

TO: Autism CARES Grantees

FROM: Kim Musheno, AUCD Director of Public Policy

DATE: July 7, 2016

RE: Policy Update

Autism CARES Act

The [Autism CARES Act](#) (H.R. 113-157) was reauthorized in June of 2014 for five years (through 2019). CARES stands for Collaboration, Accountability, Research, Education, and Support. Originally titled the Combating Autism Act (P.L. 109-419) and signed by President George W. Bush in 2006, the law was intended to dramatically increase the federal government's response to what was then perceived as a crisis in the increasing numbers of individuals diagnosed with Autism Spectrum Disorders (ASD). The law expanded and coordinated existing federal efforts in this area: research being conducted within the National Institutes of Health (NIH), surveillance and awareness activities at the Centers for Disease Control and Prevention (CDC), and professional development and research into evidence-based interventions at the Health, Resources, and Services Administration (HRSA). An [Interagency Autism Coordinating Committee](#) (IACC) was tasked with making sure that all federal agencies were coordinating their efforts, sharing information, and obtaining input from people on the autism spectrum and family members as well as other outside experts.

During the last reauthorization, the new law required a General Accounting Office (GAO) report on transition services for students with disabilities. The GAO is currently researching this topic. It is hoped that the information from this report will lead to legislation to increase services for transitioning youth.

The law also helped to expand the number of sites/programs that provide interdisciplinary training to health professionals to screen, diagnose (or rule out) ASD and other developmental disabilities and provide interventions. Since the passage of the law in 2006, the MCH funded Leadership Education in Neurodevelopmental Disabilities and Related Services (LEND) programs have increased from 34 to 49. In the latest competition, three incumbent LEND programs lost funding (PA, AL, HI), while a whopping nine new LEND programs were established (CT, RI, LA, ME, MI, NY, DE and two in CA). AUCD will continue to work on educating Members of Congress about the work being accomplished under the CARES Act.

Fiscal Year 2016 Appropriations

The Congress is way behind in its duty to pass annual appropriations bills this year. Republicans holding the majority in Congress and the Democratic Administration cannot agree on budget priorities. The austere budget caps that Congress put in place several years ago make it difficult to provide sufficient funding to existing programs and provide any new funding for new initiatives. The continued partisan atmosphere, especially in a presidential election year, add to the difficulty.

The President provided his budget request in February that provided level-funding for Autism CARES HRSA programs. The Senate Committee passed its bill for the Departments of Labor, HHS, and Education that also provides level-funding for the HRSA “Autism and other DD” budget line item which funds the LEND and DBP programs. The Centers for Disease Control and Prevention Birth Defects and DD Center would receive a \$2 million increase under the Senate bill. The biggest winner would be the National Institutes of Health (NIH), which also funds Autism research under CARES. However, most of the \$2 billion increase proposed in the Senate bill, would likely go to efforts to address Zika, Cancer, BRAIN, and precision medicine initiatives.

Since the Congress has not acted on the annual funding bills, we believe the most likely scenario will be for Congress to pass a continuing resolution. This will keep all programs funded at the same level until Congress passes and the President signs the funding bills. Unfortunately, until the Congress decides to lift the budget caps, all government programs face the threat of budget cuts in the future.

IACC

The Interagency Autism Coordinating Committee (IACC), authorized by the Autism CARES Act, charged with creating and annually updating the federal government’s priorities for research, services and policy related to autism and related developmental disabilities, recently published a [notice](#) in the Federal Register that it is seeking comments from people with autism, family members, service providers, advocates and other interested parties as it develops its 2016 update. Comments should be related to the seven key topics that the panel traditionally addresses — screening and diagnosis, underlying biology of autism, risk factors, treatments and interventions, services, lifespan issues and surveillance and infrastructure — according to the notice. The IACC is accepting comments through July 29. Click [here](#) to submit your comments

AUCD staff member, Shannon Hayworth, was appointed to be on the panel for this term. She has been participating in the IACC meetings.

