
[info] IGNITE! Public Policy and Advocacy Newsletter - Jan 2018

1 message

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BUDGET/APPROPRIATIONS

The Federal government is back to business following a three-day shutdown that began at midnight on January 19. This fourth [continuing resolution](#) (CR) was necessary because Congress has failed to pass any of the 12 annual appropriations bills for Fiscal Year 2018 that began on October 1, 2017. The current CR is set to expire on February 8. That means Congress has just three weeks to come to agreement on spending levels as well as other sticky issues such as the Deferred Action for Childhood Arrivals program. The stalemate over the CR ended when Republican leaders agreed to allow a vote on the DREAM Act within the next three weeks. The CR extends funding for the Children's Health Insurance Program (CHIP) program through Fiscal Year 2023 but did not reauthorize the program (see [more details on CR changes to CHIP](#) in the NASHP newsletter).

FAMILY SUPPORTS

The Autism Society is pleased to report that President Trump signed the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act into law on Monday ([see the Autism Society Statement](#)). The RAISE Family Caregivers Act directs the Department of Health and Human Services to develop, maintain, and periodically update a Family Caregiving Strategy, a recommendation of the Commission on Long-Term Care. The Department is also charged with convening a Family Caregiving Advisory Council for the joint development of the strategy. Elements of the strategy are to include recommended actions that Federal, State, and local governments and other entities may take to promote person and family-centered care, family involvement in assessment and service planning, information sharing and care coordination with service providers, respite options, financial security and workplace issues, and efficient service delivery. The Autism Society signed onto a [CCD letter](#) thanking Members of Congress who voted for the bill.

HEALTH CARE & HOME AND COMMUNITY SERVICES

Health and Human Services Secretary

The Senate confirmed Alex Azar on January 24 as secretary of Health and Human Services (HHS) on a 55-43 vote, with six Senate Democrats and one Independent joining nearly all Republicans to vote in favor of his appointment. Mr. Azar has served as a pharmaceutical company executive and as general counsel and deputy secretary of HHS in the George W. Bush Administration. Azar replaces Tom Price who resigned in September. Azar says he will prioritize reducing drug prices. He has also been a consistent critic of the Affordable Care Act but also says he wants to make health care more affordable in the marketplaces.

Medicaid

House and Senate Republicans and Democrats are meeting at the end of the month to determine their respective caucus' legislative priorities for 2018. Key House and Senate leaders have indicated that they would like to cut spending on federal program such as Medicaid in response to the \$1.5 trillion dollar loss of revenue due to the tax cuts. Some leaders have been careful to say that Medicare and Social Security are off the table for possible cuts but Medicaid, food assistance, Supplemental Security Income and others remain targets.

The only feasible way for Congress to enact major cuts or caps to Medicaid this year is through special budget rules (known as [reconciliation](#)) that allow the Senate to pass budget-related legislation with a simple majority (51 instead of 60 votes). A budget resolution does not have to have reconciliation instructions. The Autism Society issued an action alert yesterday urging affiliates to ask Members of Congress to refuse to include reconciliation instructions in any budget legislation and instead seek bipartisan efforts to strengthen Medicaid and other social programs people with disabilities rely on.

The disability community must remind Congress that we support the Medicaid program and that they should not take steps to cut or cap the program (send them positive stories). The Autism Society also signed onto a coalition letter this week addressed to House and Senate leaders urging them to oppose any new cuts to federal health programs or other essential components of our nation's social safety net.

Group Home Investigation

Last week, the U.S. Department of Health and Human Services, Office of Inspector General (OIG); Administration for Community Living (ACL); and Office for Civil Rights (OCR) issued [a joint report](#) regarding the health and safety of group homes. The OIG investigated group homes in three states: Connecticut, Massachusetts and Maine. According to the report, OIG found serious lapses in basic health and safety practices in group homes. The joint report provides suggested model practices to the Centers for Medicare & Medicaid Services (CMS) and States for comprehensive compliance oversight of group homes to help ensure better health and safety outcomes. In addition, the Joint Report provides suggestions for how CMS can assist States when serious health and safety issues arise that require immediate attention. See the [full report](#) on the HHS website. CMS Administrator Seema Verma sent [a letter](#) to OIG in response to the recommendations put forward in the report.

