

# REAUTHORIZING VITAL HEALTH PROGRAMS FOR AMERICAN FAMILIES

---

## HEARING BEFORE THE SUBCOMMITTEE ON HEALTH OF THE COMMITTEE ON ENERGY AND COMMERCE HOUSE OF REPRESENTATIVES ONE HUNDRED SIXTEENTH CONGRESS

FIRST SESSION

---

TUESDAY, JUNE 25, 2019

---

**Serial No. 116-51**



Printed for the use of the Committee on Energy and Commerce  
[govinfo.gov/committee/house-energy](http://govinfo.gov/committee/house-energy)  
[energycommerce.house.gov](http://energycommerce.house.gov)

---

U.S. GOVERNMENT PUBLISHING OFFICE

43-926 PDF

WASHINGTON : 2022

## COMMITTEE ON ENERGY AND COMMERCE

FRANK PALLONE, JR., New Jersey  
*Chairman*

BOBBY L. RUSH, Illinois	GREG WALDEN, Oregon
ANNA G. ESHOO, California	<i>Ranking Member</i>
ELIOT L. ENGEL, New York	FRED UPTON, Michigan
DIANA DeGETTE, Colorado	JOHN SHIMKUS, Illinois
MIKE DOYLE, Pennsylvania	MICHAEL C. BURGESS, Texas
JAN SCHAKOWSKY, Illinois	STEVE SCALISE, Louisiana
G. K. BUTTERFIELD, North Carolina	ROBERT E. LATTA, Ohio
DORIS O. MATSUI, California	CATHY McMORRIS RODGERS, Washington
KATHY CASTOR, Florida	BRETT GUTHRIE, Kentucky
JOHN P. SARBANES, Maryland	PETE OLSON, Texas
JERRY McNERNEY, California	DAVID B. McKINLEY, West Virginia
PETER WELCH, Vermont	ADAM KINZINGER, Illinois
BEN RAY LUJAN, New Mexico	H. MORGAN GRIFFITH, Virginia
PAUL TONKO, New York	GUS M. BILIRAKIS, Florida
YVETTE D. CLARKE, New York, <i>Vice Chair</i>	BILL JOHNSON, Ohio
DAVID LOEBSACK, Iowa	BILLY LONG, Missouri
KURT SCHRADER, Oregon	LARRY BUCSHON, Indiana
JOSEPH P. KENNEDY III, Massachusetts	BILL FLORES, Texas
TONY CARDENAS, California	SUSAN W. BROOKS, Indiana
RAUL RUIZ, California	MARKWAYNE MULLIN, Oklahoma
SCOTT H. PETERS, California	RICHARD HUDSON, North Carolina
DEBBIE DINGELL, Michigan	TIM WALBERG, Michigan
MARC A. VEASEY, Texas	EARL L. "BUDDY" CARTER, Georgia
ANN M. KUSTER, New Hampshire	JEFF DUNCAN, South Carolina
ROBIN L. KELLY, Illinois	GREG GIANFORTE, Montana
NANETTE DIAZ BARRAGÁN, California	
A. DONALD McEACHIN, Virginia	
LISA BLUNT ROCHESTER, Delaware	
DARREN SOTO, Florida	
TOM O'HALLERAN, Arizona	

---

### PROFESSIONAL STAFF

JEFFREY C. CARROLL, *Staff Director*  
TIFFANY GUARASCIO, *Deputy Staff Director*  
MIKE BLOOMQUIST, *Minority Staff Director*

SUBCOMMITTEE ON HEALTH

ANNA G. ESHOO, California  
*Chairwoman*

ELIOT L. ENGEL, New York	MICHAEL C. BURGESS, Texas
G. K. BUTTERFIELD, North Carolina, <i>Vice Chair</i>	<i>Ranking Member</i>
DORIS O. MATSUI, California	FRED UPTON, Michigan
KATHY CASTOR, Florida	JOHN SHIMKUS, Illinois
JOHN P. SARBANES, Maryland	BRETT GUTHRIE, Kentucky
BEN RAY LUJAN, New Mexico	H. MORGAN GRIFFITH, Virginia
KURT SCHRADER, Oregon	GUS M. BILIRAKIS, Florida
JOSEPH P. KENNEDY III, Massachusetts	BILLY LONG, Missouri
TONY CARDENAS, California	LARRY BUCSHON, Indiana
PETER WELCH, Vermont	SUSAN W. BROOKS, Indiana
RAUL RUIZ, California	MARKWAYNE MULLIN, Oklahoma
DEBBIE DINGELL, Michigan	RICHARD HUDSON, North Carolina
ANN M. KUSTER, New Hampshire	EARL L. "BUDDY" CARTER, Georgia
ROBIN L. KELLY, Illinois	GREG GIANFORTE, Montana
NANETTE DIAZ BARRAGÁN, California	GREG WALDEN, Oregon ( <i>ex officio</i> )
LISA BLUNT ROCHESTER, Delaware	
BOBBY L. RUSH, Illinois	
FRANK PALLONE, JR., New Jersey ( <i>ex officio</i> )	





## C O N T E N T S

	Page
Hon. Anna G. Eshoo, a Representative in Congress from the State of California, opening statement .....	2
Prepared statement .....	3
Hon. Michael C. Burgess, a Representative in Congress from the State of Texas, opening statement .....	4
Prepared statement .....	6
Hon. Frank Pallone, Jr., a Representative in Congress from the State of New Jersey, opening statement .....	7
Prepared statement .....	8
Hon. Greg Walden, a Representative in Congress from the State of Oregon, opening statement .....	9
Prepared statement .....	10
Hon. Eliot L. Engel, a Representative in Congress from the State of New York prepared statement .....	86

### WITNESSES

Amy Hewitt, Ph.D., Director, Institute on Community Integration, University of Minnesota .....	12
Prepared statement .....	15
Answers to submitted questions .....	147
Jill Kagan, Director, Arch National Respite Network and Resource Center, National Respite Coalition .....	22
Prepared statement .....	24
Patricia Kunz Howard, Ph.D., R.N., Enterprise Director, Emergency Services, University of Kentucky Healthcare .....	36
Prepared statement .....	38
Answers to submitted questions .....	150
Joseph A. Bocchini, Jr., M.D., Professor, Department of Pediatrics, Louisiana State University Health Sciences Center at Shreveport .....	45
Prepared statement .....	47
Answers to submitted questions .....	152

### SUBMITTED MATERIAL

H.R. 776, the Emergency Medical Services for Children Program Reauthorization Act of 2019 .....	88
H.R. 1058, the Autism Collaboration, Accountability, Research, Education, and Support Act of 2019 .....	90
H.R. 2035, the Lifespan Respite Care Reauthorization Act of 2019 .....	100
H.R. 2507, the Newborn Screening Saves Lives Reauthorization Act of 2019 ..	105
Letter of June 25, 2019, by Angela Geiger, President and CEO, Autism Speaks, to Mr. Pallone, et al., submitted by Ms. Eshoo .....	115
Letter of February 7, 2019, by Scott Badesch, Executive Director and CEO, Autism Society, to Mr. Doyle, et al., submitted by Ms. Eshoo .....	117
Letter of February 6, 2019, by Andrew Imparato, Executive Director, and Amy Hewitt, President, Association of University Centers on Disabilities, to Mr. Doyle, submitted by Ms. Eshoo .....	118
Letter of February 26, 2019, by Kyle E. Yasuda, M.D., President, American Academy of Pediatrics, to Rep. Chris Smith and Mr. Doyle, submitted by Ms. Eshoo .....	119
Letter of February 11, 2019, by Erin M. Prangle, Director, National Association of Councils on Developmental Disabilities, to Mr. Pallone, et al., submitted by Ms. Eshoo .....	120

# VI

	Page
Letter of February 14, 2019, by Jill Escher, President, National Council on Severe Autism, to Mr. Doyle, et al., submitted by Ms. Eshoo .....	121
Letter of April 18, 2019, by Mary Woolley, President and CEO, Research America, to Mr. Pallone, et al., submitted by Ms. Eshoo .....	123
Letter of June 24, 2019, by Rachel Sher, Vice President, Policy and Regulatory Affairs, National Organization for Rare Disorders, to Mr. Pallone and Mr. Walden, submitted by Ms. Eshoo .....	125
Letter of June 24, 2019, from Nation's Newborn Screening System, et al., to Rep. Lucille Roybal-Allard, et al., submitted by Ms. Eshoo .....	127
Statement March of Dimes, by Rahul Gupta, M.D., Senior Vice President and Chief Medical and Health Officer, submitted by Ms. Eshoo .....	129
Statement of June 25, 2019, by Elisa Seeger, Executive Director, Aidan Jack Seeger Foundation, submitted by Ms. Eshoo .....	132
Letter of June 25, 2019, by David Certner, Legislative Counsel and Legislative Policy Director, AARP, to Ms. Eshoo, et al., submitted by Ms. Eshoo .....	134
Letter of June 24, 2019, from Consortium for Citizens with Disabilities, et al., to Ms. Eshoo and Mr. Burgess, submitted by Ms. Eshoo .....	136
Letter of June 21, 2019, by Shari B. Robertson, Ph.D., President, American Speech-Learning-Hearing Association, to Mr. Doyle and Rep. Chris Smith, submitted by Ms. Eshoo .....	138
Letter of June 25, 2019, from Autism CARES coalitions, to Mr. Doyle, et al., submitted by Ms. Eshoo .....	139
Letter of April 30, 2019, from EMSC coalitions, to Mr. Butterfield, et al., submitted by Ms. Eshoo .....	141
Statement of June 25, 2019, from American Academy of Pediatrics, to Rep. Chris Smith and Mr. Doyle, submitted by Ms. Eshoo .....	144

## **REAUTHORIZING VITAL HEALTH PROGRAMS FOR AMERICAN FAMILIES**

**TUESDAY, JUNE 25, 2019**

HOUSE OF REPRESENTATIVES,  
SUBCOMMITTEE ON HEALTH,  
COMMITTEE ON ENERGY AND COMMERCE,  
*Washington, DC.*

The subcommittee met, pursuant to call, at 10:00 a.m., in Room 2322 Rayburn House Office Building, Hon. Anna G. Eshoo (chairwoman of the subcommittee) presiding.

Also present: Representatives Doyle and Soto.

Members present: Representatives Eshoo, Engel, Butterfield, Matsui, Castor, Sarbanes, Schrader, Kennedy, Welch, Ruiz, Dingell, Kuster, Kelly, Barragán, Blunt Rochester, Pallone (ex officio), Burgess (subcommittee ranking member), Upton, Shimkus, Guthrie, Griffith, Bilirakis, Long, Bucshon, Brooks, Mullin, Hudson, Carter, Gianforte, and Walden (ex officio).

Staff present: Jeffrey C. Carroll, Staff Director; Waverly Gordon, Deputy Chief Counsel; Tiffany Guarascio, Deputy Staff Director; Stephen Holland, Health Counsel; Josh Krantz, Policy Analyst; Aisling McDonough, Policy Coordinator; Joe Orlando, Staff Assistant; Kaitlyn Peel, Digital Director; Tim Robinson, Chief Counsel; Samantha Satchell, Professional Staff Member; Kimberlee Trzeciak, Chief Health Advisor; C. J. Young, Press Secretary; Jennifer Barblan, Minority Chief Counsel, Oversight and Investigations; Mike Bloomquist, Minority Staff Director; Adam Buckalew, Minority Director of Coalitions and Deputy Chief Counsel, Health; Robin Colwell, Minority Chief Counsel, Communications and Technology; Jerry Couri, Minority Deputy Chief Counsel, Environment and Climate Change; Jordan Davis, Minority Senior Advisor; Kristine Fargotstein, Minority Detailee, Communication Technology; Margaret Tucker Fogarty, Minority Staff Assistant; Melissa Froelich, Minority Chief Counsel, Consumer Protection and Commerce; Theresa Gambo, Minority Human Resources/Office Administrator; Caleb Graff, Minority Professional Staff Member, Health; Brittany Havens, Minority Professional Staff, Oversight and Investigations; Peter Kielty, Minority General Counsel; Bijan Koohmaraie, Minority Counsel, Consumer Protection and Commerce; Tim Kurth, Minority Deputy Chief Counsel, Communications and Technology; Ryan Long, Minority Deputy Staff Director; Mary Martin, Minority Chief Counsel, Energy and Environment and Climate Change; Sarah Matthews, Minority Press Secretary; Brandon Mooney, Minority Deputy Chief Counsel, Energy; James Paluskiewicz, Minority Chief Counsel, Health; Brannon Rains, Minority Staff Assistant; Zach Roday, Minority Communications Di-

rector; Kristen Shatynski, Minority Professional Staff Member, Health; Alan Slobodin, Minority Chief Investigative Counsel, Oversight and Investigations; Peter Spencer, Minority Senior Professional Staff Member, Environment and Climate Change; Natalie Sohn, Minority Counsel, Oversight and Investigations; Danielle Steele, Minority Counsel, Health; Everett Winnick, Minority Director of Information Technology; and Greg Zerzan, Minority Counsel, Consumer Protection and Commerce.

Ms. ESHOO. The Subcommittee on Health will now come to order.

Good morning, everyone, colleagues and everyone who has joined us in the hearing room and welcome to our witnesses.

The Chair now recognizes herself for 5 minutes for an opening statement.

**OPENING STATEMENT OF HON. ANNA G. ESHOO, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA**

Today, our subcommittee is going to consider four bills to reauthorize very important—critically important public health programs that support and improve the health and well-being of children, of adults, and their caregivers. Very important—caregivers. I know because I’ve been one. It’s not easy.

Our subcommittee’s focus for June has been to make sure that important health programs nearing their expiration are continued, and in some cases, expanded.

Last week, we held what I thought was a historic hearing about the need to address expiring Medicaid funds for the territories. All of the people that reside in the territories are American citizens.

And earlier in June, we considered extending 12 programs that strengthen public health and the Medicare and Medicaid programs.

These hearings have led to results. Last week, the House passed H.R. 3253, a bipartisan bill that extended several programs in Medicaid, including the Money Follows the Person program and the Excellence in Mental Health demonstration program.

