



MEMORANDUM

June 21, 2019

To: Subcommittee on Health Majority Members and Staff

Fr: Committee on Energy and Commerce Majority Staff

Re: Hearing on “Reauthorizing Vital Health Programs for American Families”

On **Tuesday, June 25, 2019, at 10 a.m. in room 2322 of the Rayburn House Office Building**, the Subcommittee will hold a legislative hearing titled “Reauthorizing Vital Health Programs for American Families.”

I. H.R. 1058, THE “AUTISM COLLABORATION, ACCOUNTABILITY, RESEARCH, EDUCATION, AND SUPPORT ACT OF 2019” or THE “AUTISM CARES ACT OF 2019”

A. Background

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that is defined by persistent and characteristic patterns of behavior and difficulties in social communication and interaction.¹ As its name suggests, ASD represents a spectrum of neurodevelopmental conditions; while those diagnosed with ASD share similar characteristics, individuals may have different strengths, severity of conditions, and challenges associated with those conditions.²

The number of children diagnosed with ASD has risen dramatically over the years. For children born in 1992, approximately one in every 150 children was diagnosed with ASD.³ That number grew to one in every 59 children for children born in 2006.⁴ It is unclear how much of the increase is due to broader diagnostic criteria for ASD, increased efforts to diagnose, or a

¹ National Institutes of Health, *Autism Spectrum Disorder Fact Sheet* (May 14, 2019) (www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Autism-Spectrum-Disorder-Fact-Sheet).

² *Id.*

³ Centers for Disease Control and Prevention, *Data & Statistics on Autism Spectrum Disorder* (Apr. 5, 2019) (www.cdc.gov/ncbddd/autism/data.html).

⁴ *Id.*

possible increase in the number of people with ASD.⁵ As efforts to identify children with autism have improved, so too has the ability to intervene and treat children. Early intervention for children with autism has been associated with a significant positive outcome on developmental outcomes of children.⁶

Recognizing the better understanding of ASD and greater numbers of diagnosed individuals, Congress enacted the Combating Autism Act⁷ in 2006, which authorized the expansion of federal ASD research, surveillance, early detection, prevention, treatment, education, and disability programs across several health agencies. The law also re-established the Interagency Autism Coordinating Committee (IACC), a federal advisory committee composed of representatives of federal agencies and members of the public, including people with ASD, parents or legal guardians of those with ASD, and researchers. The purpose of the IACC is to coordinate federal efforts around research and treatment of autism throughout federal agencies, and to provide advice to the Secretary of Health and Human Services (HHS) on issues related to ASD. The law was reauthorized in 2011, and again in 2014, after being renamed the Autism CARES Act.⁸ The Autism CARES Act of 2014 continued programs related to ASD surveillance, research, education, early detection, and intervention, and reauthorized the IACC. Additionally, Autism CARES required the appointment of a National Autism Coordinator within HHS and authorized funding through September 30, 2019.

B. Legislation

H.R. 1058, the Autism Collaboration, Accountability, Research, Education, and Support Act (Autism CARES Act), introduced by Reps. Chris Smith (R-NJ) and Mike Doyle (D-PA), would reauthorize funding for programs at the National Institutes of Health (NIH), Centers for Disease Control and Prevention (CDC), and Health Resources and Services Administration (HRSA) through 2024. The legislation expands efforts to conduct research, surveillance, education, detection, and intervention for all individuals with ASD across their lifespan, regardless of age. The bill also aims to reduce disparities among individuals from diverse racial, ethnic, geographic, or linguistic backgrounds, and directs additional care to rural and underserved areas. The five-year reauthorization includes annual authorizations of \$23.1 million for developmental disabilities surveillance and research, \$50.599 million for autism education, early detection, and intervention, and such sums as may be necessary to carry out the work of the IACC and other programs at the NIH.

II. H.R. 2507, THE “NEWBORN SCREENING SAVES LIVES REAUTHORIZATION ACT OF 2019”

⁵ Centers for Disease Control and Prevention, *Research on Autism Spectrum Disorder* (Apr. 26, 2018) (www.cdc.gov/ncbddd/autism/research.html).

⁶ Lonnie Zwaigenbaum et al., *Early Identification and Interventions for Autism Spectrum Disorder*, 136 *Pediatrics* S1 (Oct. 2015).

⁷ Pub. L. No. 109-416.

⁸ Pub. L. No. 113-157.

A. Background

Every year, over 12,000 newborns are born with conditions that require early detection and treatment.⁹ Newborn screening provides for early identification of certain genetic, metabolic, hormonal, and functional conditions that may be treatable, but not apparent at birth. With proper screening, parents can receive education and children can receive appropriate follow-up treatment. As medical and scientific knowledge have advanced since the first newborn screening test was developed in the early 1960s, dozens more tests and treatments became available, however a patchwork of state requirements for screening led to some newborns screened for many disorders, and others very few.¹⁰ In 2004, the American College of Medical Genetics recommended that every baby born in the United States be screened for a core set of 29 treatable disorders.¹¹ At that time, only 21 states screened for at least nine of the recommended conditions.¹² By 2008, significant improvements were made, but still, only 15 states and the District of Columbia required that infants be screened for all 29 recommended disorders.¹³

While newborn screening remains a state public health activity, Congress passed the Newborn Screening Saves Lives Act in 2008, to better standardize and improve newborn screening programs.¹⁴ The law codified the Recommended Universal Screening Panel (RUSP), which the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) at HRSA uses to make recommendations for conditions for which all newborns should be screened. To be considered as a core condition recommended for the RUSP, the condition must: (1) be able to be identified at a stage prior to when it would otherwise be apparent clinically (i.e., the screening must be necessary to identify the condition), (2) have a test with appropriate sensitivity and specificity available, and (3) have demonstrated benefits of early detection, timely intervention, and efficacious treatment of the condition.¹⁵ The law also authorized HRSA to develop a model decision-matrix for newborn screening expansion, and consider ways to ensure that all states attain the capacity to screen for the recommended conditions. The law also authorized research at the NIH to carry out research on newborn screening. Congress last reauthorized the law in 2014.

