Chair Chuck Grassley: Brett Kavanaugh Could be Confirmed to Supreme Court by Oct. 1](#) (USA Today, 8/1/18). Given the expected absence of Senator McCain (R-AZ) due to illness, all of the remaining 50 Republicans must support Kavanaugh in order to confirm him, assuming all Democrats oppose the confirmation. Senator Rand Paul (R-KY) was undecided at first but recently announced that he would vote for confirmation. So far, there are no other Republicans who have expressed potential opposition. Senators Joe Manchin (D-WV), Joe Donnelly (D-IN), and Heidi Heitkamp (D-ND) are the only Democrats who voted to confirm earlier Supreme Court nominee Neil Gorsuch. These Senators are up for reelection this year in states that voted for President Trump in 2016. On Monday Judge Kavanaugh met with Sen. Joe Manchin (D-WV), who is concerned about the possibility that the Supreme Court could overturn the ACA to the detriment of people with pre-existing conditions. See [Manchin statement](#) on meeting. See also [Democrat Manchin Undecided on Kavanaugh after 2-hour Meeting](#) (Washington Post, 7/30/18); [Kavanaugh's Obamacare Rulings under Microscope as He Meets Manchin](#) (CNN, 7/30/18).

## THE ADMINISTRATION

### REUNIFICATION OF IMMIGRANT FAMILIES (UPDATED)

July 26 was the deadline by which all immigrant children separated from their families at the southern US border were supposed to be reunited with their families pursuant to a [federal court order](#). There are over 2500 such children but, as of July 27, only 1500 children had been reunited with their families. According to a [Washington Post article](#) detailing the status of all the children, 378 of them have been otherwise discharged, meaning they were moved to sponsor households, reunited with family members released into the United States, or they turned 18. The parents of up to 463 children have been deported. The administration contends that all of the deported parents knowingly left their children behind (so that the children had a chance of obtaining asylum) but it has been reported that many parents did not understand they were doing so. See [Most Deported Migrants Were Not Asked About Leaving Children Behind, Trump Official Says](#) (Politico, 7/25/18). A court has ordered that the government find these missing parents to ensure that they willingly left their children behind. See [Judge Orders Trump Administration to Help Lawyers Find “Missing Parents” of Migrant Kids](#) (NBC, 7/28/18). [How Can the Federal Government Reunify Kids with Deported Parents? First Step: Find Them](#) (The Texas Tribune, 7/31/18).

[See more on this topic in the “Congress” section, below.]

### President signs bill to delay deadline for Electronic Visit Verification (EVV)

On July 30 the [president signed](#) a bill ([H.R. 6042](#); Public Law No: 115-222) that delays for one year (until January 1, 2020) the implementation of a requirement that Medicaid agencies adopt “[electronic](#)

[visit verification](#)” (EVV) for personal care services provided at an individual’s home. The legislation also includes language to express a “sense of Congress” that the Centers for Medicare and Medicaid Services (CMS) should hold at least one public meeting in 2018 to solicit stakeholder feedback on its May 2018 guidance on EVV, and should continue to communicate with stakeholders, including family caregivers, during EVV implementation. Disability advocates had sought this legislation because of concerns that EVV has the potential to invade the privacy of people with disabilities, limit their independence and community access, and lead to cuts in services.

## CONGRESS

### Senate Oversight Hearing on “Immigration Enforcement and Family Reunification Efforts”

On July 31, the Senate Judiciary Committee, chaired by Senator Chuck Grassley (R-IA), held a hearing on efforts to reunify the immigrant families separated at the southern US border. The witnesses were all administration officials. Notably, one witness -- a social worker who is an officer in the U.S. Public Health Service Commissioned Corps -- [told the Senators](#) that he had advised administration officials that children would be psychologically harmed if separated from their parents. A recording of the hearing and written witness testimony are available on the [committee website](#).

### Legislation to Deem People with Developmental Disabilities (DD) a Medically Underserved Population

On July 26, Representatives Seth Moulton (D-MA) and Gregg Harper (R-MS) introduced the Healthcare Extension and Accessibility for Developmentally Disabled and Underserved Population (HEADS UP) Act of 2018 ([H.R. 6611](#)). This bill would declare people with developmental disabilities to be a “medically underserved population” (MUP). Populations with this designation are entitled to priority access to certain federal programs, including community health centers and the services of the National Health Service Corps. Currently, MUPs are [defined as](#) “specific sub-groups of people living in a defined geographic area with a shortage of primary care health services who face economic, cultural, linguistic, or other barriers to health care.”