I am grateful to Representatives Dingell and Guthrie for their work on that bill. We are all grateful to them.

Today, we continue our focus by hearing testimony on four bipartisan reauthorization bills, most of which were authored by members of this committee.

These bills support people at particularly vulnerable times in their lives: when a baby is born, during a pediatric emergency, after an autism diagnosis, or when serving as the primary caregiver for a loved one.

Members of this subcommittee have no doubt experienced at least one of these vulnerable moments. As I just mentioned, I certainly have and so have millions of Americans.

Too often, these experiences go untold and what can be done to assist goes unexamined. Today, our witnesses are going to explain what people in these moments need and how these bills can help.

The first bill, the Newborn Screening Saves Lives Reauthorization Act, gives parents the peace of mind that their newborn will receive comprehensive diagnostic screening no matter where in the country they are born.

Through these screenings, each year over 12,000 babies live healthier, longer lives because they receive lifesaving treatments faster.

The Emergency Medical Services for Children Reauthorization Act is really, I think, about peace of mind. There is nothing scarier than when a child is critically ill or injured.

Parents should be able to trust that their child will receive appropriate medical care no matter what hospital they go to. This bill reauthorizes the only federal program dedicated to improving emergency medical care for children.

The Autism CARES Act expands efforts to conduct research and provide services to people who are autistic with an important focus on addressing racial disparities. Black and Latino children with autism tend to be diagnosed later than white children and are often misdiagnosed.

They have less access to services and are underrepresented in most autism research. This five-year reauthorization addresses these disparities as well as other challenges related to autism research, education, and detection.

Finally, the Lifespan Respite Care Reauthorization Act helps support the family members. I think this is just so badly needed in our country. It helps support the family members who provide full-time care to their aging or disabled loved ones.

Being the unpaid care giver for a loved one can be physically and emotionally exhausting and isolating. The average family care giver is a woman who works full-time and is providing care to both aging parents and children living at home.

That is—that should take everyone’s breath away. Through a five-year reauthorization of grant funds, this bill allows caregivers to take a temporary break from their care giving responsibility.

So today’s hearing is about helping people in situations that too often are overlooked. By making sure we don’t treat children as little adults, that minority children are included in autism research, and that we are supporting the people, mostly women, who are taking care of their loved ones every day, we are taking important steps toward the goal of quality healthcare for every American.

I stand ready to work with every single one of my colleagues to make sure these programs are reauthorized.

[The prepared statement of Ms. Eshoo follows:]

#### PREPARED STATEMENT OF HON. ANNA G. ESHOO

Today, our Subcommittee will consider four bills to reauthorize critical public health programs that support and improve the health and wellbeing of children, adults, and their caregivers.

Our Subcommittee’s focus for June has been to make sure that important health programs nearing their expiration are continued, and in some cases, expanded. Last week, we held a historic hearing about the need to address expiring Medicaid funds for the territories. Earlier in June, we considered extending 12 programs that strengthen public health and the Medicare and Medicaid programs.

These hearings led to results. Last week, the House passed H.R. 3253, a bipartisan bill that extended several programs in Medicaid, including the Money Follows the Person program and the Excellence in Mental Health demonstration program. I’m grateful to Representatives Dingell and Guthrie for their work on that bill.

Today, we continue our focus by hearing testimony on four bipartisan reauthorization bills, most of which were authored by members of this Committee.

These bills support people at particularly vulnerable times in their lives: when a baby is born, during a pediatric emergency, after an autism diagnosis, or when serving as the primary caregiver for a loved one.

Members of this Subcommittee have, no doubt, experienced at least one of these vulnerable moments. I certainly have, and so have millions of Americans.

Too often, these experiences go untold and what can be done to assist goes unexamined. Today, our witnesses will explain what people in these moments need and how these bills can help.

The first bill, the Newborn Screening Saves Lives Reauthorization Act, gives parents the peace of mind that their newborn will receive comprehensive diagnostic screening no matter where in the country they're born. Through these screenings, each year over 12,000 babies live healthier, longer lives because they receive life-saving treatments faster.

The Emergency Medical Services for Children Reauthorization Act is about peace of mind. There is nothing scarier than when a child is critically ill or injured. Parents should be able to trust that their children will receive appropriate medical care no matter what hospital they go to. This bill reauthorizes the only federal program dedicated to improving emergency medical care for children.

The Autism CARES Act expands efforts to conduct research and provide services to people who are autistic with an important focus on addressing racial disparities. Black and Latino children with autism tend to be diagnosed later than white children and are often misdiagnosed. They have less access to services and are under-represented in most autism research. This five-year reauthorization addresses these disparities, as well as other challenges relative to autism research, education, and detection.

Finally, the Lifespan Respite Care Reauthorization Act helps support the family members who provide full-time care to their aging or disabled loved ones.

Being the unpaid caregiver for a loved one can be physically and emotionally exhausting and isolating. The average family caregiver is a woman who works full-time and is providing care to both aging parents and children living at home. Through a five-year reauthorization of grant funds, this bill allows caregivers to take a temporary break from their caregiving responsibilities.

Today's hearing is about helping people in situations that too often are overlooked. By making sure we don't treat children as little adults, that minority children are included in autism research, that we are supporting the people, mostly women, who are taking care of their loved ones every day, we're taking important steps toward the goal of quality healthcare for every American.

I stand ready to work with my colleagues to make sure these programs are reauthorized.

The Chair now has the pleasure of recognizing Dr. Burgess, the ranking member of the subcommittee, for 5 minutes for his opening statement.

**OPENING STATEMENT OF HON. MICHAEL C. BURGESS, A  
REPRESENTATIVE IN CONGRESS FROM THE STATE OF TEXAS**

Mr. BURGESS. Thank you, Madam Chair.

As you said, we are here today to discuss the reauthorization of four public health programs that provide resources for critical and in some cases, even lifesaving care for Americans.

These four bills—the Emergency Medical Services for Children Program reauthorization, the Autism CARES Act, the Lifespan Respite Care Reauthorization Act, and the Newborn Screening Saves Lives Reauthorization Act—all make an immeasurable impact on individuals' lives each and every day.

The Emergency Medical Services for Children Program was enacted in 1984. This was to provide grant funding to increase the ability of emergency medical systems to care for pediatric populations.

Not only does the program provide funding so that emergency departments and hospitals can equip themselves with appropriate pe-

diatric medical tools; it enables partnerships and drives research and innovation in emergency care for children.

Last year, we reauthorized the Children's Hospital Graduate Medical Education Program and named the bill after one of my professors, Dr. Benjy Brooks. I remember Dr. Brooks telling me at the start of my medical career that children are not just smaller versions of adults.

Treating them is more complex than scaling down the size of the problem. It requires a whole host of separate tools and separate knowledge, and that is why this program is so important, especially at the hours of an emergency.

Similarly, the Newborn Screening Saves Lives Act, which passed for the first time in 2008, aims to improve the ability to address pediatric health by standardizing newborn screening programs.

Newborn screenings are incredibly important in providing physicians and families with information regarding their baby's health, enabling them to practice early intervention and treatment if necessary.

According to the March of Dimes, in 2007, only ten States and Washington, DC, required infant screening for the recommended disorders.

Since enactment of the Newborn Screening Saves Lives Act, all the States, Washington, DC, and Puerto Rico, screen for at least 29 of the 35 recommended conditions.

This bill would reauthorize funding for the Health Resources and Services Administration, the Centers for Disease Control and Prevention, and the National Institute of Health to ensure that our newborn screening remains comprehensive and that our nation's healthcare providers are adequately equipped to conduct these screenings.

Autism CARES builds upon the strong foundation that Congress laid by passing the Combating Autism Act in 2006. This legislation expanded research and expanded surveillance and treatment of autism spectrum disorder and has equipped our federal agencies with enhanced resources to expand their knowledge of this complex disorder.

As the number of children diagnosed with autism spectrum disorder has increased, it is even more important that we reauthorize this program and ensure the continuation of the Interagency Autism Coordinating Committee.

As families across our nation navigate raising children with autism, the Autism CARES Act will provide hope by authorizing funding for continued research, surveillance, and education at the NIH, the CDC, and HRSA.

I certainly want to thank our colleague, Mr. Doyle, along with Chris Smith, who has been a standard bearer for this legislation certainly as long as I have been here.

The final piece of legislation we are considering today, the Lifespan Respite Care Reauthorization Act, would reauthorize funding for the Lifespan Respite Care Program through fiscal year 2024.

Respite care is critical—it is a critical resource for caregivers who spend so much of their time helping their loved one through each day.

Most insurance plans do not cover the cost of respite care. But the Administration for Community Living and the Department of Health and Human Services works with the ARCH National Respite Network and Resource Center to provide respite care to caregivers across the United States, ensuring that we maintain access to respite care for our caregivers and for our loved ones.

I want to thank our witnesses for being here today and taking their time to testify before the subcommittee today. I look forward to a productive dialogue and moving these bills to the subcommittee and ultimately see them signed into law.

I yield back my time.

[The prepared statement of Mr. Burgess follows:]

#### PREPARED STATEMENT OF HON. MICHAEL C. BURGESS

Thank you, Madam Chair. Today we are here to discuss the reauthorization of four public health programs that provide the resources for critical, and in some cases even lifesaving, care for Americans. These four bills, the Emergency Medical Services for Children Program Reauthorization Act, the Autism CARES Act, the Lifespan Respite Care Reauthorization Act, and the Newborn Screening Saves Lives Reauthorization Act, all make a measurable impact on individuals' lives each day.

The Emergency Medical Services for Children Program was enacted in 1984 to provide grant funding to increase the ability of emergency medical systems to care for pediatric populations. Not only does this program provide funding so that emergency departments and hospitals can equip themselves with the appropriate pediatric medical tools, it enables partnerships and drives research and innovation in emergency care for children. Last year we reauthorized the Children's Hospital Graduate Medical Education Program and named the bill after Dr. Benjy Brooks. I remember Dr. Brooks telling me at the start of my medical career that children are not just smaller versions of adults - treating them is more complex than scaling down the size of the problem. It requires a whole host of separate tools and knowledge, and that is why this program is so important.

Similarly, the Newborn Screening Saves Lives Act, which passed for the first time in 2008, aims to improve the ability to address pediatric health by standardizing newborn screening programs. Newborn screenings are incredibly important in providing physicians and families with information regarding their babies' health, enabling them to practice early intervention and treatment, if necessary. According to March of Dimes, in 2007, only ten states and Washington, DC required infant screening for the recommended disorders. Since enactment of the Newborn Screening Saves Lives Act, all the states, DC, and Puerto Rico, screen for at least 29 of the 35 recommended conditions. This bill would reauthorize funding for the Health Resources and Services Administration, the Centers for Disease Control and Prevention, and the National Institutes of Health to ensure that our newborn screening remains comprehensive and that our nation's healthcare providers are adequately equipped to conduct the screenings.

The Autism CARES Act builds upon a strong foundation that Congress laid by passing the Combating Autism Act in 2006. This legislation expanded research, surveillance, and treatment of Autism Spectrum Disorder and has equipped our federal agencies with enhanced resources to expand its knowledge of this complex disorder. As the number of children diagnosed with Autism Spectrum Disorder has increased, it is even more imperative that we reauthorize this program and ensure the continuation of the Interagency Autism Coordinating Committee. As families across our nation navigate raising children with autism, the Autism CARES Act would provide hope by authorizing funding for continued research, surveillance, and education at the National Institutes of Health, Centers for Disease Control and Prevention, and Health Resources and Services Administration through 2024.

The final piece of legislation we are considering today, the Lifespan Respite Care Reauthorization Act, would authorize funding for the Lifespan Respite Care program through fiscal year 2024. Respite care is a critical resource for caregivers, who spend much of their time helping their loved ones through each day. Most insurance plans do not cover the cost of respite care, but the Administration for Community Living at the Department of Health and Human Services works with the ARCH National Respite Network and Resource Center to provide respite care to caregivers across the United States.



This legislation is vital in ensuring that we maintain access to respite care for our caregivers and their loved ones.

Thank you to our witnesses for testifying on these important programs. I look forward to a productive dialogue and to moving these bills through this Subcommittee.

Ms. ESHOO. The gentleman yields back.

The Chair now recognizes Mr. Pallone, the chairman of the full committee, for his 5 minutes for an opening statement.

**OPENING STATEMENT OF HON. FRANK PALLONE, JR., A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW JERSEY**

Mr. PALLONE. Thank you, Madam Chair.

Today, our committee is reviewing four bipartisan bills that would reauthorize programs that bolster America's medical research capacity and improve the quality of life for millions of families.

It's important that we ensure that the authorizations of these programs do not expire; and I am grateful to the many members on and off our committee who have worked on these bills that will extend these programs.

The first bill we are examining reauthorizes the Autism CARES Act. This reauthorization is important in order to continue critical research, surveillance, education, early detection, and intervention programs for people living with autism spectrum disorder, or ASD, and their families.

The legislation would also expand efforts to support all individuals with ASD across their lifespan regardless of age and it would encourage greater research efforts into reducing disparities among people from diverse racial, ethnic, geographic, or linguistic backgrounds.

The Committee will also review legislation reauthorizing the Newborn Screening Saves Lives Act. Each year more than 12,000 babies are born with conditions that might not be readily apparent, requiring early detection and treatment.

Since it was first signed into law in 2008, this law has made great strides to ensure that all children receive recommended screening; and this reauthorization bill will bring us closer to the goal of every child born in the United States receiving all recommended screening tests, ensuring better treatment and long-term health outcomes. I want to thank Representative Roybal-Allard, who has championed this program since it was first passed more than ten years ago.

While the newborn screening legislation ensures proper care for children from the moment they are born, the Emergency Medical Services for Children Program ensures that children are safe and receive proper treatment if emergency care is ever required.

As I am sure our witnesses will attest, treating children in emergency situations can be very different from treating adults. If ever a parent or care giver is required to call 911 to get emergency care for a child, they should know their children will receive the medical care they need. And this program provides the important research and training necessary to provide quality emergency care for children no matter where they are located in the country.