Conscience and Religious Freedom Division

On January 18, the U.S. Department of Health and Human Services (HHS) [announced](#) the formation of the Conscience and Religious Freedom Division in the HHS Office for Civil Rights (OCR). HHS stated that this "division has been established to restore federal enforcement of our nation's laws that protect the fundamental and unalienable rights of conscience and religious freedom." The Autism Society is concerned that this new division could lead to discrimination against individuals' right to receive health care, including people with disabilities. See OCR Director Roger Severno [public announcement](#) recorded via Facebook Live.

Medicaid Work Requirements

On January 11, CMS issued a [State Medicaid Director Letter](#) providing new guidance for Section 1115 waiver proposals that would impose work requirements (referred to as "community engagement") in Medicaid as a condition of eligibility. The guidance describes the potential scope of requirements that could be approved and presents the case for how these policies promote the objectives of the Medicaid program. CMS has already approved a work requirement waiver in Kentucky (a [class action lawsuit](#) against the KY waiver was announced yesterday). Eight other states (AR, AZ, IN, KS, ME, NH, UT, and WI) have pending waiver requests that would require work as a condition of eligibility for expansion adults and/or traditional populations (see [Kaiser Family Foundation Waiver Tracker](#)).

Twenty-nine Senate Democrats, led by Senate Finance Committee Ranking Member Ron Wyden (D-OR), sent a [letter](#) to Acting Health and Human Services (HHS) Secretary Eric Hargan expressing serious concern with recent administrative actions and calling into question the Administration's authority to approve state Medicaid waivers that violate the statutory intent of the program to provide health care to Americans who lack the resources to afford necessary medical services.

While the work and community engagement requirements do not apply to individuals eligible for Medicaid based on a disability, CMS notes that some other Medicaid-eligible individuals could have an illness or disability as defined by other federal statutes that could affect their ability to comply with Medicaid work and community engagement requirements. Advocates in States seeking these waivers must make sure individuals are not denied Medicaid due to any inability they may have to comply with the requirements. People with disabilities in these states will need help navigating the system to obtain an exemption for which they qualify and end up losing coverage.

For more details, see [Six Reasons Work Requirements Are a Bad Idea for Medicaid](#) by Families USA, an [issue brief](#) by the Center on Budget and Policy Priorities, an [analysis](#) by the National Academy for State Health Policy, and [New York Times article](#).

GAO Report on HCBS

The General Accounting Office (GAO) published a [report](#) on January 26 regarding how states assess needs for eligibility for Medicaid Home and Community Based Services (HCBS). The report addresses (1) how selected states assess needs for HCBS, and (2) steps CMS has taken to improve coordination and effectiveness of needs assessments, among other objectives. In the report, GAO recommends that CMS ensure that all Medicaid HCBS programs have requirements for states to address both service providers' and managed care plans' potential for conflicts of interest in conducting assessments. HHS concurred with GAO's recommendation (see [full report](#) for more).

Kevin and Avonte's Law

Right before the Congress adjourned for the Christmas holiday, the Senate unanimously passed Kevin and Avonte's Law (S. 2070). It was hoped that the House would also pass its companion bill before adjournment but Congress ran out of time. The bill reauthorizes the expired Missing Alzheimer's Disease Patient Alert Program, and broadens it to support to people with autism and other developmental disabilities. Unfortunately, a provision identified to pay for the cost of this legislation was used in the most recent continuing resolution. The Autism Society is setting up Hill visits with other national partners to urge the House to take action on this bill. Advocates are encouraged to meet with Representatives and urge them to co-sponsor this bill. The more co-sponsors we have, the better! Find your member of Congress on [GovTrack](#).

EDUCATION

Secretary DeVos recently announced the approval of a number consolidated state plans under Every Student Succeeds Act: [Minnesota](#) and [West Virginia](#) (January 10 [release](#)) and [Arkansas](#), [Maryland](#), [Missouri](#), [New York](#), [Ohio](#), [Pennsylvania](#), [South Dakota](#), [Washington](#), [Wisconsin](#), [Wyoming](#), and [Puerto Rico](#) (January 16 [release](#)) were among the 34 states and Puerto Rico to submit their state plans by the final deadline of September 18, 2017.