## MEDICAID AND CHIP NEWS, INFORMATION AND RESOURCES

### Medicaid Waivers

#### Resources on Medicaid work requirements

The National Disability Navigator Resource Collaborative (NDNRC) has compiled a bank of news and resources relating to Medicaid work-requirement waivers: [Summary of Posts and Resources on Medicaid Work Requirements](#).

A blog post from the Georgetown Center on Children and Families (CCF) – [A Disturbing Trend of Hiding the Coverage Losses is Emerging in Medicaid Waivers](#) (7/17/18) – addresses the lack of information on

budget neutrality in state waiver applications, which may be helpful for advocates commenting on their state’s waiver proposals. Waivers are supposed to be budget-neutral.

### **Kentucky Waiver – Open for Public Comment Again**

As reported in the [July 3 Washington Update](#) (under “Courts”), a federal [court vacated](#) the Department of Health and Human Services (HHS) approval of a Kentucky Medicaid waiver proposal to impose work requirements on Medicaid beneficiaries. The court’s ruling was based on the failure of the Centers for Medicare and Medicaid Services (CMS) to consider the evidence provided in numerous public comments that the waiver would lead to loss of coverage. The court included excerpts from organizations’ comments as an appendix to its opinion, demonstrating the importance of public comments in establishing a record that must be considered by the agency in making waiver decisions.

On July 18 CMS [announced](#) that it would provide another 30-day public comment period for the Kentucky waiver. **The comment period ends on August 18.** Rather than following the usual process for submitting comments through [Regulations.gov](#), CMS is taking comments through [Medicaid.gov](#).

### **Mississippi Waiver – Open for Public Comment Again**

Mississippi has also requested a waiver to establish work or community engagement requirements for Medicaid beneficiaries. Under that proposal, those who are employed the required number of hours and get paid minimum wage will then make too much to qualify for Medicaid. (Those who meet non-paying community engagement requirements would still be eligible.) In light of an amendment to the waiver proposal, CMS is providing [another comment period for the Mississippi proposal](#) as well. **Comments are due on August 18.**

### **Other States’ waivers and waiver proposals – comments**

The Kentucky court ruling does not affect the status of other states’ waivers or waiver applications, and the administration has let it be known that it still plans to promote work requirements for Medicaid beneficiaries. See [Trump Administration to Push Forward on Medicaid Work Requirements after Court Loss](#) (The Hill, 7/26/18); [Red States May Be Ready to Expand Medicaid — In Exchange for Work](#) (Pew blog, Stateline, 7/30/18).

In addition to Kentucky, **Arkansas, Indiana, and New Hampshire** have been granted waivers to establish Medicaid work requirements, although Arkansas is the only state to have implemented them as yet. See [One Month into Medicaid Work Requirement in Arkansas, Warning Lights are Already Flashing](#) (Say Ahhh!, blog of the Georgetown Center on Children and Families, 7/20/18).

Waiver proposals from several other states are also open for public comment: [Rhode Island’s Global Waiver Renewal](#) (due August 17); [Maine’s Demonstration for Individuals with HIV/AIDS](#) (due August 18); [Maryland’s Health Choice](#) (due August 18); [Utah’s Primary Care Network](#) (due August 11); [Delaware’ Diamond State Health Plan SUD Amendment](#) (due August 12); and [Delaware’s Diamond State Health Plan Extension](#) (due August 12).

### **New: State-Level Comment Periods**

Several states are currently taking comments on their waiver proposals to establish Medicaid work requirements. Alabama is providing a second comment period.

- [Healthy Michigan](#) - comments are due August 12.

- [Alabama Medicaid Workforce Initiative](#) - comments are due August 30. (See second paragraph of Public Notice for submission details.)
- [Oklahoma Soonercare](#) - comments are due September 3.

## MEDICAID RESOURCES

A new report from the Georgetown Center on Children and Families (CCF) -- [Medicaid and CHIP Provide Health Coverage for Many School-Age Children, Yet Gaps Remain](#) -- provides state-level data on Medicaid coverage for children ages 6 through 18. The related [blog post](#) links to the [school-district-level data](#) on the percent of children on Medicaid.

The Georgetown Center on Children and Families (CCF) and the American Academy of Pediatrics (AAP) have updated their [state snapshots](#) on children's Medicaid and CHIP coverage.