And finally, the committee will review a proposal by Representative Langevin to reauthorize the Lifespan Respite Care Program. This program provides much-needed respite services and educational resources to family caregivers of children and adults of all ages with special needs and I urge support for its reauthorization.

I want to thank all the witnesses. I look forward to the testimony, and now I yield the remainder of my time to Representative, also known as Coach Doyle, the leader of the Autism Caucus and a long-time champion of the Autism CARES Act.

Mr. DOYLE. Thank you, Mr. Chairman, for yielding your time to me and I also want to thank Chairwoman Eshoo, my good friend, for holding this important hearing today.

You know, when Chris Smith and I founded the Autism Caucus almost 19 years ago, most members of Congress's knowledge of autism was if they saw the movie "The Rain Man."

NIH and CDC weren't spending much money doing any research and little was known about this disorder. We have come a long way, but we still have a long way to go.

Back in 2006, when we first started working on the first CARES Act, over \$3.1 billion has now been dedicated to the NIH, CDC, and HRSA to understand autism spectrum disorders and to find the right intervention and support for each unique individual.

Funding has also been used to support the training and education of health professionals, to provide resources for families, and coordinate efforts across the federal agencies at the Interagency Autism Coordinating Committee.

These efforts have translated into real-life support for individuals and families, although, as I said, we still have a long way to go.

This room today is full of self-advocates, family, friends, and neighbors who have worked tirelessly to pass this legislation, including our witness, Dr. Hewitt.

It is for all of you that we are here today and that we are especially grateful to because none of this would have happened without your support and persistence and pushing us to keep going further and further.

So I want to thank not only all the advocates in the audience and the parents. The parents are the reason we have come this far.

You deal with the parent of an autistic child, you're dealing with someone determined to make sure that this Congress does what we need to do and we are going to try to continue to do that.

Madam Chair, I want to thank you. I came to your earlier and asked for this hearing and you have been very gracious, as has Chairman Pallone. I hope that we can move quickly to markup in the subcommittee and full committee and get this bill passed as soon as possible with the commensurate authorization and funding levels.

So I thank you very much and I yield back my time.

[The prepared statement of Mr. Pallone follows:]

#### PREPARED STATEMENT OF HON. FRANK PALLONE JR.

Today our Committee is reviewing four bipartisan bills that would reauthorize programs that bolster America's medical research capacity and improve quality of life for millions of families. It's important that we ensure that the authorizations

of these programs do not expire, and I'm grateful to the many members on and off our Committee who have worked on these bills that will extend these programs.

The first bill we are examining reauthorizes the Autism CARES Act. This reauthorization is important in order to continue critical research, surveillance, education, early detection, and intervention programs for people living with Autism Spectrum Disorder, or ASD, and their families. The legislation would also expand efforts to support all individuals with ASD across their lifespan, regardless of age. And it would encourage greater research efforts into reducing disparities among people from diverse racial, ethnic, geographic, or linguistic backgrounds.

The Committee will also review legislation reauthorizing the Newborn Screening Saves Lives Act. Each year, more than 12,000 babies are born with conditions that might not be readily apparent, requiring early detection and treatment. Since it was first signed into law in 2008, this law has made great strides to ensure that all children receive recommended screening. This reauthorization bill will bring us closer to the goal of every child born in the United States receiving all recommended screening tests, ensuring better treatment and long-term health outcomes. I want to thank Representative Roybal-Allard, who has championed this program since it was first passed more than ten years ago.

While the Newborn Screening legislation ensures proper care for children from the moment they are born, the Emergency Medical Services for Children, Program ensures that children are safe and receive proper treatment if emergency care is ever required. As I'm sure, our witness will attest, treating children in emergency situations can be very different from treating adults. If ever a parent or caregiver is required to call 911 to get emergency care for a child, they should know that children will receive the medical care they need. This program provides the important research and training necessary to provide quality emergency care for children no matter where they are located in the country.

Finally, the Committee will review a proposal by Representative Langevin to reauthorize the Lifespan Respite Care program. This program provides much needed respite services and educational resources to family caregivers of children and adults of all ages with special needs and I urge support for its reauthorization.

I thank all of the witnesses for being here today and look forward to their testimony. I now yield the remainder of my time to Representative Doyle, the leader of the Autism Caucus and a longtime champion of the Autism CARES Act.

Thank you.

Ms. ESHOO. The gentleman yields back.

I would say to Mr. Doyle promises made, promises kept. Thank you for your magnificent work.

It's a pleasure to recognize the ranking member of the full committee, the gentleman from Oregon, Mr. Walden.

#### **OPENING STATEMENT OF HON. GREG WALDEN, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF OREGON**

Mr. WALDEN. Good morning, Madam Chair.

Ms. ESHOO. Good morning.

Mr. WALDEN. Thanks for having this hearing. Thanks to you and Ranking Member Burgess for your work on this and the other members of the committee, Mr. Doyle, and certainly off the committee, Chris Smith has been so involved in this autism effort.

The four bipartisan bills we are considering today are a great start. Obviously, we all know we have some more work to do to fund our nation's community health centers and special diabetes programs and some other priorities I know the committee is working on.

So I want to thank our witnesses today for helping us better understand these bills and issues. We look forward to your testimony. Our work will be improved by your participation.

At this hearing, as you've heard, we will consider four bipartisan bills to reauthorize these common-sense public health programs

that make a real difference for patients, for families, and for communities.

And, as you've heard, H.R. 1058, the Autism CARES Act of 2019 introduced by Representative Smith and Doyle, the number of children diagnosed with autism spectrum disorder has increased over the last several years and part of this trend may be due to improvements in diagnosis and data collection.

But, we need to learn more about autism spectrum disorders and identify them at a younger age, and we need to continue our push to more effectively treat this spectrum of conditions.

The second bill, as you've heard, the Newborn Screening Saves Lives Reauthorization Act of 2019, authorizes a five-year extension of this really important program to screen newborns, to boost transparency, to get better data, and to have states participate in the best practices for newborn screening. So I think this one is really important as well.

And then H.R. 776, the Emergency Medical Services for Children Program Reauthorization Act, is the only federal program I believe that specifically focuses on addressing the unique needs of children in emergency medical systems.

These grants represent an investment in research regarding best practices, state partnerships to boost capacity for pediatric care, and better data to inform innovation, all with the goal of improving care for our children in the healthcare system across our nation.

And then, finally, H.R. 2035, the Lifespan Respite Care Reauthorization Act of 2019, this program is really important to me; first, in 1997, my home state of Oregon became the first state in the nation to create a Lifespan respite program to provide relief to family caregivers.

Other states soon followed suit and since 2009, the Federal Government has offered grants, aid, and the implementation of these programs. I've often joined my colleagues on both sides of the aisle to boost resources for family caregivers because as taking care of a child or an adult with special needs is an important duty.

Now I am pleased to be considered—to be considering the five-year reauthorization of the National Respite Care Program to help reduce the burnout and stress associated with caring for a family member.

So, in closing, thanks again to our witnesses. We appreciate your being here today and thanks to Chairwoman Eshoo and Ranking Member Burgess for this hearing.

And I yield back the balance of my time.

[The prepared statement of Mr. Walden follows:]

#### PREPARED STATEMENT OF HON. GREG WALDEN

Thank you, Chairwoman Eshoo and Ranking Member Burgess, for holding this hearing today. I'm glad we're getting to work on extending several key healthcare programs that expire at the end of the fiscal year, which is just a few months away. The four bipartisan bills we are considering today are a great start. But we have more work to do to fund our nation's community health centers, special diabetes programs, and other priorities. Thank you to our witnesses for being here today, and I look forward to hearing from you on the bills before us.

At this hearing, we'll consider four bipartisan bills to reauthorize commonsense public health programs that have a real effect on patients in our communities.

First up is H.R. 1058, the Autism CARES Act of 2019, introduced by Representative Chris Smith (R-NJ) and Representative Mike Doyle (D-PA). The number of

children diagnosed with Autism Spectrum Disorder has increased over the last several years. Part of this trend may be due to improvements in diagnosis and data collection. As we learn more about Autism Spectrum Disorders and identify them at a younger age, we must continue our push to more effectively treat this spectrum of conditions.

The second bill we'll consider today is H.R. 2507; the Newborn Screening Saves Lives Reauthorization Act of 2019, introduced by Representative Lucille Roybal-Allard (D-CA), Representative Mike Simpson (R-ID), Representative Katherine Clark (D-MA), and Representative Jaime Herrera Beutler (R-WA). This bill authorizes a five-year extension of newborn screening programs to boost transparency, data collection, and state participation in newborn screening best practices. As our understanding of these conditions has improved over the years, we have realized just how much early intervention care can improve the outcomes for newborns. State-run newborn screening programs are the starting point for our children to live full, healthy lives, and I am glad we're taking up this effort in a bipartisan way.

We're also considering H.R. 776, the Emergency Medical Services for Children Program Reauthorization Act, introduced by Representative Peter King (R-NY), Representative Kathy Castor (D-FL), and Representative Chris Stewart (R-UT), and Representative G. K. Butterfield (D-NC). This program is the only federal grant program specifically focused on addressing the unique needs of children in emergency medical systems.

These grants represent an investment in research regarding best practices, state partnerships to boost capacity for pediatric care, and better data to inform innovation—all with the goal of improving care for our children in healthcare systems across the country.

Finally, we'll examine H.R. 2035, the Lifespan Respite Care Reauthorization Act of 2019, authored by Representative Jim Langevin (D-RI) and Representative Cathy McMorris Rodgers (R-WA). This program is very important to me: first, because in 1997, my home state of Oregon became the first state in the nation to create a Lifespan Respite Program to provide relief to family caregivers. Other states soon followed suit; and since 2009, the Federal Government has offered grants to aid in the implementation of these programs. I have often joined my colleagues on both sides of the aisle to boost resources for family caregivers taking care of a child or adult with special needs. Now, I'm pleased to be considering the five-year reauthorization of the national respite care program, to help reduce the burnout and stress associated with caring for a family member.

In closing, let me once again thank our witnesses for being here today and Chairwoman Eshoo and Ranking Member Burgess for this hearing. I yield back the balance of my time.

Ms. ESHOO. The gentleman yields back. I know that all the Members have fabulous opening statements and remind you that pursuant to committee rule, your written opening statements shall be made part of the record. So submit those for the record.

I now would like to introduce the witnesses for today's hearing and thank you for joining us today. We depend on you for expertise and we have four of you.

The first, Dr. Amy Hewitt, the Director of the Institute on Community Integration, College of Education and Human Development at the University of Minnesota, welcome to you and our collective thanks to you.

Ms. Jill Kagan, the Director of ARCH National Respite Network and Resource Center of National Respite Coalition. Thank you to you for your fine work and for being here.

Dr. Patricia Kunz Howard, the President of Emergency Nurses Association—thank you to you and a warm welcome—and Dr. Joseph Bocchini, Professor of Pediatrics, Louisiana State University Health Sciences Center at Shreveport. Thank you to you, Doctor, and a warm welcome.

At this time the Chair is going to recognize each witness for 5 minutes to provide your opening statements. Bring the micro-

phones close to you so that everyone can hear you very well, and when it's time to testify, make sure you turn it on.

The red light means stop. You'll see green, yellow, and red light. Don't run the red light. How's that?

So with that, we will start with Dr. Amy Hewitt. Again, welcome, and our thanks to you for being here today to offer your expert testimony. You have 5 minutes.

**STATEMENTS OF 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; 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**

**STATEMENT OF AMY HEWITT, Ph.D.**

Dr. HEWITT. Thank you.

Chairwoman Eshoo, Ranking Member Burgess, and distinguished members of the subcommittee, thank you for inviting me here to testify about H.R. 1058 that will reauthorize the CARES Act. It's a great honor to appear here before you today.

I am the Director of the Institute on Community Integration at the University of Minnesota. Our center is privileged to have several CARES projects, including an Autism and Developmental Disabilities Monitoring program, or the ADDM, the Centers for Disease Prevention and Control "Learn the Signs Act Early" campaign, and a Leadership Education in Neurodevelopmental and Related Disabilities program known as the LEND.

I am also the proud alum of a LEND program, having received training at Riley Child Development Center in Indiana over 30 years ago.

I am the current president of the board of directors of the Association of University Centers on Disabilities, a network that includes all of the LEND programs and a national resource center that provides technical assistance to CARES programs.

Autism and related neurodevelopmental disabilities pose significant challenges to communities across the United States. Our ADDM data estimates that 1 in 59 children have autism and, roughly, 1 in 6 children have related developmental disabilities.

What this means is that it's highly likely that everyone in this room knows someone that has a family member with autism or a developmental disability.

While I am here in my professional role as a researcher, I understand these issues as a family member, too. My brother-in-law, Nathan, is 45 years old and he has autism.

He reminds me daily that early intervention is critical and that children grow up to become working adults who want good lives in their communities.

We have so much to learn from autistic adults about the systems we create to support people across their lives. CARES has helped

to build a critical infrastructure addressing our understanding of autism.

It supports the ADDM network funded by the CDC to estimate the number of children and other developmental disabilities. ADDM's findings identify characteristics of children with autism and the age at which they were evaluated and diagnosed.

Reauthorization provides hope that in Minnesota, we will be able to increase our geographic area and gather Lifespan data. This is important because, in addition to demographic categories routinely studied by the CDC, we want to understand prevalence for our Somali, Hmong, and other immigrant populations.

Expansion of the geographic area is the only way we will be able to know with certainty if differences exist among these groups.

The CARES Act also funds workforce programs. Nationally, there's a serious shortage of personnel trained about autism. LEND programs provide advanced training to fellows from a broad array of disciplines in the identification, assessment, and treatment of children, youth, and young adults with developmental disabilities, including ASD.

The developmental behavioral pediatrics training program trains the next generation of physicians to build capacity to develop and provide evidence-based interventions. CARES reauthorization includes a priority to award DBP programs in rural communities, which is also important.

CARES authorizes the Interagency Autism Coordinating Committee, known as the IACC committee, to coordinate federal efforts to advise the secretary of health and human services on issues related to ASD.