⁹ Government Accountability Office, GAO-17-196, *Newborn Screening Timeliness* (Dec. 15, 2016).

¹⁰ *Examining Public Health Legislation to Help Local Communities: Hearing on H.R. 1281 Before the Subcommittee on Health, Committee on Energy & Commerce*, 113th Cong. (Nov. 20, 2013) (statement of Edward R.B. McCabe, Chief Medical Officer, March of Dimes Foundation).

¹¹ *Id.*

¹² S. Rept. No. 110-280, at 2.

¹³ *Id.*

¹⁴ Pub. L. No. 110-204.

¹⁵ National Conference of State Legislatures, *State Newborn Health Screening Policies*, 25 LegisBrief 14 (Apr. 2017).

Today, the RUSP includes 35 core conditions.¹⁶ While all states have caught up to testing for the original 29 recommended conditions,¹⁷ and some have exceeded the current 35 recommended core conditions, others have lagged behind as more tests have been added.¹⁸

B. Legislation

H.R. 2507, introduced by Reps. Roybal-Allard (D-CA), Simpson (R-ID), Clark (D-MA), and Herrera Beutler (R-WA) would reauthorize newborn screening programs for five years. The bill includes reforms to ensure that the activities of the ACHDNC are transparent, including requiring the creation of a publicly accessible website which details the uniform screening panel nomination process. The bill also requires CDC to standardize data collection and reporting to track and monitor newborn screening in real time. Additionally, the bill orders a study on the modernization of newborn screening. The bill authorizes appropriations of \$60.65 million per year through 2024.

III. H.R. 776, THE “EMERGENCY MEDICAL SERVICES FOR CHILDREN PROGRAM REAUTHORIZATION ACT OF 2019”

A. Background

First enacted in 1984 as part of the Preventive Health Amendments of 1984,¹⁹ the Emergency Medical Services for Children (EMSC) Program is the only federal grant program specifically focused on addressing needs of children in emergency medical systems.²⁰ The program consists of six main investments: (1) the Pediatric Emergency Care Applied Research Network, which conducts research in Emergency Department (ED) and prehospital Emergency Medical Service (EMS) settings to improve health outcomes; (2) the State Partnership, which improves a state’s capacity for delivery of evidence-based pediatric emergency care while maintaining best practices; (3) State Partnership Regionalization of Care, which develops models of regionalized care for pediatric emergency services for children in tribal and rural communities; (4) the Targeted Issues initiative, which supports investigator-driven research translation into practice; (5) EMSC Data Center, which provides monitoring, data management, and other support for Pediatric Emergency Care Applied Research Network studies; and (6) the EMSC Innovation and Improvement Center, which helps state EMS systems achieve improved health outcomes in pediatric emergency care by testing and scaling demonstrated improvements.²¹

¹⁶ Health Resources and Services Administration, *Recommended Uniform Screening Panel* (Feb. 2019) (www.hrsa.gov/advisory-committees/heritable-disorders/rusp/index.html).

¹⁷ Scott M. Shone, *Newborn Screening Policy Decisions*, 80 N.C. Med. J. 1, 43 (Jan. 2019).

¹⁸ See note 15.

¹⁹ Pub. L. No. 98-555.

²⁰ Health Resources and Services Administration, *Child Health* (June 2019) (mchb.hrsa.gov/maternal-child-health-topics/child-health).

²¹ *Id.*

B. Legislation

H.R. 776, introduced by Reps. King (R-NY), Castor (D-FL), Stewart (R-UT), and Butterfield (D-NC), would reauthorize the Emergency Medical Services for Children Program at \$22.334 million dollars each year through 2024.

IV. H.R. 2035, LIFESPAN RESPITE CARE REAUTHORIZATION ACT OF 2019

A. Background

The Lifespan Respite Care program was first authorized by Congress in 2006.²² Respite care is defined as “planned or emergency care provided to a child or adult with a special need in order to provide temporary relief to the family caregiver of that child or adult.”²³ Respite services may be provided in settings such as a person’s home, adult day care centers, or residential care facilities.²⁴ States have flexibility to use program funds to support the availability of respite services in a variety of ways. For example, some states use funds for consumer-directed respite vouchers, training of volunteer and paid respite providers, or educating families about how to access respite care. The program is administered by the Administration for Community Living (ACL) and currently 20 states receive grants. Since 2009, ACL has contracted with the ARCH National Respite Network and Resource Center to provide technical assistance to program grantees.

B. Legislation

H.R. 2035, introduced by Reps. Langevin (D-RI) and McMorris Rodgers (R-WA), would reauthorize the Lifespan Respite Care program at \$20 million in fiscal year (FY) 2020, and increase the funding level by ten million each year thereafter through FY 2024. It would also add new reporting requirements for program grantees.

V. WITNESSES

Amy Hewitt, Ph.D.

Director

Institute on Community Integration, University of Minnesota

Joseph Bocchini, M.D.

Professor, Department of Pediatrics

Louisiana State University Health, Shreveport

²² Pub. L. No. 109-442.

²³ *Id.*

²⁴ Administration for Community Living, *The Lifespan Respite Care Program* (acl.gov/programs/support-caregivers/lifespan-respite-care-program).

Patricia Kunz Howard, Ph.D., RN

President, Emergency Nurses Association

Director, Emergency Services, University of Kentucky Healthcare

Jill Kagan

Director

ARCH National Respite Network and Resource Center