A [Center for American Progress](#) report provides new data that reveals that although children with disabilities represent a relatively small proportion of the population of children ages 3 to 5 attending preschool, they make up a disproportionately large share of suspensions and expulsions. Children with any disability or social-emotional challenge make up only 13 percent of the preschool population, but they constitute 75 percent of all early suspensions and expulsions. The odds of being suspended or expelled were more than 43 times higher for children with behavioral problems. The authors also provide policy recommendations for reducing such suspensions and expulsions.

RIGHTS

On December 21, the U.S. Department of Justice rescinded its Statement on Application of the Integration Mandate of Title II of the Americans with Disabilities Act and *Olmstead v. L.C.* to State and local Governments' Employment Service Systems for Individuals with Disabilities. The statement, which was issued last year, described the obligations of states to administer their employment services for people with disabilities in the most integrated setting appropriate. Evidence-based supported employment services help people with disabilities secure and maintain competitive, integrated employment. They are critical to achieving the ADA's goals of independent living and economic self-sufficiency. The CCD and CPSD issued a [joint statement](#) in response to this action and met with the Office of Civil Rights to discuss our concerns.

ABLE ACT

The Able National Resources Center developed a [summary of changes](#) to the ABLE programs as a result of the recently signed tax law. These include the ability to increase financial contributions and a new ability to rollover 529 plans.

In addition, the ABLE National Resource Center, a collective group of leading, national disability organizations (including the Autism Society) united to help implementation of the ABLE Act, seeks to identify up to eight ABLE account owners to participate as an Advisor Group to the Center. See the [announcement](#) with more information on the Resource Center site.

INTER-AGENCY AUTISM COORDINATING COMMITTEE

On January 18, the Inter-agency Autism Coordinating Committee (IACC) met for its quarterly meeting. Jim Ball, Immediate Past National Board President, represented the Autism Society at the meeting. He reports that the meeting started out with an excellent presentation by Marcella Ronyak, Ph.D., Deputy Director, Division of Behavioral Health, Indian Health Service (IHS) Headquarters, HHS. It discussed, Advancing Behavioral Health in the Indian Health System. Dr. Ronyak and for sized heavily working with families and building trust with the system.

The committee then discussed Summary of Advances. These are research studies that have been recently published looking at a variety of different issues for those with autism spectrum disorder.

The afternoon started with a very lively discussion after one of the oral comments. Dr. Lee Wachtel Spoke about those with an autism spectrum disorder that can't speak for themselves. She urged the IACC to have greater participation from family members who have children that are significantly challenged on the spectrum. This was followed by a very frank discussion about everybody's unique role on the committee and how they represent autism.

The last presentation on early identification of children with autism was focused on research results related to early detection; however all of the speakers also addressed treatment options for families. The panel consisted of the following

presenters:

Denise Pintello, Ph.D., M.S.W.
Chief, Child and Adolescent Research Program, NIMH
Acting Chief, Dissemination and Implementation Research Program, NIMH

Amy Wetherby, Ph.D., C.C.C.-S.L.P.
Distinguished Research Professor, Department of Clinical Sciences, Florida State University
Director, Autism Institute, Florida State University

Emily Feinberg, Sc.D. C.P.N.P.
Associate Professor, Department of Community Health Sciences, Boston University School of Public Health
Associate Professor of Pediatrics, Division of General Pediatrics, Boston University School of Medicine

Alice Carter, Ph.D.
Professor, College of Liberal Arts, University of Massachusetts, Boston

The treatment options discussed by this panel were specific to each of the geographical areas, but families after diagnosis were connected with the appropriate agencies. For more information, or to watch the archived event, visit the IACC [website](#).

AUTISM SOCIETY NATIONAL CONFERENCE

The Autism Society of America is headed back to the Nation's Capitol for its 50th Annual National Conference and Exposition, July 10 - 12, 2018. Washington, D.C. is home to the Autism Society's inaugural convening of individuals and families impacted by autism. This year's conference features innovative educational sessions, one-of-a-kind networking opportunities, great guest speakers, and a wealth of information on how the [Autism Society's Quality of Life goals](#) can help shape the future of autism. At our national conference, attendees will also engage with Congressional insiders and policy experts to gain insight on impacting change on Capitol Hill and at home. The event culminates with a Day on the Hill, where autism advocates from across the country meet with Congressional leaders and staff to discuss issues of critical importance to the autism community.

Stay tuned for more information – registration opens in early February 2018.

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