With both federal and public members, including people with lived experience of autism, the IACC helps to ensure that a wide range of perspectives are represented on the committee.

Reauthorization expands the IACC membership to include representatives from the Departments of Labor, Justice, Housing, and Urban Development.

CARES programs have intentionally focused on strategic partnerships in states with maternal and child health Title V programs, resulting in more effective and coordinated leadership with coalitions.

Actor early ambassadors work with programs to reach diverse communities with the focus on parent-to-parent networking, and in Minnesota, we see how the alignment of research and systems ensures that we are more effectively supporting people.

CARES supports NIH-funded research through autism centers of excellence, which conduct research on possible treatments and interventions, then report findings to the national database on autism research.

This research answers critical questions that influence policy.

CARES requires an evaluation report on both progress and needs. Evaluation findings were used to introduce new requirements to report—so that the evaluation reporting includes information on community-based services, reflecting a growing need to expand research, service, and collaboration across all ages.

In closing, the CARES shows the commitment from each of you to provide a coordinated federal response to the needs of individuals with ASD in your districts throughout the United States.

This legislation has answered critical questions to address disparities through research, public health surveillance and workforce development.

I urge you to renew the investment and enact a five-year reauthorization before it expires on September 30th.

Thank you.

[The prepared statement of Dr. Hewitt follows:]



Testimony for the Record  
Submitted to the  
House Committee on Energy & Commerce  
Subcommittee on Health  
For the Hearing  
"Reauthorizing Vital Health Programs for American Families"  
Tuesday, June 25, 2019  
Amy Hewitt, PhD  
Director of the Institute on Community Integration (ICI), College of Education and  
Human Development at the University of Minnesota

Chairwoman Eshoo, Ranking Member Burgess, and distinguished Members of the Subcommittee, thank you for inviting me to participate in today's hearing. It is a great honor to appear before you to share my experience as Director of the Institute on Community Integration (ICI) at the University of Minnesota, to discuss the work and impact of Autism Collaboration, Accountability, Research, Education, and Support (CARES) over the past five years, and the importance of Congress' reauthorization of HR 1058 CARES Act.

In my role at the University of Minnesota, I am the director of the Institute on Community Integration (ICI), a University Center of Excellence on Developmental Disabilities (DD). My research, training and outreach work has focused on community long-term services and supports for children, youth and adults with intellectual and developmental disabilities, including autism. Currently our Center has several CARES projects, including the Autism and Developmental Disabilities Monitoring Network, targeted efforts to integrate the CDC's "Learn the Signs Act Early" campaign tools across our state, and the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program. I am proud to share that I am a Maternal and Child Health LEND Trainee Alumni, having received training at the Riley Child Developmental Center in Indiana over 25 years ago. I am the current President of the Board of Directors for the Association of University Centers on Disabilities, a network that includes all 52 LEND centers, as well as the CARES-funded national resource center that provides technical assistance to LENDs, Developmental Behavioral Pediatrics (DBP) Training Programs and the CDC "Act Early" Ambassadors that have a presence in nearly every state and territory in the United States.

#### **DATA AND NEEDS**

Autism and related neurodevelopmental disabilities continue to pose significant challenges to communities across the United States. The prevalence of autism spectrum disorder (ASD) diagnoses has risen dramatically – over 600% -- in the past several decades. According to the CDC, autism affects about 1 in 59 children, and boys are four times more likely than girls to be identified with ASD. Beyond autism, about 1 in 6 children has a developmental disability.<sup>1</sup> This means that it is highly likely that everyone in this room knows someone that has a family member with autism or another developmental disability. While I am here in my professional role as a researcher and professor, I understand the importance of these issues as a family member, too. My brother-in-law, Nathan, is 45 years old and is autistic. He has lived with our family, in his own apartment in our home, for the past 25 years. He reminds me daily that children grow up and become working adults who want good lives in our communities. Nathan makes me aware that we have much to learn from autistic adults about the systems we

---

<sup>1</sup> <https://www.cdc.gov/ncbddd/autism/data.html>

create to support autistic people and that we need these systems of support across the lifespan.

The Autism CARES Act has helped to build a critical infrastructure to further advance our understanding of autism. The Autism CARES Act supports several important programs. It supports the Autism and Developmental Disabilities Monitoring (ADDM) Network, a group of programs funded by the CDC to estimate the number of children with ASD and other developmental disabilities living in different areas of the United States. The CDC also established regional centers of excellence for ASD and other developmental disabilities. They make up the Centers for Autism and Developmental Disabilities Research and Epidemiology Network (CADDRE) that are working in part to help identify factors that may put children at risk for ASD and other developmental disabilities.

Findings from the Minnesota-Autism and Developmental Disabilities Monitoring Network (MN-ADDM) helps us to understand more about the number of children with Autism Spectrum Disorder (ASD), the characteristics of these children, and the age at which they are first evaluated and diagnosed.

This is the first time Minnesota has been a part of the ADDM network, and we are building our geographic area. Through this work, we know that 1 in 42 8-year-old children were identified with ASD in 2014.<sup>2</sup> We now know that boys were 4.6 times more likely to be identified than girls and that there were no significant differences found in the percentage of white, black, and Hispanic children identified with ASD.

The findings in our report reflect a limited number of children concentrated in a large metropolitan area. Through the reauthorization of the Autism CARES Act, we are hopeful that we will be able to increase our scope geographically and include the lifespan of individuals with autism. This is particularly important because in addition to the race/ethnicity categories routinely studied by CDC, in Minnesota we were interested in understanding prevalence for our local Hmong, Somali and other immigrant populations. Expansion of the geographic area in which we gather data is the only way we will be able to know with certainty if differences exist among these groups in Minnesota.

The data that has emerged on disparate populations has resulted in partnerships with the CDC-funded "Learn the Signs Act Early" initiative to conduct outreach and education activities on early developmental screening and early identification directly in under-identified communities such as Latino, American Indian, Hmong, and Somali communities.<sup>3</sup>

ADDM's critical findings across the nation are being used to promote early identification of ASD, plan for ASD services and training, guide future ASD research, and inform

---

<sup>2</sup> <https://www.cdc.gov/ncbddd/autism/addm-community-report/minnesota.html>

<sup>3</sup> Ibid.

policies promoting improved outcomes in health care and education for individuals with ASD. Most importantly, we know that behind each of these numbers is a child and their family needing access to services and supports to live a full life in their communities.

### **WORKFORCE INVESTMENTS**

The Autism CARES Act also funds workforce programs. The Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs have been funded for nearly 50 years to provide advanced training to students and fellows from a broad array of professional disciplines – including medicine, social work, public health, nursing, psychology, physical therapy and many others – in the identification, assessment, and treatment of children, youth and young adults with a wide range of developmental disabilities including ASD, intellectual disability, fragile X syndrome, cerebral palsy, spina bifida, Down syndrome, epilepsy and many other genetic and metabolic disorders. Importantly, individuals with autism and family members are part of these LEND training cohorts, building the skills and partnerships needed for successful systems of support for children, youth and adults with ASD. Nationally, and particularly in more rural communities, there are tremendous shortages of personnel trained to screen, diagnose and provide treatment to individuals with autism and related developmental disabilities. As a result, families often must wait months and travel long distances to get a comprehensive diagnosis for their child. LEND programs train the next generation of leaders who will move the field of autism and developmental disabilities forward by improving research, clinical services, and public policy.

In 2006, the Combating Autism Act (P.L. 109-416) amended the Public Health Service (PHS) Act to add an emphasis in the early identification, diagnosis, and treatment of children with ASD because of the rising prevalence rates across the U.S. This law was reauthorized in 2011 as P.L. 112-32 and again in 2014 as the Autism CARES Act (P.L. 113-157). The law recognized the benefits of the LEND network in addressing this significant public health issue by authorizing the expansion of the network. The law extended the reach of the LEND program by gradually adding LEND host and/or partnership sites in each of the thirteen states that did not then have such a presence.

There are currently 52 LEND programs located in 44 U.S. states, with an additional six states and three territories reached through program partnerships. According to the Congressionally-mandated report to Congress on Autism CARES (2018)<sup>4</sup>, the LEND programs have collectively made significant strides toward improved screening and diagnosis of autism among younger children while helping train a variety of healthcare professionals who treat a number of different developmental and intellectual disabilities.

Critical voices in this work are the people who have lived experiences including autistic adults and families. Ensuring the first-person perspective, the role of autistic trainees, partners, and faculty has provided an imperative lens for LEND programs to increase

---

<sup>4</sup> [https://iacc.hhs.gov/publications/report-to-congress/2018/report\\_to\\_congress\\_2018.pdf](https://iacc.hhs.gov/publications/report-to-congress/2018/report_to_congress_2018.pdf)

the quality of care provided. Thanks to the expanded number of LEND grantees and trainees representing a broad range of roles within healthcare systems, the national LEND network provided interdisciplinary diagnostic evaluations for an average of 113,623 infants and children annually between 2014 and 2017.<sup>5</sup> By continuing to meet the growing demand for these services, LENDs are reducing wait times for diagnostic evaluation and entry into intervention services. Moreover, because LENDs typically target underserved populations, their efforts are also helping to address disparities in early identification of ASD and other developmental disabilities. Additionally, the law authorized a technical assistance award for the interdisciplinary training network that helps to build connections across programs and provides a venue for collecting efficacy data, shared learning, curricula development, and identification/sharing of exemplary practices.

The Developmental-Behavioral Pediatrics (DBP) Training Program is training the next generation of leaders within the medical community and building capacity to evaluate, diagnose or rule out, develop and provide evidence-based interventions to individuals with ASD and other developmental disabilities through primary care practitioners. Right now, the average wait time for a family to see a Developmental-Behavioral Pediatrician is 14.5 weeks.<sup>6</sup> CARES currently funds twelve DBP programs that provide extensive, multi-year training to doctors post-residency. Importantly, reauthorization includes new language directing the prioritization of awards to Developmental-Behavioral Pediatrics Training Programs located in rural areas or underserved areas. This is imperative as entire predominantly-rural states such as North Dakota and Wyoming do not have a Developmental-Behavioral Pediatrician.<sup>7</sup>

## SYSTEMS

Through current legislation, the Interagency Autism Coordinating Committee (IACC) coordinates federal efforts and provides advice to the Secretary of Health and Human Services on issues related to ASD. Through its inclusion of both federal and public members, including people with lived experience of autism, the IACC helps to ensure that a wide range of ideas and perspectives are represented and discussed in a public forum. I am excited that changes in the CARES reauthorization expand the IACC membership to include representatives from the Department of Labor, Department of Justice, and Department of Housing and Urban Development, and reflect the role these agencies fulfill related to individuals with autism and their families. In addition, the restrictions that non-federal members of the IACC may only be reappointed for one additional four-year term instead of one or more terms as statute currently reads will allow for a broader representation of voices.

<sup>5</sup> <https://mchb.hrsa.gov/sites/default/files/mchb/autism-cares-act-report.pdf>

<sup>6</sup> <https://www.childrenshospitals.org/issues-and-advocacy/graduate-medical-education/factsheets/2012/pediatric-specialist-physician-shortages-affect-access-to-care>

<sup>7</sup> <https://www.abp.org/content/us-distribution-abp-diplomates-state#overlay-context=content/general-information-all-certified-diplomates>

The coordination created by the IACC at the federal level translates to local levels. In addition, CARES provides State Implementation Grants (SIGs) for Improving Services for Children and Youth with Autism Spectrum Disorder. I have seen in Minnesota how these grants improve access to care through referrals, timely diagnosis and feedback, and entry into quality, coordinated care across systems for children with ASD and other developmental disabilities through family navigation and provider training.

Act Early Ambassadors are state-level experts who work to improve early identification practices. They serve as state liaisons to the "Learn the Signs Act Early" campaign and work as community champions with programs that serve young children and their parents, such as Head Start and Early Head Start, WIC, home visiting, and others, as well as with health care and childcare professionals, to improve early identification of developmental delay. In Minnesota this project has provided the opportunity to reach families in diverse communities with a focus on parent-to-parent networking that promotes early identification and connection to services directly in communities. With this approach, we know we have reached families with young children with early developmental delays we would not have reached through more traditional means.

A hallmark of the CARES programs has been an intentional and strategic partnership with Maternal and Child Health Title V programs in the states. The close working relationships between CARES programs and Title V results in more effective, coordinated and collaborative leadership on state and local coalitions. In Minnesota and across the country, we see how the alignment between research and systems helps to ensure that we are more effectively supporting people.

## **RESEARCH**

The Autism CARES Act supports NIH-funded research, including studies of the developmental processes underlying autism biology, research on the molecular and neurological underpinnings of ASD and gene function, and research on potential environmental risk factors and biomarkers for ASD, including gene-environment interactions. The NIH Autism Centers for Excellence across the country conduct research on possible treatments and interventions, then report findings to the National Database for Autism Research, which increases the efficacy of and access to the research. This research is answering questions and addressing needs of individuals and families with the most effective treatments and interventions for both ASD and co-occurring conditions. It also directs policy by tracking the impact of policy changes on ASD health care spending, patterns of injury mortality, and prevalence differences across demographic groups.

## **SUPPORTING THE FUTURE**

Importantly, Autism CARES mandates a progress report on activities related to autism and other developmental disabilities, which provides a chance for stakeholders and policymakers to reflect on both progress and needs. It is a consequence of this learning that reauthorization introduces new requirements for the report to include information on

home and community-based services and residential services - vital issues for adults with ASD and other developmental disabilities. This inclusion of the life course of autism reflects the growing need to expand our research, service, and collaboration to all ages of individuals with autism.

In addition, a new report authorized by the 2019 bill will focus on health and well-being of individuals on the autism spectrum; this includes an overview of programs and policies, proposals on establishing best practices, and proposals to improve health outcomes for individuals with autism.

The continued investment in building a workforce in every state and territory that is able to meet the needs of individuals with autism and their families has far-reaching implications. These include the potential to drive how thousands of health professionals are trained via LEND and DBP programs and also the many individuals and systems that are touched by the technical assistance and continuing education provided by these programs.