Kevin and Avonte's Law Act

Kevin and Avonte’s law (S. 2614), a bill introduced by Sen. Chuck Schumer (D-NY) on April 1, 2016, is intended to protect and prevent harm to individuals with ASD and other disabilities who tend to wander or elope. It Amends the Omnibus Crime Control and Safe Streets Act of 1968 to authorize grants to law enforcement agencies to: (1) reduce the risk of injury and death relating to the wandering characteristics of some individuals with autism and other disabilities, and (2) safeguard the well-being of individuals with disabilities during interactions with law enforcement. The bill directs the Bureau of Justice Assistance (BJA) grants to set aside \$11M for these grants.

The bill specifically requires grant awards to be used to: (1) provide education and resources to law enforcement agencies, first responders, schools, clinicians, and the public in order to reduce the risk of wandering by such individuals, help to identify signs of abuse in such individuals, increase their personal safety and survival skills, and facilitate effective communication with individuals who have

communication-related disabilities; (2) provide training and emergency protocols for school administrators, staff, and families; (3) provide response tools and training for law enforcement and search-and-rescue agencies, including tracking technology; or (4) provide response tools and training to law enforcement agencies in order to recognize and respond to individuals with intellectual and developmental disabilities. The bill also directs the Attorney General to establish standards and best practices relating to the use of tracking technology to monitor children with autism and other disabilities. AUCD signed on in support of this bill.

Family Supports

Currently, the majority (70 percent) of individuals with developmental disabilities are cared for at home with their families. There are several bills introduced in this Congress that support these family caregivers.

The Healthy Families Act ([HR 932](#) , [S. 497](#)) requires certain employers to provide paid sick leave to: (1) meet their own medical needs; (2) care for the medical needs of certain family members (including a domestic partner or the domestic partner's parent or child); or (3) seek medical attention, assist a related person, take legal action, or engage in other specified activities relating to domestic violence, sexual assault, or stalking.

The Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act of 2015(S. 1719/ H.R. 3099) was introduced by Senators Collins (R-ME), Baldwin (D-WI) and Reps. Harper (MS) and Castor (D-FL). This bill prioritizes family caregivers through the development and implementation of a national strategy to tackle the many problems and issues facing caregivers. The bill passed the Senate unanimously last December. The next step is for House consideration. Our current focus is on building cosponsors and urging Education & Workforce Committee leadership to support passage of the Senate-passed bill under suspension of the rules.

The Credit for Caring Act of 2016 (H.R 4708, S. 2759) amends the Internal Revenue Code to provide a nonrefundable credit for working family caregivers. The amendment will provide support to family caregivers who choose to care for a family member with a disability. These bicameral bills are identical and have bipartisan support in both chambers. The House bill was sponsored by Rep. Tom Reed (R-NY-23) and introduced on March 3rd; it was referred to the House Committee on Ways and Means. The Senate bill was sponsored by Joni Ernst (R-IA) and introduced on April 7th; it was referred to the Senate Finance Committee.

The Lifespan Respite Care Program was created in 2006 to increase the availability and coordination of respite care services for family caregivers of individuals with disabilities, regardless of age. The program received a small increase to \$3.36 million in 2016, but never received more than \$2.5 million per year from FY 2009 to FY 2015. AUCD is urging the Congress to reauthorize the program and increase funding so that every state can benefit.

Community Based Services

AUCD is actively participating in a coalition working on the implementation of the Home and Community Based Services (HCBS) Rule. In January 2014, the Centers for Medicare and Medicaid Services (CMS) released the final [HCBS Settings Rule](#). Services governed by this rule benefit individuals with intellectual or developmental disabilities (I/DD), mental illness, physical disabilities, and/or aging populations. This rule requires that the places where people receive HCBS waiver services offer full access to the benefits of community life similar to those who do not receive Medicaid funds. This includes being provided support and opportunities for employment, independence, inclusion in an array of community activities, and realizing individual rights. States were given 15 months to develop and submit a [statewide transition plan](#) (STP) to meet the requirements of the new rule. Following submission of the initial plan, states were given five years (through March 2019) to come into compliance. Currently, CMS is reviewing each plan and communicating with states any clarification and/or modifications needed for final approval. On April 13, 2016 CMS granted Tennessee final approval of their STP (the only state thus far to be granted full approval) and in June granted initial approval to Ohio and Kentucky.

