

# **Greetings from Washington!**

Congress, the administration, and the courts have been active on issues related to child health and well-being during the past week. The Department of Health and Human Services (HHS) announced that it will significantly reduce funding for "Navigators" to conduct outreach and help people enroll in Affordable Care Act insurance plans. The administration also shut down federal websites that provided treatment and quality guidelines for health care providers. On another front, the administration has been struggling to comply with a court order to reunify immigrant families. One federal court temporarily halted deportation of recently reunified families, and another denied the administration's request to allow detention of children for longer than 20 days. In the House, the full Appropriations Committee approved a FY 2019 spending bill for the Departments of Labor, HHS, and Education. In the Senate, the Finance Committee held a hearing on paid medical leave. Read about all these issues and more in this week's Update.

July is <u>National Minority Mental Health Awareness Month</u>. Join a <u>Twitter chat</u> on July 18, 2-3:00 pm ET

## **UPCOMING WEBINARS AND CALLS**

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

## EPSDT Education for Providers and Advocates

**Wednesday, July 18, 1:00-2:30 ET** *Georgetown Center on Children and Families and the American Academy of Pediatrics* 

# NEW Health Action Webinar: The Impacts of Family Separation on Child and Family

Health Wednesday, July 18, 2:00-3:00 ET Families USA

# The Game-Changing Impact of Empowering Patients with Health Data

**Thursday, July 19, 1:00-2:00 ET** *FasterCures, the Milken Institute* 

# Cannabidiol (CBD) Use in Pediatric Treatment-Resistant Epilepsy

**Thursday, July 19, 3:00-4:00 ET** Family Voices of California

# NEW How to Talk About "Public Charge": A Communications Webinar for Policy

#### **Wonks**

Monday, July 23, 1:00-2:00 ET National Immigration Law Center and Center for Law and Social Policy

# **NEW** <u>Partnerships to Advance Tribal Health (PATH): A National Town Hall on</u> Combatting Opioids and Substance Abuse

Tuesday, July 24, 8:30 am-12:00 pm ET

(This is a live event in DC that will be <u>live-streamed</u>. *Register by <u>July 23</u>* for either type of participation.) *U.S. Department of Health and Human Services (HHS)* 

# **NEW Ticket to Work and Reasonable Accommodations**

Wednesday, July 25, 3:00-4:00 ET Social Security Administration

# **NEW The HOPE Initiative Launch Webinar**

#### Thursday, July 26, 11:00 ET

The Health Opportunity and Equity (HOPE) Initiative is a new resource that provides data on health, opportunity, and equity for all 50 states and the District of Columbia, funded by Robert Wood Johnson Foundation.

National Collaborative for Health Equity and Texas Health Institute in partnership with Virginia Commonwealth University's Center on Society and Health

# <u>A Conversation on Care Coordination for Children with Medical Complexity: Whose</u> Care Is It, Anyway?

**Thursday, July 26, 1:00-2:00 ET** Lucile Packard Foundation for Children's Health

## **NEW Ask TRICARE**

## Thursday, July 26, 1:00-2:00 ET

This Q&A webinar will include a panel of subject matter experts to answer your questions about TRICARE health care, pharmacy, and dental programs. <u>Read more</u>. *Military One Source* 

## **Collaborating with Non-Traditional Partners to Develop Diverse Family Leaders**

(for family organizations) Thursday, July 26, 1:30-2:30 ET National Center for Family/Professional Partnerships

# **NEW Outreach and Enrollment Strategies to Reach Rural Communities**

Tuesday, July 31, 1:00-2:30 ET

Insure Kids Now (HHS Connecting Kids to Coverage National Campaign)

# NEW Innovations in Education for Youth Recipients of Supplemental Security Income

(SSI) (Part 3 of a 5-part series on transitioning to employment for youth receiving SSI) **Tuesday, July 31, 2:00-3:00 ET** 

# Health and Human Services Partnership Success Story

**Tuesday, July 31, 3:30-4:30 ET** Alliance for Strong Families and Communities

# NEW Advisory Committee on Heritable Disorders in Newborns and Children (webcast)

Thursday, August 2, 9:30 am-3:00 pm ET
Register by Monday, July 30, at noon ET
Comments due July 27
Office of Disability Employment Policy, U.S. Department of Labor