In closing, the reauthorization of the Autism CARES Act shows the commitment from each of you to provide a coordinated federal response to the needs of individuals diagnosed with ASD. This legislation has provided the opportunity to answer critical questions and address disparities in the area of autism through research, public health surveillance, and workforce development. Therefore, I urge Congress to renew its investment and enact a 5-year reauthorization before it expires on September 30, 2019.

Thank you for your time and for this opportunity to share my experiences as a former LEND trainee, director of CARES projects, an advocate in the field of autism and developmental disabilities and most importantly as a family member, to provide my perspectives on the importance of CARES and its potential for the future. If I can provide you with any additional information I am happy to do so and I look forward to further discussion on this important topic.

Ms. ESHOO. Thank you, Dr. Hewitt.

I want to thank all the advocates that are here. We all know what to do from inside the institution. But the truth about the Congress is, is that we are not a proactive institution. We are reactive. So there always has to be a push, push, push, from the outside, and pushing you are and we are going to respond to it. So thank you for being here. You're really important.

Ms. Kagan, welcome to you and you have 5 minutes for your testimony.

#### STATEMENT OF JILL KAGAN

Ms. KAGAN. Thank you.

Chairwoman Eshoo, Ranking Member Burgess, and distinguished members of the subcommittee, I am Jill Kagan, director of the ARCH National Respite Networking and Resource Center, and I am testifying today on behalf of the National Respite Coalition, which is the policy division of ARCH.

I want to thank you for this opportunity to testify today in support of the Lifespan Respite Care Program. I would also like to thank our original co-sponsors of the legislation to reauthorize the program, Representative Jim Langevin and Representative Cathy McMorris Rodgers, for their leadership in support of the bill.

As many of you have already talked about; you know what respite is. It is the planned or emergency care provided to an individual of any age with special needs in order to provide temporary relief to the family caregivers.

For the more than 40 million family caregivers providing care to a child or adult with a disability or chronic condition, respite is a lifeline.

Care giving is a lifespan issue, with more than half of family caregivers caring for someone under the age of 75, including adults with multiple sclerosis, adults with intellectual and developmental disabilities or mental health issues, young veterans with PTSD or traumatic brain injury, and nearly 14 million children with special healthcare needs including children and adults with autism.

Respite is among the most frequently requested services by family caregivers by helping to reduce stress, caregiver burden, and social isolation. The beneficial effects of respite on family health and—family caregiver health and well-being on their family's quality of life and also helping to reduce or avoid more costly out-of-home placements, these benefits are well documented.

Yet, 85 percent of family caregivers of adults and a similar percentage of parents of children are not receiving services at all because of fragmented and narrowly-targeted services, long waiting lists, prohibitive costs to families who don't qualify for public programs, and the lack of information about respite—what it is, how to find it, and how to use it.

Moreover, a critically short supply of well-trained respite providers and respite program options may prohibit a family from using this service that they so desperately need.

By providing more respite care and making it easier to find, pay for, and use, Lifespan respite care programs are helping to overcome many of these barriers.



The Administration for Community Living awards grants to states on a competitive basis. To date, 37 States and the District of Columbia have received at least one grant since 2009, when the program was first funded; and the Lifespan respite grantee activities have really evolved from that time from systems building of coordinated statewide respite programs to now really allowing states to provide more direct services.

Eighteen states have helped families not eligible for public programs or on waiting lists actually pay for a planned and emergency respite through consumer-directed respite voucher programs.

Other states have provided respite by expanding community, faith-based, and volunteer respite services. States are engaged in the very important role of building capacity through recruiting and training respite providers and volunteers and partnerships between state and local agencies are able to them maximize use of existing resources that may also exist in a state.

We are very pleased to announce too that states are collaborating with aging and disability resource centers or states' "no wrong doors" systems to increase access to respite services information and providers, and other grantees have been very successful with their partners in leveraging additional federal, state, and private dollars because of their federal grants.

The National Respite Coalition and 47 national organizations have endorsed H.R. 2035 to ensure the program's stability, allow states to continue to serve more family caregivers and provide opportunities for new states to participate.

Current law gives states the flexibility and local control to meet the program's requirements so that each state can determine the best approaches to address their own unique identified needs for respite and provide critical gap-filling services.

The Lifespan Respite Care Program is the only federal program that prioritizes respite for all ages and conditions, allows states to use funds for startup of new, innovative, and evidence-informed programs and supports training of respite providers to address the direct care worker shortage.

This is a very tall order, but states are meeting the challenges head on and we urge Congress to support its initial investment in these successful efforts and reauthorize the program in a timely way.

Thank you very much.

[The prepared statement of Ms. Kagan follows:]

**Testimony of Jill Kagan, Director**  
**ARCH National Respite Network and Resource Center**  
**National Respite Coalition**  
**Before the House Subcommittee on Health, Committee on Energy and Commerce**  
**Hearing on the “Reauthorizing Vital Health Programs for American Families”**  
**Tuesday, June 25, 2019**

Chairman Pallone, Ranking Member Walden, Chairwoman Eshoo, Ranking Member Burgess and distinguished members of the Subcommittee,

I am Jill Kagan, Director of the ARCH National Respite Network and Resource Center. I am testifying today on behalf the National Respite Coalition (NRC), the policy division of ARCH. ARCH houses the Lifespan Respite Technical Assistance Center funded by the Administration for Community Living to provide training and technical assistance to the Lifespan Respite program grantees and their state and community partners. The National Respite Coalition is a network of state respite coalitions, respite providers, family caregivers, and national, state and local organizations that support respite. Thank you for the opportunity to testify today in support of the Lifespan Respite Care Reauthorization Act of 2019 (H.R. 2035). I would also like to thank the original cosponsors of the legislation, Rep. Jim Langevin (D-RI) and Rep. Cathy McMorris Rodgers (R-WA) for their support of the program.

***Lifespan Respite Care Program***

The Lifespan Respite Care Program is a competitive grant program administered by the Administration for Community Living (ACL). The premise behind the program is both care relief and cost effectiveness. Respite care provides temporary relief for family caregivers from the ongoing responsibility of caring for an individual of any age with special needs. The Lifespan Respite Care Program provides funding to states to expand and enhance local respite services across the country, coordinate community-based respite services to maximize use of existing resources and reduce duplication and fragmentation, and improve respite access and quality. Under the program, states are required to establish statewide coordinated Lifespan Respite care programs to serve families regardless of age or special need, provide new planned and emergency respite services, train and recruit respite workers and volunteers, and assist caregivers in gaining access. Family members, foster parents or other adults providing unpaid care to adults who require care to meet basic needs or prevent injury and to children who require care beyond basic needs are eligible.

To date, 37 states and the District of Columbia have received basic grants to build coordinated systems of community-based respite services. The Lifespan Respite Program grantee activities have evolved from important systems building grants first awarded in FY 2009 to direct service grants that are helping families pay for planned and emergency respite through consumer-

directed voucher programs, supporting community, faith-based and volunteer respite services through mini-grants, recruiting and training respite providers and volunteers, and helping family caregivers access these services. Most importantly, states are able to give priority to family caregivers who are caring for individuals with disabilities and chronic illness of all ages who are not currently eligible for existing public programs, on Medicaid waiver waiting lists, or who have complex medical needs or behavioral issues for whom finding qualified and well-trained providers is especially difficult. Grantees have focused on serving the unserved, including family caregivers of individuals between the ages of 18-60, including adults with physical disabilities, MS, ALS, brain injury, paralysis, or I/DD; children and adults with special medical needs, mental health, autism or behavioral health issues; older adults with Alzheimer's disease or other dementias; grandparents raising grandchildren; rural family caregivers; culturally diverse groups and others identified as having unmet needs in the state. To sustain these efforts, many states are working on or have already successfully integrated respite activities and resources into statewide long-term services and supports and No Wrong Door systems. There are currently 20 states with active Lifespan Respite grants (AL, AR, AZ, CO, ID, MA, MD, MS, MT, ND, NV, NY, NC, OK, RI, SC, SD, TN, VA, and WA).

#### ***Respite Care Saves Money and Benefits Families***

Compelling budgetary benefits accrue because of respite. Delaying a nursing home placement for individuals with Alzheimer's or avoiding hospitalization for children with autism can save Medicaid billions of dollars. Researchers at the University of Pennsylvania studied the records of 28,000 children with autism enrolled in Medicaid in 2004. They concluded that for every \$1,000 states spent on respite, there was an 8% drop in the odds of hospitalization (*Mandell, et al., 2012*). A U.S. Department of Health and Human Services report found that reducing key stresses on caregivers through services such as respite would reduce nursing home entry (*Spillman and Long, USDHHS, 2007*). Additional research has corroborated the role that respite may play in reducing or delaying facility-based placements (*Gresham, 2018; Avison, et al., 2018*). Respite may reduce administrative burdens and improve maternal employment (*Caldwell, 2007*), strengthen marriages (*Harper, 2013*), and significantly reduce caregiver depression, stress and burden levels linked to caregiver health (*Broady and Aggar, 2017; Lopez-Hartmann, et al., 2012; Zarit, et al., 2014*). In a survey of caregivers of individuals with Multiple Sclerosis, two-thirds said that respite would help keep their loved one at home. When the care recipient with MS also has cognitive impairment, the percentage of those saying respite would be helpful to avoid or delay nursing home placement jumped to 75% (*NAC, 2012*).

With at least two-thirds (66%) of family caregivers in the workforce (*Matos, 2015*), U.S. businesses lose from \$17.1 to \$33.6 billion per year in lost productivity of family caregivers (*MetLife Mature Market Institute, 2006*). Higher absenteeism among working caregivers costs the U.S. economy an estimated \$25.2 billion annually (*Witters, 2011*).

Lack of available respite care may interfere with parents accepting job opportunities (*Abelson, A.G., 1999*). The University of NE Medical Center conducted a survey of caregivers receiving respite through the NE Lifespan Respite Program and found that 36% of family caregivers reported not having enough money at the end of the month to make ends meet, but families overall reported a better financial situation when receiving respite (*Johnson, J., et al., 2018*).

### ***Who Needs Respite?***

More than 43 million adults in the U.S. are family caregivers of an adult or a child with a disability or chronic condition (*National Alliance for Caregiving (NAC)*). They are the linchpin of the nation's long-term services and supports system. The estimated economic value of family caregiving of adults alone is approximately \$470 billion annually (*Reinhard, et al., 2015*). Eighty percent of those needing long-term services and supports (LTSS) are living at home. Two out of three (66%) older people with disabilities who receive LTSS at home get all their care exclusively from family caregivers (*Congressional Budget Office, 2013*).

With 10,000 individuals turning 65 every day, immediate concerns about how to provide care for a growing aging population are paramount. However, caregiving is a lifespan issue with the majority of family caregivers caring for someone between the ages of 18 and 75 (53%) (*NAC, 2015*). In addition, the 2017 National Survey of Children's Health found that 13.3 million children under age 18 have special health care needs, who are defined as "having or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally." (*Child and Adolescent Health Measurement Initiative, 2019*).

National, State and local surveys have shown respite to be among the most frequently requested services by family caregivers (*Anderson, L., et al., 2018; Maryland Caregivers Support Coordinating Council, 2015*). By helping to reduce stress, caregiver burden and social isolation, the beneficial effects of respite on family caregiver health and well-being, on caregivers' and care recipients' quality of life, and other positive familial, societal, and cost-savings outcomes are well-documented (*Kirk, R, 2015; Avison, C, et al., 2018*).

**Yet, 85% of family caregivers of adults are not receiving respite services at all** (*NAC, 2015*). Nearly half of family caregivers of adults (44%) identified in the *National Study of Caregiving* were providing substantial help with health care tasks. Of this group, despite their high level of care, fewer than 17% used respite (*Wolff, et al., 2016*). A 2014 Rand Corporation report prepared for the Elizabeth Dole Foundation, *Hidden Heroes: America's Military Caregivers*, recommended that more appropriate community-based respite care should be more widely available to military caregivers (*Ramchand, et al., 2014*).

### ***Respite Barriers and the Effect on Family Caregivers***

While most families want to care for family members at home, and many family caregivers rate their caregiving experiences as positive, research shows that family caregivers are at risk for emotional, mental, and physical health problems (*Population Reference Bureau, 2016; American Psychological Association, 2012; Spillman, J., et al., 2014*). When caregivers lack effective coping styles or are depressed, care recipients may be at risk for falling, developing preventable secondary health conditions or limitations in functional abilities. The risk of care recipient abuse increases when caregivers are depressed or in poor health (*American Psychological Association, nd*). Parents of children with special health care needs report poorer general health, more physical health problems, worse sleep, and increased depressive symptoms compared to parents of typically developing children (*McBean, A., et al., 2013*).

Respite, that has been shown to ease family caregiver stress, is too often out of reach or completely unavailable. In a survey of more than 3000 caregivers of individuals with intellectual and developmental disabilities (ID/DD), nine in ten reported that they were stressed. Nearly half (49%) reported that finding time to meet their personal needs was a major problem. Yet, more than half of the caregivers of individuals with ID (52%), Autism Spectrum Disorder (ASD) (56%) or ID and ASD (60%) reported that it was difficult or very difficult to find respite care (*Anderson, L., et al., 2018*). Despite their higher burden of care, caregivers of persons with dementia are more prone to underutilizing and/or delaying respite. The 2013 Johns Hopkins Maximizing Independence at Home Study, in which researchers surveyed persons with dementia residing at home with their family caregivers, found that nearly half of the caregivers had unmet needs for mental health care and most of these, needed emotional support or respite care (*Black, B., et al., 2013*). Respite may not exist at all for children with autism, adults with ALS, MS, spinal cord or traumatic brain injuries, or individuals with serious emotional conditions.

Barriers to accessing respite include difficulty navigating fragmented and narrowly targeted services, prohibitive cost to the family, and the lack of information about respite or how to find or choose a provider. Moreover, a critically short supply of well-trained respite providers or preferred respite programs available in community settings or for overnight or extended care, even when families have the resources to pay for respite, may prohibit a family from making use of a service they so desperately need.