ACA

AUCD continues to support the implementation of the ACA and works in partnership with the CCD Health Task Force to provide comments and recommendations on how to implement it in the most appropriate and effective manner. In light of the upcoming election, on June 22, Speaker of the House Paul Ryan (R-WI) unveiled the Republican [blueprint](#) to replace the Affordable Care Act and fundamentally restructure the Medicaid and Medicare programs. The proposal claims an increased flexibility by providing states the option to choose a block grant for the Medicaid program or a per capita cap (though a per capita cap would be the default option); a block grant provides a set amount of federal spending regardless of enrollment, whereas a per capita cap does account for enrollment while establishing a limit on how much to reimburse states per enrollee. Either option results in a fundamental restructuring of Medicaid financing with the goal of achieving federal savings. Furthermore, if costs are above per enrollee amounts, the states would need to cover the costs or make cuts to provider reimbursement, eligibility or services, or shift costs to individuals receiving services or their family members. The plan also proposes to give states additional flexibility to increase cost sharing, add waiting lists, and limit benefits. Additionally, the plan intends to add a work requirement to the Medicaid program, end the option to expand Medicaid, and phase out the increased federal match for the states that have already expanded Medicaid. AUCD, along with the CCD Health Taskforce, is in the process of reviewing the proposal and will continue to provide input to Congress.

Medicaid and CHIP Managed Care Final Rule

In May 2016, the Centers for Medicare & Medicaid Services (CMS) finalized regulatory changes for managed care in Medicaid and the Children's Health Insurance Program (CHIP) (which is the first update to managed care regulations for Medicaid and CHIP since 2002). The Final Rule's effective date is July 5, 2016; the new provisions will be implemented in phases over three years, beginning July 1, 2017 and compliance with CHIP provisions beginning with the state fiscal year starting on or after July 1, 2018. The application of the various provisions in the rule varies depending on the type of managed care entity: managed care organization (MCO), primary care case management (PCCM) and primary care case

management entity (PCCM entity), prepaid inpatient health plan (PIHP) and prepaid ambulatory health plan (PAHP). Among its several goals, the new rules strengthen network adequacy by requiring states to establish quantitative time and distance standards for specified provider types and by recognizing the unique needs of children. At a minimum, they must establish such standards for: Pediatric and adult primary care; Pediatric and adult specialty care; Pediatric dental care; OB/GYN; Pediatric and adult behavioral health; Hospital; Pharmacy; and Long-term services and supports (LTSS) for enrollees that must travel to the LTSS provider. The regulations have long required that states ensure that care and services are coordinated for all MCO, PIHP, and PAHP enrollees. Plans were required to implement mechanisms to identify persons with special health care needs, to ensure that they are assessed, have treatment plans, and their needs are met. The final rule modified this requirement to include the needs of those who need LTSS. Despite requests from stakeholders, CMS declined to define the term “special health care needs,” preferring to leave it to the states’ discretion. There is therefore an opportunity for child health stakeholders to urge their states to include a specific definition of “children and youth with special health care needs” (CYSHCN) when they define the term generally.

Furthermore, the proposed regulations added a requirement that MCO, PIHP, and PAHP contracts define medical necessity in a manner that meets Early Periodic Screening, Diagnostic and Treatment’s (EPSDT) requirements, including the broad medical necessity standard. CMS stated that it “believed the change was necessary to ensure that state definitions of medical necessity complied with federal EPSDT laws.” However, in the final regulation, CMS removed the reference to EPSDT and revised the regulation to provide – “Each contract between a state and an MCO, PIHP, or PAHP must do the following: Require that the services be furnished in an amount, duration and scope that is no less than the amount, duration, and scope for the same services furnished to beneficiaries under Fee For Service (FFS) Medicaid.