# **NEW Demonstrating Medicaid's Value through Storytelling**

Wednesday, August 8, 3:00 ET Georgetown Center on Children and Families

# THE COURTS

Here are some analyses of healthcare decisions issued by Supreme Court nominee Brett Kavanaugh:

- <u>Kavanaugh Pick Could Affect Future of Obamacare, Medicaid Work Requirements</u> (Modern Healthcare, 7/10/18)
- <u>Examining Supreme Court Nominee Kavanaugh's Health Care Opinions</u> (To the Point, blog of the Commonwealth Fund, July 16, 2018)

# THE ADMINISTRATION

# **Reunification of immigrant families**

As reported in earlier Updates, the president instituted a policy of separating immigrant children and parents when they enter the US at the southern border in order to deter people from trying to enter the country illegally. The children were put into the custody of the Office of Refugee Resettlement in the Department of Health and Human Services (HHS), and were sent to various facilities across the country to be housed while their parents were detained separately by the Department of Homeland Security (DHS). Although the president later reversed the policy of family separation, there are more than 2000 children who have been separated from their parents.

On June 26, a <u>federal court ordered</u> that children under age five be reunited with their families by July 10, and that all other children be reunited with their families by July 26. The administration did not meet the first deadline; only about half of the young children were reunited with their parents. The

administration was using DNA tests to identify young children and to ensure that they were not reunited with a purported parent who is not actually the parent. They were also checking to see whether parents might be abusive.

In a <u>July 13 statement</u> HHS said that it has identified 2,551 minors 5 to 17 years of age in the department's custody who could potentially have been separated from a parent at the time of entry into the United States and therefore could potentially be eligible for reunification with a parent in the custody of DHS. To speed up the process, DNA tests will not be used for older children, as they should be able to identify themselves. See <u>HHS Submits Updated Plan for Reuniting Migrant Children with</u> <u>Parents</u> (Politico, 7/15/18).

Meanwhile, another <u>federal court refused</u> to grant the administration's request to change a current judicial settlement (the Flores Agreement) that forbids children to be held in detention facilities for more than 20 days. If children could be detained longer, the administration would detain parents and children together until their immigration hearings, which usually take place after a period much longer than 20 days.

In a related matter, on July 16 the federal judge handling the reunification case temporarily halted the deportation of families that have been recently reunited. The American Civil Liberties Union (ACLU), which represents the separated family members, requested this order because they had reason to believe that the administration planned immediate deportations of reunified families. In some cases, the children of parents who can be deported may be eligible to stay in the US, and the judge agreed that parents need time to carefully decide whether to have their children deported along with them. See Judge Temporarily Halts Trump Admin from Deporting Reunited Families (The Hill, 07/16/18).

# CONGRESS

# House Appropriations Committee Approved FY 2019 Labor-HHS-Education Appropriations Bill

Last week, the full House Appropriations Committee <u>approved</u> a bill to provide FY 2019 funding for the Departments of Labor, Health and Human Services, and Education. In total, the draft bill includes \$177.1 billion in discretionary funding, essentially the same as the 2018 enacted level. It provides a total of \$38.3 billion for NIH, an increase of \$1.25 billion above the fiscal year 2018 enacted level and \$4.1 billion above the President's budget request. Among the various NIH programs that received an increase is the Gabriella Miller "Kids First" pediatric cancer research initiative. Also of note: the bill provides \$655 million for the **Maternal and Child Health Block Grant**, an increase of \$3 million over the fiscal year 2018 enacted level, and \$12.3 billion for **IDEA special education grants** to states, an increase of \$50 million over the fiscal year 2018 enacted level, which will maintain the federal share of special education funding to states. The bill does **not** include additional funding to implement Affordable Care Act programs, prohibits funds for the "Navigators" program, and prohibits the collection of user fees from the Health Insurance Exchanges. The bill also includes the longstanding prohibition against using federal funds to advocate or promote gun control.