### ***How is Lifespan Respite Program Making a Difference?***

In describing the Lifespan Respite Care Program, a distinguished panel from the National Academies of Sciences, Engineering, and Medicine recently concluded in the report *Families Caring for an Aging America*, “Although the program is relatively small, respite is one of the most important caregiver supports.”

**Lifespan Respite grantees are engaged in innovative activities to provide respite services to families:**

- **AL, AZ, CO, DE, IL, MD, MT, NE, NV, NC, OK, RI, SC, TN, TX, VA, WI and WA,** have successfully used consumer-directed respite vouchers for serving underserved populations often not eligible for other public programs, including individuals with traumatic brain injury, MS or ALS, adults with intellectual or developmental disabilities (I/DD), children with autism or special medical needs, individuals with mental health issues, rural caregivers or those on waiting lists for services.
- During their 3-year grant, Aging and Disability Resource Centers (ADRCs) and a network of community partners in **Texas** delivered 37,063 hours of direct service respite care to 993 caregivers of children, youth, and older adults with physical, intellectual and cognitive and developmental disabilities, including respite provided through new nonprofit providers that included summer camps and emergency respite programs.
- **Rhode Island** leverages grant funds with the Older Americans Act Title III-E National Family Caregiver Support Program and RI state funds designated for respite services to increase participation in the CareBreaks (CB) program. The CB program, established with Lifespan Respite grant funds, helps pay part of the respite care costs for families with low to moderate income who have no access to any other program for subsidized respite care.
- The statewide **Virginia** Lifespan Respite Voucher Program covered regions representing significant cultural and economic diversity, from extremely rural to large urban areas. Working with local partners, the Virginia Department for Aging and Rehabilitative Services provided 711 families, on average, 41 hours of respite care and reached caregivers in urban as well as isolated underserved rural areas, and in diverse cultural communities during their 2014-2017 grant.
- The **Washington** State lead agency for the Lifespan Respite grant and key partners expanded respite services to underserved populations, including tribal nations, through a streamlined, user-friendly voucher system. Thirty-seven Respite Provider Agencies joined the Voucher Program providing in-home and medical in-home care, adult day programs, specialized case aides and camps, parks, and recreation programs.
- States are reporting positive family caregiver outcomes. **Alabama's** respite voucher program found a substantial decrease in the percentage of caregivers reporting how often they felt overwhelmed with daily routines after receiving respite. Caregivers in **Nebraska's** Lifespan Respite program reported significant decreases in stress levels, fewer physical and emotional health issues, and reductions in anger and anxiety. The reduction of reported health symptoms was consistent across all three years of the evaluation.

- Innovative and sustainable respite services funded in **CO, MA, NC, NY, OH, PA, and SC** through mini-grants to community-based agencies have demonstrated caregiver benefits. During the three years of funding from 2014-2017 in **Massachusetts**, through Respite Innovation Mini-Grants, 455 caregivers received 5,553 hours of respite.
- **AL, AR, CO, NE, NY, PA, RI, SC and TN** are providing new volunteer or faith-based respite services through mini-grants and other capacity building approaches. In **Alabama**, 4-5 mini-grants were awarded each year to faith-based programs, and to agencies representing YMCA, Alzheimer's organizations, The Arc, Hospice, Mental Health, Autism organizations and others to provide respite services.
- **AL, IL, MD, ND and NE** offer emergency respite support. **Maryland's** emergency respite program provides financial assistance to family caregivers to pay for emergency respite and contracts with a statewide home care agency to provide a respite provider on short notice.

**States are engaged in capacity building through respite worker and volunteer training and through public education.**

- Respite provider recruitment and training are priorities in **AR, CO, MA, NE, NV, NY, SC, VA, and WI**. In **New York**, by the end of 2017, 3 master trainers, 100 trainers, and 100 companion volunteers were trained to provide respite in 26 counties. In **Tennessee**, the TN Respite Coalition (TRC) and the state agency grantee, in partnership with Tennessee Tech University (TTU), are developing curricula and training delivery methods, including technology supported training. The TRC entered into a three-year agreement with TTU to create a respite provider training video.
- In 2016, the **Rhode Island** grantee launched the Student Respite Initiative, a workforce development respite option with RI Island College (RIC) and University of Rhode Island (URI) nursing programs that offered student nurses clinical experience and course credit while being matched to low to moderate income families who had no access to subsidized respite care. In 2018, they added two more nursing programs to the initiative.
- Grantees in **AL, CO, FL, MA, MT, NE, TN, and TX** engaged in statewide public awareness campaigns to educate family caregivers about respite and how to find it. The **Florida** grantee launched a statewide public education campaign using PSAs distributed via television, radio, web, and social media that directed traffic to the Florida Lifespan Respite Alliance website. Through the Montana Broadcasters Association, the **Montana Lifespan Respite Coalition** developed and aired more than 10,000 radio and television PSAs about the importance and availability of their Lifespan Respite voucher program.

**Partnerships between state agencies are changing the landscape for respite service delivery.**

- **Lifespan Respite WA**, housed in WA's Aging & Long-Term Support Administration, partnered with WA's Children with Special Health Care Needs Program to provide respite vouchers to families across ages and disabilities. The WA Lifespan Respite grantee also partnered with Tribal entities to provide respite to kinship caregivers. Currently, they are working with Traumatic Brain Injury and developmental disability organizations to expand services to these populations.
- The **OK Lifespan Respite program** partnered with the state's Transit Administration to develop mobile respite to serve isolated rural areas of the state.
- **North Carolina** expanded the No Wrong Door partnership between the Division of Aging and Adult Services (DAAS) and United Way 2-1-1 by increasing the quantity and quality of respite resources available for caregivers through the 2-1-1 system and by enhancing training on respite resources for 2-1-1 Call Center staff. Recognizing the importance of a No Wrong Door approach to long-term services and support, the NC General Assembly appropriated funding for a full-time position within DAAS to partner with United Way 2-1-1 for statewide information and assistance with access.

**State grantees are collaborating with their Aging and Disability Resource Centers (ADRCs) or No Wrong Door (NWD) Systems to increase access to respite services and providers.**

- Grantees in **AL, FL, ID, MT, NC, NV, NY, SC, SD, TN, TX** are building respite registries and "no wrong door systems" in partnership with Aging and Disability Resource Centers/No Wrong Door systems to help family caregivers access respite and funding sources.
- New York State Office for Aging, the **NY Lifespan Respite grantee**, expanded access to caregiver services through improved respite listings in the NY Connects Resource Directory, the state No Wrong Door System, across all ages and disabilities. This interagency directory provides consistent and comprehensive information on long-term services and supports, including respite.
- In **Alabama**, a Universal Intake Form (UIF) for respite, a screening tool, was developed for use by ADRC staff at 13 Area Agencies on Aging to ensure callers enter a "no wrong door". Callers are screened and referred to appropriate resources within their local community. Follow-up is provided to ensure the individual's needs were addressed. All ADRC Specialists received training collaboratively planned and provided by Alabama Lifespan Respite staff and Alabama Department of Senior Services.
- The **Idaho** Lifespan Respite grantee, working with the ADRC and the Idaho Department of Health and Welfare 211 Careline, created a caregiver landing page on the 211 website that includes an online respite information site with search capability.



- **The Montana** Lifespan Respite grantee and the MT Lifespan Respite Coalition coordinated with the ADRCs to expand the online statewide resource database to include respite providers. A state map was also added to the website, allowing caregivers and stakeholders to view where the Lifespan Respite vouchers are being used.
- The **Florida** grantee established partnerships with the ADRCs providing the infrastructure for a No Wrong Door single point of entry. The partnership ensures linkages for respite inquiries statewide across all disability types. Over 1,000 respite care resources added or updated in the Aging and Disability Resource Centers' (ADRCs') Statewide Resource Database.

**Grantees and their partners are leveraging other federal and state dollars because of their federal grants.**

- The **Colorado Lifespan Respite Care Program**, with the help of Easterseals Colorado and in partnership with the Colorado Respite Coalition, successfully advocated for \$350,000 State General Funds for State Fiscal Years (SFY) 2016 and 2017, an increase from \$250,000 in 2015 and \$150,000 in 2014. The funds were designated for Lifespan Respite supports, with the majority distributed as community grants and family respite vouchers.
- In 2015, the lead agency in **South Carolina** and the South Carolina Respite Coalition successfully advocated for the creation of a \$1 million-line item in the state budget for vouchers for lifespan respite and a process for disseminating those vouchers to traditionally underserved caregivers. By SFY 17-18, with advocacy from respite champions and coalitions built across the state, the total appropriation was further increased to \$2.4 million in recurring respite funds. In addition, lead partner groups worked to incorporate short-term respite services as a benefit under the state's Medicaid home and community-based waivers, including a 1915(c) Medicaid waiver for children and youth with severe behavioral conditions.

***Funding Levels***

In 2006, Congress passed the Lifespan Respite Care Program Act in a bipartisan manner and the program maintains strong, bipartisan support in Congress. The program was initially authorized at \$289 million over five years based on the magnitude of the nation's family caregivers' needs. However, Congress appropriated only \$2.5 million annually from FY 2009 through FY 2012. The program received slightly less funding in FY13-FY15 due to sequestration. In FY16, given the strong bipartisan support for the program, Congress increased appropriations by \$1 million to \$3.36 million. This allowed six of the current grantees to receive one-year expansion grants to provide direct services to unserved groups and provided first-time awards to Maryland and Mississippi. For FY 2017, the program was once again funded at \$3.36, permitting funding of two new states (ND and SD) and enabling 12 grantees to continue their ground-breaking work to

serve more families. An increase in funding to \$4.1 million in FY18 and FY19 allowed an additional four states to continue to implement their Lifespan Respite grant activities.

***Recommendation to Reauthorize the Program and Retain Current Law – It's Working***

Reauthorization will ensure the stability of the program so that states can continue to serve more family caregivers, build respite capacity as the demand for respite increases, and have expectations that they will have time to develop sustainability plans for their innovative state efforts. ACL will be able to work to expand grants to new states that have not yet received a Lifespan Respite grant.

The Lifespan Respite Care Program is the only federal program that prioritizes respite for all ages and conditions, allows states to use funds for start-up of new innovative and evidence-informed programs, encourages and supports collaboration to maximize use of existing funds, and supports training and recruitment of respite providers to address the direct service worker shortage. That is a tall order, but states are meeting the challenges head on. Given that it is working so well, the National Respite Coalition recommends no changes to the pending bill, H.R. 2035, which modifies current statutory language only to give ACL additional authority for improved data collection.

A strong knowledge base about state best practices has emerged from ten years of program implementation. The Lifespan Respite grantees and partners freely share respite best practices information and models that can be adapted to meet states' needs without having to reinvent the wheel. Most importantly, current law gives states flexibility and local control in meeting the program's requirements so that each state can determine the best approaches to address their own unique, identified needs for respite and provide critical gap-filling services. We urge you to reauthorize the Lifespan Respite Care Act with minimal changes to current law as written in H.R. 2035. Families will be able to keep loved ones at home, saving Medicaid and other federal programs billions of dollars.

Thank you for the opportunity to testify.

**For more information, please contact Jill Kagan, ARCH National Respite Coalition at [jkagan@archrespite.org](mailto:jkagan@archrespite.org) or by phone at 703-256-2084.**

**References**

Abelson, A.G. (1999). Economic consequences and lack of respite care. *Psychological Reports*, 85, 880-882.

Alabama Department of Senior Services (2018). Alabama's Lifespan Respite Sustainability Program Semi-Annual Performance Report, March 30, 2018. Huntsville, AL: Author.

- American Psychological Association, 2012, Stress in America.  
<http://www.apa.org/news/press/releases/stress/2011/health-risk.aspx>
- American Psychological Association (nd). *Caregiver Briefcase: Family Caregiver Well-Being is Important to Care Recipient Health*.  
<http://www.apa.org/pi/about/publications/caregivers/faq/well-being.aspx>
- Anderson, L., Hewitt, A., Pettingell, S., Lulinski, A., Taylor, M., & Reagan, J. (2018). *Family and Individual Needs for Disability Supports (v.2) Community Report 2017*. Minnesota: Research and Training. Center on Community Living, Institute on Community Integration, University of Minnesota. <https://www.thearc.org/FINDS>
- Avison, C, Brock, D, Campione, J, Hasell, S, Rabinovich, B, Ritter, R, Severynse, J, Yang, D-H (2018). *Final Report prepared for the U.S. Administration for Community Living: Outcome Evaluation of the National Family Caregiver Support Program*. Washington, D.C.: Westat.
- Black, BS, PhD; Johnston, D MB, Rabins, PV, MD, MPH, Morrison, A PhD, RN, Lyketsos, C MD, MHS, and Samus, QM, PhD, Unmet Needs of Community-Residing Persons with Dementia and Their Informal Caregivers: Findings from the Maximizing Independence at Home Study. *Journal of the American Geriatrics Society*, Volume 61, Issue 12, pages 2087–2095, December 2013.
- Broady, T. and Aggar, C. (2017). Carer interventions: An overview of service effectiveness. *J of the Australasian Rehabilitation Nurses' Association*, 20 (2), 5-11.
- Caldwell, J. (2007). Experiences of families with relatives with intellectual and developmental disabilities in a consumer-directed support program. *Disability and Society*, 549-562.
- Child and Adolescent Health Measurement Initiative. 2017 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by Cooperative Agreement U59MC27866 from the U.S. Department of Health and Human Services, Health Resources and Services Administration's Maternal and Child Health Bureau (HRSA MCHB). Retrieved [04/07/19] from [www.childhealthdata.org](http://www.childhealthdata.org). CAHMI: [www.cahmi.org](http://www.cahmi.org).
- Congressional Budget Office (2013). *Rising Demand for Long-Term Services and Supports for Elderly People*. Washington, DC: Author <https://www.cbo.gov/publication/44363>
- Gresham M., Heffernan, M., and Brodaty, H. (2018). The Going to Stay at Home program: combining dementia caregiver training and residential respite care. *International Psychogeriatrics*, 1-10.
- Harper, A; Dyches, TT; Harper, J; Roper, SO; and South, M. (2013). Respite Care, Marital Quality, and Stress in Parents of Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, March 2013.
- Johnson, J., Swanson, S., and Falk, K. (2018). *Nebraska Lifespan Respite Network: Producing Positive Outcomes for Families, 2015-2017*. Munroe-Meyer Institute and the Interdisciplinary Center of Program Evaluation, University of Nebraska Medical Center.
- Kirk, R, PhD (2015). *A Research Agenda for Respite Care: Deliberations of an Expert Panel of Researchers, Advocates and Funders*. Chapel Hill, NC: ARCH National Respite Network and

Resource Center.

