

Documents for the Record

Full Committee Markup

June 12, 2024

Majority:

- June 11, 2024 - Statement submitted by the Association of University Centers on Disabilities
- June 11, 2024 - Statement submitted by the National Association of Pediatric Nurse Practitioners
- June 12, 2024 - Statement submitted by Autism Speaks



June 11, 2024

Dear Chairwoman McMorris Rogers, Ranking Member Pallone, and Members of the Energy and Commerce Committee,

We are writing to thank you for including the Autism CARES Act of 2024, H.R. 7213, in tomorrow's Energy and Commerce mark-up. The Association of University Centers on Disabilities (AUCD) fully supports the H.R. 7213 and the proposed amendments. This piece of legislation is crucial to maintaining and improving the monitoring, training, and research programs throughout the U.S. Department of Health and Human Services focused on children and adults with autism, other neurodevelopmental disabilities, and their families.

The CARES Act was first signed into law by President George W. Bush in 2006 (P.L. 109-416). The purpose of the CARES Act is to create a coordinated response and increase investments across the U.S. Department of Health and Human Services to address the dramatically rising numbers of children and adults diagnosed with autism. According to the Centers for Disease Control and Prevention (CDC), approximately 1 in 36 children have been diagnosed with autism - an increase of approximately 300 percent since 2006.

AUCD is the national non-profit membership organization that supports and promotes a national network of 143 university-based interdisciplinary programs, including the University Centers for Excellence in Developmental Disabilities, Leadership Education in Neurodevelopmental Disabilities programs, and Eunice Kennedy Shriver Intellectual and Developmental Disability Research Centers. AUCD members conduct research, create innovative programs, provide training, and disseminate information about best practices in the service delivery system that support people with disabilities and their families in every state and territory. The programs serve as a bridge between the university and the community, bringing together the resources of both to achieve meaningful change.

To improve the diagnosis, treatment and health and well-being of children and adults with autism and other neurodevelopmental disabilities, two training programs are included. AUCD is pleased to see H.R. 7213 strengthens the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs. The current CARES Act also includes a training program to train developmental behavioral pediatricians (DBP). These two programs support the training of future professionals in a range of professional disciplines that diagnose and manage the health of individuals with autism and other neurodevelopmental disabilities. In Fiscal Year 2021, LEND and DBP programs provided diagnostic services to over 137,000 children; and provided training to over 22,000 trainees in pediatrics, other health professions and people with lived experience.

Derrick Willis, MPA
President

Ilka Riddle, PhD
President-Elect

Carol Salas Pagán, PsyD
Past-President

Linda Russo, MAEd
Secretary/Treasurer

Melanie Davis
Council on Leadership and Advocacy

Wendy A. Jones, MEd, MSW
Multicultural Council

Beth Boone, PhD, BCBA
Community Education and Dissemination Council

Eric J. Moody, PhD
Council on Research and Evaluation

Jenean A. Castillo, PhD
National Training Directors Council

Pablo Juárez, MEd, LBA, BCBA
Member at Large

Sharon Milberger, ScD
Member at Large

Rhonda M. Eppelsheimer, MSW
Member at Large

Mark Crenshaw, MTS
Member at Large

Marcia Moriarta, PsyD
Member at Large

Michael Thornton
Member at Large

Randall Owen, PhD
Member at Large

John Tschida, MPP
Executive Director



AUCD is pleased to see that H.R. 7213 also includes provisions to ensure research includes persons with autism with a higher level of functional support needs and on the aging process for individuals with autism. AUCD also is pleased to see that H.R. 7213 requires a Government Accountability Office study to increase the number of DBPs and to establish a new Center focused on communication needs.

The training, research and services included in the H.R 7213 are working to effectively address the rising number of children and adults diagnosed with autism and other neurodevelopmental disabilities to ensure they have the best opportunity to receive the care and treatment they need so they can live inclusive lives in their communities.