During the markup, Members from both parties offered **amendments related to the separation of immigrant families.** Adopted were amendments: to require HHS to submit a plan to reunify immigrant children with their parents; to clarify standards for family detention; to permit detention of families as Family Voices, Inc. • Mailing Address: P.O. Box 37188, Albuquerque, NM 87176 • Physical Address: 3701 San Mateo Blvd NE, Suite 103, Albuquerque, NM 87110 • Phone: 505-872-4774 • Toll Free: 888-835-5669 • Fax: 505-872-4780 • Website: www.familyvoices.org a unit; to support efforts to house immigrant children who are siblings together; to prohibit the administration of medication to unaccompanied alien children unless certain conditions deem such medication medically necessary; to require an Inspector General report on family separation and reunification politics; to reaffirm HHS statutory responsibilities for unaccompanied alien children; to direct \$10 million to fund mental health services for children separated from their families at the border; to prohibit funding for HHS to use questions of religion in the process of family reunification; to require a report on pre-literate unaccompanied alien children; to protect personal and genetic information of children and adults if used in the process of family reunification; and to require a report on the mental health of separated children.

See the bill <u>summary</u> (6/14/18), <u>report</u>, and <u>text</u> (6/13/18, without amendments).

#### Senate Finance Committee Holds Hearing on Paid Family Leave

On July 11, the U.S. Senate Finance Committee's Subcommittee on Social Security, Pensions, and Family Policy held a <u>hearing</u> – "Examining the Importance of Paid Family Leave for American Working Families." Among the witnesses was Sen. Joni Ernst (R-IA), who <u>testified</u> that she is working with colleagues Senators Marco Rubio (R-FL) and Mike Lee (R-UT) on legislation to provide new parents (only) with the option to receive paid leave, in exchange for which their Social Security retirement benefits would be deferred. Another witness was Senator Kirsten Gillibrand (D-NY), who <u>testified</u> in favor of the <u>FAMILY Act</u> (S. 337), which she sponsored. The FAMILY Act would establish a tax to fund paid leave taken for one's own illness, birth or adoption, or the care of other family members. A related bill (<u>H.R. 947</u>) has been introduced in the House.

#### MEDICAID AND CHIP NEWS, INFORMATION AND RESOURCES

## More than 7,000 fail to meet Medicaid work requirements in Arkansas

(The Hill, 07/16/18)

## WORTH REPEATING: Medicaid Social Media Toolkit

The American Association on Health & Disability has developed a <u>social media toolkit for Medicaid</u>. The toolkit provides sample social media posts as well as graphics and relevant hashtags which can be combined to underscore the importance of the Medicaid program, particularly for people with disabilities. The toolkit also provides lists of social media accounts to follow, digital materials, and Medicaid statistics. The toolkit is available on the website of the <u>National Disability Navigator Resource</u> <u>Collaborative</u>, where it can be downloaded as a zip drive.

# AFFORDABLE CARE ACT (ACA)

## **CMS to Reduce Funding for ACA Navigators**

Last week the administration announced that it will significantly reduce funding for ACA Navigators for the next open enrollment period (Nov. 1-Dec. 15, 2018, for 2019 plans). (See the <u>CMS press release</u>.) The Funding Opportunity Announcement for the Navigator Cooperative Agreement can be found <u>here</u>, and entering CA-NAV-18-001 in the "Opportunity Number" box under "Basic Search Criteria." Navigator **applications are due on August 9**.

# WORTH REPEATING: New Application/Renewal Process for the Certified Application Counselor (CAC) Program

As reported last week, (CMS) is also implementing a new application and renewal process for <u>Certified</u> <u>Application Counselor Designated Organizations</u> (CDOs). Any organization seeking to become a <u>Certified Application Counselor</u> (CAC) for Plan Year 2019 must apply to become a CDO. Existing CDOs that fail to reapply during the CAC Program re-application window will be de-designated and will not be permitted to certify CACs or assist consumers. In preparation for the next Open Enrollment Period, the **deadline to submit an application to become a CDO is September 14, 2018.** The CDO Application can be accessed <u>here</u>; guidance for completing the application can be found <u>here</u>.