In addition, the American Academy of Pediatrics (AAP) has developed [state-specific EPSDT reports](#) provide detailed information about each state Medicaid program's Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) benefits and how they compare to the AAP/ Bright Futures 4th edition guidelines and recommendations. The reports also outline the state's quality performance information on pediatric preventive care measures and best practices. These profiles can be used to: compare visit/screening recommendations, review your **state's definition of medical necessity**, examine your state's use of quality measures and performance, evaluate your state's promising practices, and consider next steps. See [Using Your State EPSDT Profile](#).

In addition, for each state, the [AAP provides](#):

- **State Medicaid and CHIP Snapshots, 2018:** Underscores importance of Medicaid in providing coverage for children help them grow up healthy and thrive (in partnership with Georgetown University Policy Institute Center for Children and Families)
- **Children's Coverage Snapshot Fact Sheets:** Uses data on the ACA, Medicaid and CHIP to highlight how all three programs have worked together to ensure children's access to health coverage (in partnership with Georgetown University Policy Institute Center for Children and Families)
- **CHIP Fact Sheets:** Outlines how each state's CHIP program works for children (in partnership with the Georgetown University Policy Institute Center for Children and Families )
- **Medicaid Fact Sheets:** Explains the importance of Medicaid for children in each state (in partnership with the Children's Hospital Association)
- **EPSDT State Profiles:** Provides detailed information each state Medicaid program's Early and Periodic Screening, Diagnosis and Treatment (EPSDT) benefit and how this compares to AAP/Bright Futures guidelines and recommendations (supported by the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration).

## Advocates' Guide to Accessibility in Medicaid Managed Care Grievances and Appeals

The [Disability Rights Education and Defense Fund](#), [Justice in Aging](#) and [National Health Law Program](#) have developed the [Advocates' Guide to Accessibility in Medicaid Managed Care Grievances and Appeals](#). The guide describes steps to implement new HHS regulations on grievances and appeals in a manner that ensures equal access to these processes for people with disabilities.

## **AFFORDABLE CARE ACT (ACA)**

### **Administration Issues Final Rule on “Short-Term, Limited-Duration” Plans**

On August 1, the Internal Revenue Service, Department of the Treasury, Department of Labor, and Department of Health and Human Services (HHS) issued a [final rule](#) on “short-term, limited-duration” insurance (STLDI) plans. See [HHS press release](#). Under this rule, insurers will be able to offer insurance policies that do not offer the same “essential health benefits” or consumer protections that apply to plans meeting the standards of the Affordable Care Act (ACA). Such STLDI plans were permitted under the ACA, intended for people transitioning between jobs or needing temporary coverage for some other reason. Under regulations issued by the Obama administration, these plans were limited to a maximum period of less than three months. Under the new rule, STLDI plans can cover an initial period of less than 12 months, and, taking into account any extensions, a maximum duration of no longer than 36 months in total. Premiums for these plans will be less expensive than premiums for ACA-compliant plans because they can offer less robust benefits, can be denied to people with pre-existing conditions, and do not offer the other consumer protections of the ACA, such as the ban on annual and lifetime caps. Experts expect that these plans will attract younger, healthier consumers, meaning that consumers who need more robust coverage will end up paying higher premiums than they would if the insurance pool included everyone. In addition, consumer advocates are concerned that purchasers of STLDI plans may find that they do not have the coverage they need if they become sick or injured. See [Coverage That \(Doesn't\) Count: How the Short-Term, Limited Duration Rule Could Lead to Underinsurance](#) (blog of the Georgetown Center on Health Insurance Reform, 7/26/18).

The recent rule expanding “Association Health Plans” is expected to have the same impact. See [Buyer Beware of Association Health Plans](#) (The Hill, 7/25/18); [The New Association Health Plan Rule: What Are the Issues and Options for States](#) (blog of the National Academy for State Health Policy, 6/26/18).

### **HHS Resumes ACA Risk-Adjustment Payments to Insurers**

As reported earlier, the administration had decided several weeks ago that it would stop collecting and paying out the risk-adjustment payments established by the Affordable Care Act (ACA). These payments essentially transfer funds from insurance plans with low-risk consumers to plans with higher-risk ones. Cessation of the payments could have resulted in higher premiums. On July 24, CMS issued a [final rule](#) on the risk-adjustment methodology, and resumed the risk adjustment program. See [New Regulation Justifies CMS Risk Adjustment Formula For 2017; Program Will Resume](#).