[http://archrespice.org/images/docs/2015\\_Reports/ARCH\\_Respice\\_Research\\_Report\\_web.pdf](http://archrespice.org/images/docs/2015_Reports/ARCH_Respice_Research_Report_web.pdf)

Lopez-Hartmann, M., Wens, J., Verhoeven, V., and Remmen, R. (2012). The effect of caregiver support interventions for informal caregivers or community-dwelling frail elderly: a systematic review. *International Journal of Integrated Care*, 12: 1-14.

Mandell, David S. ScD; Xie, Ming, MS; Morales, Knashawn H., ScD; Lawer, Lindsay, MA; McCarthy, Megan, MA; Marcus, Steven C., PhD. (2012). The Interplay of Outpatient Services and Psychiatric Hospitalization among Medicaid-Enrolled Children with Autism Spectrum Disorders. *Arch Pediatr Adolesc Med*. 2012;166(1):68-73.

Maryland Caregivers Support Coordinating Council, MD Department of Human Resources (2015). *Understanding Caregiver Needs in Maryland -- Summary of Key Findings: Caregiver Survey Maryland 2015*.

Matos, K. (2015). Highlights from the 2014 Older Adult Caregiver Study. New York, NY: Families and Work Institute. <http://www.familiesandwork.org/downloads/2014-Older-Adult-Caregiver-Study.pdf>

McBean, Amanda L. and Schlosnagle, Leo (2013). *Relations between Sleep Disturbance, General Health, and Memory among Parents of Children with Special Health Care Needs*. Poster Presentation at the AUCD Annual Meeting, November 2013.

MetLife Mature Market Institute. (2006). *The MetLife Caregiving Cost Study: Productivity Losses to U.S. Business*. <https://www.metlife.com/assets/cao/mmi/publications/studies/mmi-caregiver-cost-study-productivity.pdf>

National Academies of Sciences, Engineering, and Medicine (2016). *Families Caring for an Aging America*. Washington, DC: The National Academies Press.

National Alliance for Caregiving and AARP Public Policy Institute (2015). *Caregiving in the U.S. 2015*. Washington, DC: Authors. <http://www.caregiving.org/caregiving2015/>

National Alliance for Caregiving. (2012). *Multiple Sclerosis Caregivers*. Washington, DC: Author. [http://www.caregiving.org/pdf/research/MSCaregivers2012\\_FINAL.pdf](http://www.caregiving.org/pdf/research/MSCaregivers2012_FINAL.pdf)

Population Reference Bureau. Family Caregiving. *Today's Research on Aging*, No. 33, February 2016. <http://www.prb.org/pdf16/TodaysResearchAging33.pdf>

Ramchand, R, Tanielian, T, Fisher, MP, Vaughan, CA, Trail, TE, Epley, C; Voorhies, P, Robbins, M, Robinson, R, Ghosh-Dastidar, B (2014). *Hidden Heroes: America's Military Caregivers*. Santa Monica, CA: The Rand Corporation. [http://www.rand.org/pubs/research\\_reports/RR499.html](http://www.rand.org/pubs/research_reports/RR499.html)

Reinhard, SC; Feinberg, LF; Choula, R; Houser, A (2015). *Valuing the Invaluable: 2015 Update Undeniable Progress, but Big Gaps Remain*. Washington, DC: AARP Public Policy Institute. <http://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-new.pdf>

Spillman, Brenda C, and Long, S, prepared for the USDHHS (U.S. Department of Health and Human Services). (2007). *Does high caregiver stress lead to nursing home entry?* Washington, DC: Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-term

Care Policy. January 26, 2007 DHHS Report. <https://aspe.hhs.gov/basic-report/does-high-caregiver-stress-lead-nursing-home-entry>

Spillman, BC, J Wolff, VA Freedman, and JD Kasper. *Informal Caregiving for Older Americans: An Analysis of the 2011 National Survey of Caregiving*. Report to the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging, and Long-Term Care Policy, April 2014. <https://aspe.hhs.gov/report/informal-caregiving-older-americans-analysis-2011-national-study-caregiving>

Wolff, JL; Spillman, BC; Freedman, VA; and Kasper, JD (2016). A National Profile of Family and Unpaid Caregivers Who Assist Older Adults with Health Care Activities. *JAMA Intern Med.* 2016; 176(3):372-379.

Witters, Dan. The Cost of Caregiving to the U.S. Economy. *Gallup Business Journal*, December 2011. <http://businessjournal.gallup.com/content/151049/Cost-Caregiving-Economy.aspx>

Zarit, S.H., Whetzel, C.A., Kim, K., Femia, E.E., Almeida, D.M., Rovine, M.J., Klein, L.C. (2014). Daily Stressors and Adult Day Service Use by Family Caregivers: Effects on Depressive Symptoms, Positive Mood, and Dehydroepiandrosterone-Sulfate. *Am J Geriatr Psychiatry.* 22(12):1592-602.

Ms. ESHOO. Thank you, Ms. Kagan.

I would now like to recognize Dr. Kunz Howard for your testimony. You have 5 minutes, and welcome and thank you again.

**STATEMENT OF PATRICIA KUNZ HOWARD, Ph.D., R.N.**

Dr. HOWARD. Thank you.

Chairwoman Eshoo, Ranking Member Burgess, and distinguished members of the subcommittee, thank you for inviting me to testify at this important hearing on vital healthcare programs that serve American families and in support of the Emergency Medical Services for Children Program Reauthorization Act of 2019.

I am Patricia Kunz Howard, the Enterprise director for emergency services at the University of Kentucky healthcare, which includes a full-service academic medical center and a community hospital in Lexington.

Between the two emergency departments, we treat over 35,000 children each year and for the past 29 years, I have also served as the EMS educator for Lexington Fire and Emergency Services, training paramedics.

In addition, I am the 2019 president of the Emergency Nurses Association, the largest professional healthcare organization dedicated to improving emergency care with over 44,000 members worldwide.

As a registered nurse and educator, I have dedicated my professional career to providing the best possible care for all patients regardless of their age, and as a pediatric clinical nurse specialist, I know that caring for children is one of the greatest responsibilities we have as healthcare professionals.

In the United States, children and adolescents make up 27 percent of all emergency department visits. As you know, this patient population presents unique challenges for healthcare professionals during an emergency requiring specific types of equipment and often different medication dosage regimens.

Nevertheless, this reality is that many facilities and healthcare professionals in the most vulnerable areas of our country would struggle to maintain these resources if not for the existence of the EMSC program.

As you know, in 1984, Congress recognized the disparities that existed in emergency care between adult and pediatric patients and created the EMSC for Children program.

More than 30 years later, it is the only federal program wholly devoted to improving pediatric emergency care. The EMSC program enhances care no matter where children live, travel, or attend school.

It accomplishes this by helping ensure that hospitals and EMS systems have access to pediatric appropriate training, education, and resources.

Under the EMSC state partnership grants, funds are made available to each state EMSC program which in turn are used to help hospitals and EMS systems meet performance measures to improve pediatric readiness and to deliver quality care to children.

For example, state partnership grants have helped develop inter-facility transfer guidelines that define the process for selecting the

correct hospital for the pediatric patient to be transferred to, ensuring appropriate staffing on the transport vehicle to match the needs of the child in their clinical condition as well as having the plans to help immediately facilitate that transfer to the receiving facility.

These guidelines have assured higher quality care for ill or injured pediatric patients and ultimately better outcomes. EMSC support has also been used to help with the purchase of specialized equipment and supplies.

One great example is the various types and sizes of lifesaving airway equipment used by EMS to be able to treat a tiny pre-term infant or a much larger child.

Another key component of the EMSC program is the Pediatric Emergency Care Applied Research Network, or PECARN, which is the first federally supported research initiative focused on improving emergency care for children.

Because of the research conducted by PECARN, advancements have been made in many treatment options for children. One of these that is so important in emergency care is the pediatric head injury and treatment algorithm that was developed to lead to the reduction in unnecessary radiation exposure by CT scans when children have suffered minor head injuries, which helps reduce their long-term risk for cancer.

EMSC-developed research has also led to better identification of adolescents at risk for substance abuse and improved strategies to quickly identify children suffering from bacterial infections, which have an increased risk of sepsis.

As an emergency nurse, I know from first-hand experience what a critical resource the EMSC program is to facilities across the country. Working as a team, nurses, EMS, and physicians are better able to manage all types of pediatric emergencies thanks to the resources and training that the EMSC programs have helped to provide.

In my home state of Kentucky, the EMSC program has sponsored education for pre-hospital as well as in-hospital professionals regarding emergency care for children.

Ambulance services now have access to correct equipment and specialized knowledge, thanks to this program. Without this program, the critical care we are to provide for children in Kentucky and I am sure in other states would suffer.

Emergency nurses and our professional colleagues passionately care about providing the highest quality care to all of our patients and we strive for them to have the best outcomes possible for their illnesses and injuries.

This is especially the case for those who are among the most vulnerable in our society and who are in need of specialized, high-quality healthcare services—our children.

Thank you again for providing me the opportunity to represent the emergency care community and speak in support of reauthorizing the Emergency Medical Services for Children program.

[The prepared statement of Dr. Howard follows:]

Written Statement of  
**Patricia Kunz Howard, PhD, RN, CEN, CPEN, TCRN,  
NE-BC, FAEN, FAAN**

Enterprise Director, Emergency Services, University of Kentucky Health Care,  
Lexington, Kentucky;  
2019 President, Emergency Nurses Association

On behalf of the  
Emergency Nurses Association (ENA)

Before the  
House Committee on Energy and Commerce, Subcommittee on Health

Hearing on  
“Reauthorizing Vital Health Programs for American Families”

Tuesday, June 25, 2019



## **I. Introduction**

Chairwoman Eshoo, Ranking Member Burgess, and distinguished members of the Subcommittee, thank you for inviting me to testify at this important hearing on health care programs that serve American families and in support of the Emergency Medical Services for Children Program Reauthorization Act of 2019. My name is Patricia Kunz Howard and I am the Enterprise Director of Emergency Services for the University of Kentucky HealthCare, a full-service academic medical center and community hospital located in Lexington, Kentucky.

I am also the 2019 President of the Emergency Nurses Association (ENA), the largest professional health care organization dedicated to improving emergency nursing care, with more than 44,000 members worldwide.

ENA is a recognized leader in improving emergency health care for every American. However, we are especially proud of our long-standing efforts to provide better health care for our nation's children. These include the development of the premier emergency nursing pediatric course used by hospitals around the world.

Additionally, in support of EMSC program initiatives, ENA has collaborated with the American College of Emergency Physicians, American Academy of Pediatrics, National Association of Emergency Medical Technicians and National Association of State EMS Officials on position statements, guidelines, and quality improvement programs to enhance emergency department and EMS readiness in caring for this vulnerable population.

## **II. Caring for Pediatric Patients in the Emergency Department**

As a registered nurse and an educator, I have dedicated my professional career to providing the best possible care for my patients,

regardless of their age or condition. Moreover, as a pediatric clinical nurse specialist, I know that caring for children is one of the greatest responsibilities we have as health care professionals.

The Albert B. Chandler Medical Center on the campus of the University of Kentucky is verified by the American College of Surgeons as Level I trauma center for both adult and pediatric patients. As such, we serve as a major referral center for Central and Eastern Kentucky, as well as bordering states providing complex, comprehensive care for all patients.

Between the two emergency departments in our system, we treat more than 35,000 children each year. In fact, our own Makenna David Pediatric Emergency Center is the only dedicated children's emergency department in central and eastern Kentucky. And in 2019 was recognized as a Pediatric Ready Emergency Department by the Kentucky EMSC program.

In the United States, children and adolescents make up 27 percent of all visits to emergency departments. As you know, this patient population presents unique challenges for health care professionals during an emergency. Diseases and conditions manifest themselves differently in children. These patients are not simply "little adults" as many people might assume, and they require specific types of equipment and medication doses unique to this population during an emergency. Nevertheless, the reality is many facilities and health care professionals in the most vulnerable areas of our country would struggle to maintain these resources if not for the existence of the EMSC program.

### **III. The EMSC Program**

In 1984, Congress recognized the disparities that existed in emergency care between adult and pediatric patients and created the Emergency Medical Services for Children Program. More than 30 years

later, it remains the only federal program wholly devoted to improving pediatric emergency care.

Its overall mission is to reduce the prevalence of morbidity and mortality in children that may occur as a result of acute illness and severe injury.

In addition, the EMSC program, because it covers both pre-hospital EMS and emergency departments, enhances care no matter where children live, attend school or travel. It accomplishes this by helping ensure that hospitals and EMS systems have access to pediatric appropriate medication and state-of-the-art equipment and training.

One of the most important initiatives within the EMSC program are the State Partnership Grants. Under this grant, funds are made available to each individual state EMSC program, which in turn is used to help hospitals and EMS agencies to meet performance measures to improve their pediatric readiness and delivery of emergency health care to children.

As an example, when an emergency department lacks the necessary resources to care for a child, the child should be transferred to the closest appropriate facility with minimal delays. State Partnership Grants have helped develop and implement interfacility transfer guidelines that define the process for selecting the optimal hospital for the pediatric patient, ensuring appropriate staffing of the transport service to match the needs of the child and having a plan to immediately transfer the patient's medical records to the receiving facility. These guidelines, which have been adopted by 50 percent of hospitals, assure a higher quality of care for the ill or injured pediatric patient and ultimately, better outcomes.

EMSC support to states has also been used for the purchase of specialized equipment and supplies to improve how children are cared for following a severe accident or during an illness.