### CMS to Withhold Risk-Adjustment Payments to Insurers - Updated

As reported in the last Update, CMS <u>announced</u> that it will not be making the "risk adjustment" payments to insurers as prescribed by the ACA. These payments are intended to prevent adverse selection by consumers, and risk selection ("cherry-picking") by insurance companies by redistributing funds from plans with lower-risk enrollees to plans with higher-risk enrollees. See <u>Explaining Health</u> <u>Care Reform: Risk Adjustment, Reinsurance, and Risk Corridors</u> (Kaiser Family Foundation, 8/17/16); <u>Trump Administration Freezes Payments to Affordable Care Act Insurers with Sicker Patients</u> (Fortune, 7/8/18).

**Update:** Some health-policy experts believe that this decision will cause insurance premiums to rise, disproportionately affecting people with pre-existing conditions. Insurance and consumer groups are also very concerned. On July 17, a group of House and Senate Democrats who serve on health committees wrote to HHS Secretary Azar and CMS Administrator Verma to express their disagreement with the decision and ask for information about how it was reached. See Democrats Ask Trump to Backpedal Decision on Obamacare Risk Adjustment Program (Washington Examiner, 7/16/18). More significantly, it has been reported that the Chairman of the House Ways & Means Committee, Rep. Kevin Brady (R-TX), is in conversations with the administration about restoration of the payments, and that he has not ruled out legislative action to address the problem. See GOP Chairman in Talks with Trump Officials on Restarting Key Obamacare Payments (The Hill, 7/16/18).

## TRICARE

#### Ask TRICARE webinar

On Thursday, July 26, 1:00-2:00 ET, TRICARE will present a Q&A <u>webinar</u> about TRICARE health care, pharmacy, and dental programs. <u>Read more</u>.

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

#### **NEWS:**

## **Government Shuts Down Websites on Treatment and Quality Guidelines**

On July 16, the administration took down two "microsites" from the website of the Agency for Healthcare Research and Quality (AHRQ) – the National Guideline Clearinghouse (guideline.gov), a source of vetted treatment guidelines for health care providers, and the National Quality Measures Clearinghouse (qualitymeasures.ahrq.gov). See <u>The Trump Administration Is about to Delete an</u>

Important Medical Resource (Vox, 7/16/18), and the administration's <u>Statement about the National</u> <u>Guideline Clearinghouse</u>.

# INFO:

# Spurring Innovation: The Role of Child Health Policy

A new report from AcademyHealth and Nemours reflects expert recommendations aimed at advancing child health policy on four pressing issues including Medicaid and CHIP delivery and payment reforms, consumer digital health, precision medicine, and opioid addiction and neonatal abstinence syndrome.

# **RESOURCES:**

## **Referral and Care Coordination Forms**

(National Academy for State Health Policy)

On this page, you can find examples of referral forms that are compliant with federal health (<u>HIPAA</u>) and education (<u>FERPA</u>) privacy and confidentiality requirements; feedback forms to inform primary care providers of the results of evaluations; and referral guidelines. The site also provides a map showing states that have standardized referral forms.

# A Guide to Taking Care of Your Family Member after Treatment in the Emergency Department (for attempted suicide).

SAMHSA has published an update to this guide that offers information about what to expect in the emergency room, and how to take care of yourself and your family member following a suicide attempt. This guide is also available in <u>Spanish</u> language. (From the Substance Abuse and Mental Health Services Administration.)

# **YOUR INPUT SOUGHT**

[Listed in order of due date.]

## **Best Practices in Guardianship**

<u>@SenateAging</u> is taking comment on best practices in guardianship through July 20, 2018, to inform a report they are producing. Email <u>comment@aging.senate.gov</u>. Topics include data collection, avoiding exploitation by guardians, removing guardianships when no longer needed, and others. (Thanks to Jennifer Akers)

# 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 <u>online survey</u>. 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 <u>here</u>.

# **OF POSSIBLE INTEREST**

# Seeking Clarity On Racial Disparities, Democrats Ask Insurers About Maternal Health Coverage (Fiercehealthcare, 7/16/18)

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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!

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

Yours truly, Janis Guerney Director of Public Policy Family Voices

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