Thank you for considering our views. If you have any questions, please do not hesitate to contact Cindy Smith, Director of Public Policy at [REDACTED].

Regards,

John Tschida
Executive Director, Association of University Centers on Disabilities

cc: Representative Smith, and Representative Cuellar

Derrick Willis, MPA
President

Ilka Riddle, PhD
President-Elect

Carol Salas Pagán, PsyD
Past-President

Linda Russo, MAEd
Secretary/Treasurer

Melanie Davis
Council on Leadership and Advocacy

Wendy A. Jones, MEd, MSW
Multicultural Council

Beth Boone, PhD, BCBA
Community Education and Dissemination Council

Eric J. Moody, PhD
Council on Research and Evaluation

Jenean A. Castillo, PhD
National Training Directors Council

Pablo Juárez, MEd, LBA, BCBA
Member at Large

Sharon Milberger, ScD
Member at Large

Rhonda M. Eppelsheimer, MSW
Member at Large

Mark Crenshaw, MTS
Member at Large

Marcia Moriarta, PsyD
Member at Large

Michael Thornton
Member at Large

Randall Owen, PhD
Member at Large

John Tschida, MPP
Executive Director

June 11, 2024

The Honorable Cathy McMorris Rodgers
Chair
Committee on Energy and Commerce
U.S. House of Representatives
2125 Rayburn House Office Building
Washington, D.C. 20515

The Honorable Frank Pallone
Ranking Member
Committee on Energy and Commerce
U.S. House of Representatives
2322 Rayburn Office Building
Washington, D.C. 20515

Dear Chair Rodgers and Ranking Member Pallone,

On behalf of more than 8,000 pediatric nurse practitioners (PNPs) and pediatric-focused advanced practice registered nurses (APRNs) committed to providing optimal health care to children, the National Association of Pediatric Nurse Practitioners (NAPNAP) appreciates your consideration in advancing the "Accelerating Kids' Access to Care Act" (H.R. 4758). This bipartisan legislation will improve access to essential health care services for children enrolled in Medicaid or the Children's Health Insurance Program (CHIP) by streamlining provider screening and enrollment processes.

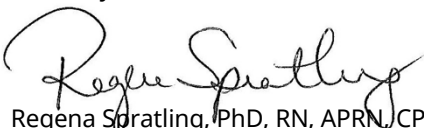
As the nation's only professional association for pediatric-focused APRNs, NAPNAP is dedicated to improving the quality of health care for infants, children, adolescents and young adults. With 18 special interest groups and 53 chapters, NAPNAP has been advocating for children's health since 1973 and was the first APRN society in the U.S. Our mission is to empower pediatric-focused APRNs and key partners to optimize child and family health. In a wide variety of primary, specialty, and acute care settings including children's hospitals and clinics, NAPNAP members are involved daily in providing services and care specifically suited to children with complex health conditions.

When a child enrolled in Medicaid or CHIP has clinical needs that cannot be met by providers in his or her home state, the state Medicaid agency and/or Medicaid managed care organization will work with the child's health care provider to determine that care needs to be delivered out-of-state. When this occurs, the out-of-state provider must be screened and subsequently enrolled in the child's home state Medicaid program. Under current law, states have the ability to use provider screenings done by other states or by Medicare, but no process currently exists to facilitate streamlined Medicaid screening and enrollment, meaning that providers frequently spend significant amounts of time addressing those requirements, which vary significantly between states. When this happens, access to care is delayed and, in too many cases, the child's health situation worsens.

The Accelerating Kids' Access to Care Act addresses this problem in a measured approach that balances access to care with the need for program integrity. It will establish a pathway for pediatric providers including PNPs and APRNs to enroll in multiple state Medicaid programs if they meet specific requirements including that they are in the lowest category for potential program integrity issues and are enrolled as providers in their home state Medicaid program. It focuses solely on the screening and enrollment of providers, not on authorization of care by an out-of-state provider or payment rates for any care - leaving both of those issues in the hands of state Medicaid agencies.