### **CMS Issues Waivers for State Reinsurance Programs**

The Centers for Medicare & Medicaid Services (CMS) has approved waivers under Section 1332 of the ACA (“innovation waivers”) to permit Wisconsin and Maine to create reinsurance programs. Under such programs, the state helps insurance issuers cover very expensive claims in order to prevent premium increases. See [The Health 202: Meet the Unicorn of Health-Care Policy](#), (PowerPost blog of the Washington Post, 7/31/18). New Jersey and Maryland have also proposed reinsurance waivers. The Kaiser Family Foundation is maintaining a [Section 1332 Waiver Tracker](#).

### **More about Cuts in Navigator Funding**

As reported earlier, the administration announced in July that it would drastically reduce funding for ACA Navigators before the upcoming enrollment period. The Kaiser Family Foundation has developed a [state-by-state table](#) of the cuts in Navigator funding. A July 12 [post in the Health Affairs blog](#) provides

background information on the Navigator program and discusses the administration's rationale for reducing its funding. See also [Bracing for an Affordable Care Act Enrollment Season without Navigators: Risks for Consumers and the Market](#) (Blog of the Georgetown Center on Health Insurance Reform, 7/24/18).

### **In Other ACA News:**

[Individual market enrollment dropping amid premium increases](#)

## **TRICARE**

### **[Stay Covered After Age 21 with TRICARE Young Adult](#)**

(TRICARE Benefits Update, 7/25/18):

"Have you recently graduated from college, but you haven't found your dream job yet? Or did you just turn 21, and you're not enrolled in college? If you're worried about your health care coverage as a military dependent, TRICARE Young Adult (TYA) may give you the coverage you need. TYA eligibility begins when regular TRICARE coverage ends at age 21, or up to age 23 if enrolled in college."

## **OTHER NEWS, INFORMATION, AND RESOURCES**

### **Infographic: Financial Hardship in Families Raising CYSHCN**

The Catalyst Center has developed a [one-page infographic](#) to illustrate elements of financial hardship for families who have children and youth with special health care needs (CYSHCN). Resources about family financial hardship are listed at the bottom of the infographic.

### **Evaluation of State/Territorial Compliance with IDEA**

In its [Determination Letters on State Implementation of IDEA](#) (revised July 24, 2018) the Department of Education provided its annual assessment of state compliance with the Individuals with Disabilities Education Act (IDEA). With respect to Part B of the Act (for ages 3-21), the Department found that 21 states and territories earned the "meets requirements" designation for the 2016-2017 school years; 28 states and territories were in the "needs assistance" category; and Michigan, the District of Columbia, and two territories were in the "needs intervention" category, and the Bureau of Indian Education was classified as "needs intervention (7 consecutive years)." With respect to Part C (early intervention), 30 states and Puerto Rico were in the "meets requirements" category; 8 states were in the "needs assistance" category, and 13 states and four territories were in the "needs assistance (2 consecutive years)" category.

## **YOUR INPUT SOUGHT**

[Listed in order of due date, if applicable.]

### **[NEW CMS Tribal LTSS Program Survey](#)**

This survey is being conducted by the Centers for Medicare and Medicaid Services (CMS) to help them develop a list of tribally operated long-term services and supports (LTSS) programs across Indian

Country. The results will enable the sharing of LTSS best practices across Indian Country. Tribes and tribal organizations may provide these services directly, or through a contract or agreement with an outside organization.

**Research Survey for Caretakers of Women with Intellectual and Developmental Disabilities**

A researcher at Brandeis University is conducting a study on sexual and reproductive health care for women with intellectual and developmental disabilities. She is seeking family caregivers of such women to complete an [online survey](#). The goal of the survey is to understand the perspectives and experiences of family caregivers about sexual and reproductive health care for women with intellectual and developmental disabilities. The survey is available [here](#).

**OF POSSIBLE INTEREST**

[What It Says To My Daughter When Lawmakers Treat Accessibility as an Afterthought](#)  
(HuffPost, 7/26/18)

[Texas Couples Feel Pressure to Divorce to Afford Care for Disabled, Ill Children](#)  
(Dallas Morning News, 7/15/18)

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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! Comments and questions can be directed to [jguerney@familyvoices.org](mailto:jguerney@familyvoices.org).

Yours truly,  
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