Education

ESEA

The reauthorization of the Elementary and Secondary Education Act (ESEA) was a major priority for AUCD. In December, the President signed into law the Every Student Succeeds Act (ESSA), which replaced No Child Left Behind. AUCD worked extensively with members of both the Senate Health, Education, Labor and Pensions Committee and the House Education and Workforce Committee to ensure that the interests of individuals with disabilities were represented in the final bill. AUCD is now working with its DD and civil rights partners on plans to work together to assist state advocates to implement the law effectively.

Higher Education

The reauthorization of the Higher Education Act (HEA) is on the list of priorities for the House and Senate Education Committee chairmen, although time is running out for this Congress. AUCD took the lead on developing principles and recommendations for the Consortium for Citizens with Disabilities (CCD) regarding disability in the HEA.

The House and Senate Education Committees are also currently working on the reauthorization of the Carl D. Perkins Career and Technical Education (CTE) Act. AUCD helped to put together a set of principles and recommendations on how to include students with disabilities within the law. AUCD staff

recently met with staff of key members of the HELP Committee working on the CTE bill to discuss the recommendations.

On June 28, Reps. Glenn “GT” Thompson (R-PA) and Katherine Clark (D-MA), introduced the bipartisan “Strengthening Career and Technical Education for the 21st Century Act”. The [bill](#) reauthorizes and reforms the Carl D. Perkins Career and Technical Education Act and improves alignment with the updated Every Student Succeeds Act and the Workforce Innovation and Opportunity Act. Reps. Bradley Byrne (R-AL), Carlos Curbelo (R-FL), Jim Langevin (D-RI), and Rick Nolan (D-MN) are also original co-sponsors. See the House Committee on Education and the Workforce for a [staff summary](#). AUCD provided suggestions for changes to this legislation to provide greater access for students with disabilities in CTE programs.

Employment

AUCD is continuing to monitor state plans and current deadlines related to the implementation of the Workforce Innovation and Opportunity Act (WIOA). This law provides more emphasis on assisting people with disabilities to obtain and retain competitive, integrated employment. For example, the law requires the state VR agencies to maintain 15% of its allotment for youth transition services; a new Section 511 limits the use of subminimum wage by requiring individuals to be provided numerous services and to at least try competitive, integrated work before accepting a subminimum wage job; and more resources are provided for supported employment.

In addition, an Advisory Committee on Increasing Competitive Integrated Employment for Individuals with Disabilities ([ACICIEID](#)) was authorized. This committee is charged with developing recommendations on ways to increase competitive integrated employment opportunities for individuals with intellectual or developmental disabilities or other individuals with significant disabilities, and on the use of certificate programs under [section 14\(c\)](#) of the Fair Labor Standards Act (FLSA) and ways to improve oversight of the use of such certificate. IN UCEDD director, David Mank, chairs the committee. The committee is set to announce its final recommendations in the Fall.

The U.S. Department of Education and Department of Labor released final rules for W.I.O.A. on June 30th. The [joint DOL and DoED rules](#) address state plans and performance accountability for One-Stop and Vocational Rehabilitation systems. The [Rehabilitation Services Administration rules](#) address pre-employment transition services, limitations on subminimum wage placements, and supported employment services. States will be implementing these changes over the next three months.

Autism Awareness and Acceptance

During April, AUCD celebrated Autism Awareness and Acceptance month by inviting selected speakers to write about any experiences or thoughts related to ASD. AUCD’s public policy director contributed stories to the selection. In addition, several issues of [Tuesdays With Liz: Disability Policy For All](#) were dedicated to interviewing individuals on the spectrum and family members.