Again, NAPNAP and its members deeply appreciate your continued commitment to improving children's access to essential health care services. We strongly support the "Accelerating Kids' Access to Care Act" and urge you to favorably report it out of committee. We look forward to working with you to see this legislation enacted this year.

Sincerely,



Regena Spratling, PhD, RN, APRN, CPNP-PC, FAANP, FAAN
President

Cc: The Honorable Lori Trahan
The Honorable Mariannette Miller-Meeks



Autism Speaks *Support of the Autism CARES Act of 2024 (H.R. 7213)*

House Committee on Energy and Commerce

June 12, 2024 at 10:00am – 2123 Rayburn

Autism Speaks is a national, non-profit organization dedicated to creating an inclusive world for all individuals with autism throughout their lifespan. We do this through advocacy, services, supports, research and innovation, and advances in care for autistic individuals and their families. We are grateful to Chair McMorris Rodgers and Ranking Member Pallone for convening this markup and for co-chairs of the Autism Caucus, Reps. Chris Smith and Henry Cuellar, for introducing the *Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2024 (H.R. 7213)* to invest in autism research and training programs that ensure better care and well-being for autistic people.

As discussed in our statement submitted for subcommittee consideration, the Autism CARES Act exemplifies how bipartisan collaboration has fundamentally transformed our understanding of autism and shaped the landscape of services and support for the **1 in 36 children and 1 in 45 adults on the autism spectrum in the United States**.¹² The Autism CARES Act has been the single most important driver of federal investment in autism research and training programs since first passing in 2006 and, because of the investments made over the past two decades under previous iterations of the law, we are poised to take the next steps to advancing support for autistic people and their families. We are grateful to the leadership and members of this Committee for their recognition of this progress and for their efforts to continue **the Autism CARES Act, which must be renewed before September 30, 2024**, when significant provisions of the current law sunset.

As far as we have come in terms of our understanding of autism and acceptance of autistic people, there is so much work to do to ensure that every autistic person can access the personalized health care, services, and supports that meet their needs. **The Autism CARES Act of 2024 offers the opportunity to help close this gap and ensure that every autistic person can reach their full potential.** In addition to continuing the vital programs that have led to key progress, the bill includes important enhancements that would encourage research focused on the daily life challenges of autistic people across the lifespan with a new emphasis on autism and aging. The bill would add an Autism Intervention Research Network for Communication Needs (AIR-C) to address how to best support autistic people who are non-speaking or may need additional communication support. And it would further efforts for greater inclusivity in research activities, so that people

¹ Maenner MJ, Warren Z, Williams AR, et al. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020. *MMWR Surveill Summ* 2023;72(No. SS-2):1–14. DOI: <http://dx.doi.org/10.15585/mmwr.ss7202a1>.

² Dietz PM, Rose CE, McArthur D, Maenner M. National and State Estimates of Adults with Autism Spectrum Disorder. *J Autism Dev Disord*. 2020;50(12):4258–4266. doi:10.1007/s10803-020-04494-4

across the spectrum are better represented as we move closer to meeting the entire autism community's outstanding needs.

Finally, the Autism CARES Act of 2024 will for the first time provide the autism community with a **comprehensive, forward-looking budget plan for autism research** through the addition of a Professional Judgment Budget for Autism Research. This will provide the autism community and Congress with a clearly articulated resource on the priority research areas and resources needed to accomplish important research goals for the autism community, as outlined in recommendations by the Interagency Autism Coordinating Committee's Strategic Plan. Autism Speaks applauds the Committee for providing the transparency and accountability that the autism community deserves through this bill enhancement.

We are grateful for the Energy and Commerce Committee's work to advance the Autism CARES Act of 2024 and look forward to working with the Committee and House leadership to ensure the bill is quickly passed before portions expire in September. The Committee's leadership continues to be key in drawing attention to the urgent priority for federal research, training and data programs to meet the current and future needs of the autism community.