Because a child's size and anatomy are very different from an adult, the use of appropriately sized equipment is crucial to providing safe, quality care. One example is the use by EMS providers of various sizes of lifesaving airway equipment to be able to treat a tiny, pre-term infant or a much larger adolescent.

Another key component of the EMSC program is the Pediatric Emergency Care Applied Research Network (PECARN), which is the first federally supported research initiative focused on improving emergency care for children.

Among the areas that have seen innovative research through this network include:

- Development of the Pediatric Head Injury/Trauma Algorithm, which has led to the reduction in unnecessary radiation exposure from CT scans in children who have suffered minor head injuries, thereby reducing the long-term risk of developing cancer
- Improved mental health screening of children
- Development of tools to allow rapid identification of adolescents at risk for substance abuse
- The development of cutting-edge strategies to quickly identify children with a bacterial infection, thereby distinguishing those more at risk for sepsis.

Since 2013, EMSC has also facilitated the National Pediatric Readiness Project, a quality improvement initiative which promotes collaboration among emergency care professionals to provide the highest quality of care to children at the bedside. Based on a national assessment of the capabilities of emergency departments and hospitals to care for children, this project calls on nurse and physician coordinators, or "champions," to provide leadership in assuring quality care for

pediatric patients. This is achieved through staff training, pediatric facility recognition and the development of quality improvement indicators that address pediatric care in situations such as disasters and medication administration.

As an emergency nurse, I know what a critical resource the EMSC program is to facilities across the country. Working as a team, nurses, EMS and physicians are better able to manage all types of pediatric emergencies, such as seizures, traumatic brain injuries, and illnesses like bronchiolitis and sepsis, thanks to the resources and training EMSC helps to provide.

As the lead paramedic educator for the Lexington Division of Fire and Emergency Services, and as one of the original authors of the Pediatric Education for Prehospital Professionals program, I know from firsthand experience that the care provided by EMTs and Paramedics before the child arrives at the hospital can often save a life or mitigate further injury.

In Kentucky, the EMSC program has sponsored courses and training for prehospital as well as in-hospital professionals regarding emergency care for children. Ambulance services around my state have access to the correct equipment, knowledge and training thanks to the EMSC program. Without the EMSC program, the critical, lifesaving care we are able to provide for children in my state, and I am sure in other states, would suffer.

The EMSC program is cost-effective and responsive to the needs of nurses, physicians and EMS personnel who provide emergency care. For more than 30 years, it has resulted in tangible improvements to pediatric emergency care throughout the country.

With the expiration of this program on the horizon, it is especially important that members of Congress work together to reauthorize EMSC, which is the only one of its kind dedicated to improving emergency care for pediatric patients.

**IV. Conclusion**

Emergency nurses and our professional colleagues passionately care about providing the best possible care for all of our patients, regardless of age or geographic location. This is especially the case for those who are among the most vulnerable in our society and who are also in need of specialized, high-quality health care services – our children.

Thank you again for allowing me the opportunity to represent the Emergency Nurses Association and speak for my fellow emergency care colleagues in support of the Emergency Medical Services for Children Program.

Ms. ESHOO. Thank you very much, Dr. Kunz Howard.

I would now like to recognize Dr. Bocchini. You have 5 minutes for your testimony. Am I pronouncing your name?

Dr. BOCCHINI. That is correct, yes.

Ms. ESHOO. Thank you.

Dr. BOCCHINI. Thank you.

Ms. ESHOO. OK.

#### **STATEMENT OF JOSEPH BOCCHINI, Jr., M.D.**

Dr. BOCCHINI. Madam Chairwoman Eshoo, Ranking Member Burgess, and distinguished Health Subcommittee members, thank you for inviting me to speak before this committee today.

I have recently had the privilege of serving an eight-year term as the chairman of the Advisory Committee on Heritable Disorders in Newborns and Children, the advisory committee whose current activities are determined by the Newborn Screening Saves Lives Act of 2014.

I have seen the benefits of this act through the eyes of the Advisory Committee, in my clinical practice, and in the infants whose lives have been improved and, in many cases, saved through the prompt diagnosis and treatment of conditions identified by newborn screening.

The Newborn Screening Saves Lives Reauthorization Act of 2019 is a critical piece of legislation which supports one of the most successful public health disease prevention programs in the United States.

Congress first enacted the Newborn Screening Saves Lives Act in 2008 with the realization that federal input was essential to developing a uniform, evidence-based national newborn screening panel that would lead to the universal application by states of the new technologies and treatments becoming available for a number of serious and life-threatening conditions affecting infants and children which were not apparent at birth.

Congress also recognized that federal agencies served an important role in supporting states through a variety of mechanisms including educational and training activities, research, technical assistance, and infrastructure development.

Over the past 11 years, federal input from the Advisory Committee, approval of its recommendations by the secretary of the Department of Health and Human Services, research supported by the National Institute of Health, laboratory improvement efforts by the Centers for Disease Control and Prevention, and funding to help improve state screening programs from the Health Resources and Services Administration have greatly benefited infants and families and by helping to advance this highly successful state-based public health system.

Although each of the conditions recommended for newborn screening is considered rare, one in approximately 300—every 300 screened newborn infants is found to have a condition for which treatment is beneficial.

Early diagnosis enables the infants identified through newborn screening to receive the treatments necessary to prevent serious and often permanent developmental and other complications or death.

For many of the conditions on this panel, early diagnosis and treatment not only benefit the infant but it cost saving. In 2010, the secretary of HHS officially adopted the first recommended uniform screening panel, our RUSP, which included 29 primary conditions and primary, secondary conditions.

Within a few years, all states were screening for these conditions. With the screening panel, as has been mentioned before, approximately 12,500 newborn infants were being identified annually with serious genetic, endocrine, and metabolic conditions, including congenital hypothyroidism, cystic fibrosis, sickle cell disease, and hearing loss as well as a number of other metabolic conditions that are significantly rarer.

Rapid advances in diagnosis and treatment has led to inclusion of six additional conditions on the RUSP. They include severe combined immunodeficiency, critical congenital heart disease, Pompe disease, mucopolysaccharidosis type 1, adrenoleukodystrophy, and, most recently, spinal muscular atrophy.

Much remains to be done to continue to improve the capacity and effectiveness of the newborn screening system. H.R. 2507 as written, will strengthen newborn screening programs in individual states, help meet the research and clinical challenges in this rapidly advancing field, and have a significant positive impact on the health and well-being of the nearly four million children born each year in the United States and its territories.

I expect that new screening and diagnostic tests and therapies will soon bring more conditions to the Advisory Committee for its evidence-based evaluations.

H.R. 2507 will also strengthen the efforts to evaluate new technologies and to bring new conditions to newborn screening programs by increasing needed funding for the efforts of HRSA, the NIH through the Hunter Kelly Newborn Screening Research Program, and the CDC.

The additional funding will allow for enhanced technical assistance and financial support for states, which will reduce barriers to implementation of new conditions and shorten the time needed for states to begin screening once a condition is approved for inclusion on the RUSP.

Once again, I thank you for the opportunity to provide testimony and support of this reauthorization act. I look forward to your questions.

Thank you.

[The prepared statement of Dr. Bocchini follows:]



**TESTIMONY OF  
JOSEPH A. BOCCHINI, JR, MD  
PROFESSOR OF PEDIATRICS  
LOUISIANA STATE UNIVERSITY HEALTH SCIENCES CENTER AT SHREVEPORT**

**BEFORE THE ENERGY AND COMMERCE SUBCOMMITTEE ON HEALTH HEARING  
"REAUTHORIZING VITAL HEALTH PROGRAMS FOR AMERICAN FAMILIES"  
JUNE 25, 2019**

Madam Chairman Eshoo and Ranking Member Burgess, Health Subcommittee Members

My name is Joseph Anthony Bocchini, Jr. I am a pediatrician and a pediatric infectious diseases specialist. I serve as a Professor of Pediatrics at Louisiana State University Health Sciences Center in Shreveport.

I have recently had the privilege of serving an eight-year term as Chairman of the Advisory Committee on Heritable Disorders in Newborns and Children, the Advisory Committee established with the original authorization of the Newborn Screening Saves Lives Act in 2008 and continued in its reauthorization in 2014. I have seen the benefits of this Act through the eyes of the Advisory Committee, in my practice, and in the infants whose lives have been improved and, in many cases, saved, through the prompt diagnosis and treatment of conditions which untreated, can cause serious health problems in infancy or childhood.

I am pleased to provide testimony today in strong support of the Newborn Screening Saves Lives Reauthorization Act of 2019 (H.R. 2507). This is a critical piece of legislation which supports the activities of one of the most successful public health disease prevention programs in the United States. The activities imbedded in this reauthorization provide the additional infrastructure needed to build on the successes of the past 11 years and address how to continue to adapt and adjust this rapidly growing and changing program.

Newborn screening began 56 years ago with the development of a heel stick blood test to screen for phenylketonuria, a metabolic condition which untreated, can lead to brain damage or death. With rapid advances in the understanding of the cause of multiple disorders, and the availability of new diagnostic testing platforms and treatments over the next decades, many other conditions were being considered for newborn screening. States were making individual decisions about which conditions to include in their screening programs without the benefit of a systematic review of the evidence as to whether an infant would benefit from being screened or treated for a particular condition. This resulted in considerable health inequities with children born in one state being screened for perhaps only one or two conditions, and just across the state line infants being screened for a much larger number of conditions, and without a good understanding of the outcome or benefits of either approach.

Congress first enacted the Newborn Screening Saves Lives Act (Pub.L.110-204) in 2008 with the realization that Federal input was essential to improving the evidence-based, universal application by states of the new technologies and treatments becoming available for a number of serious and life threatening conditions affecting infants and children which are not apparent at birth.

Congress also recognized that Federal Agencies served an important role in supporting states through a variety of mechanisms including educational and training activities, research, technical assistance and infrastructure development. Over the past 11 years, Federal input from the Advisory Committee, approval of its recommendations by the Secretary of the Department of Health and Human Services (HHS), research supported by the National Institute of Health (NIH), laboratory improvement efforts at the Centers for Disease Control and Prevention (CDC), and funding to help improve state screening programs from the Health Resources and Services Administration (HRSA) have greatly benefited families by helping to advance this highly successful state-based public health system.

Although each of the conditions recommended for newborn screening are considered rare, 1 in approximately every 300 screened newborn infants is found to have a condition for which treatment is beneficial.

Today, almost every one of the approximately 4 million infants born annually in the United States undergoes newborn screening. In 2010, the Secretary of HHS officially adopted the first uniform newborn screening panel, now called the Recommended Uniform Screening Panel, or RUSP, which included 29 primary conditions and 25 secondary conditions. Within a few years, all states were screening for these conditions. With this recommended screening panel, each year approximately 12,500 newborn infants were being identified as having one of the screened conditions according to CDC research.<sup>1</sup> Early diagnosis enables these infants identified through newborn screening to receive the treatments necessary to prevent serious and often permanent complications, and in many cases, even death. The conditions for which we screen include genetic, endocrine and metabolic disorders, and hearing loss. For many of the conditions on the panel, early diagnosis and treatment not only benefits the infant, it is cost saving.

Since 2010, six additional conditions were recommended for inclusion on the RUSP and accepted by the HHS Secretary, increasing the primary conditions recommended for routine screening to 35.<sup>2</sup> Today, all states are screening for at least 31 of the primary conditions.

I would like to briefly tell you about two of the added conditions.

Severe Combined Immunodeficiency (SCID) was added to the RUSP in 2010. All states now screen for SCID. Infants with SCID are born without an effective immune system. The first infection they develop is often fatal. Infants identified with SCID because they have a serious infection often fail therapy and die of complications of the infection. Screening allows a diagnosis to be made in most cases before an infection occurs and allows for the therapy

needed to reconstitute the immune system. California<sup>3</sup> reported this year on the results of the first 8 years (2010 through 2017) of its newborn screening program for SCID. California identified 50 infants with SCID during this time period. Of the 49 available for treatment of the type of SCID identified, 46 of the infants (94%) survived. Another article detailing newborn screening for SCID in 11 states<sup>4</sup>, reported an 87% survival rate in the 52 identified cases following the introduction of newborn screening for SCID.

Critical Congenital Heart Disease (CCHD) was added to the RUSP in 2011. Congenital heart disease is responsible for approximately 3% of all infant deaths in the first year of life. A number of infants born with critical congenital heart disease will have no symptoms in the newborn period and become critically ill within the first few weeks to months of life. A significant number of these infants can be detected in the newborn nursery by measuring their blood oxygen saturation before they are discharged home. A study<sup>5</sup> of infant cardiac deaths between 2007 and 2013 demonstrated a 33.4% decrease in early infant deaths from critical congenital heart disease in eight states after implementation of mandatory screening for CCHD.

Screening for CCHD is one of two ‘point of care’ tests on the RUSP that do not involve testing of a blood spot obtained from the heel of an infant. The other is hearing testing.

The other conditions added to the RUSP in recent years are:

- Pompe Disease (2013) – now being screened for in 19 state programs
- Mucopolysaccharidosis, type 1 (2016) – now being screened for in 17 state programs
- Adrenoleukodystrophy (2016) – now being screened for in 15 state programs
- Spinal Muscular Atrophy (2017) – now being screened for in 9 state programs

Much remains to be done to continue to improve the capacity and effectiveness of the newborn screening system and to meet the challenges of this rapidly changing field of health care.

H.R. 2507, as written, will strengthen the newborn screening program and will have a significant positive impact on the health and wellbeing of the nearly 4 million children born each year in the United States and its territories.

It will strengthen the efforts to bring new conditions to the newborn screening program by increasing needed funding for the efforts of HRSA, NIH and the CDC to improve state developmental readiness and training opportunities. The additional funding will allow for enhanced technical assistance and financial support for states, which will reduce barriers to implementation of new conditions and shorten the time needed for states to begin screening once a condition is approved for addition to the RUSP.

In addition, as scientific advances and the ability to utilize new technologies such as genomic sequencing are evaluated, additional research, ethical and clinical questions will need to be answered. These technological advances could significantly alter the approach to newborn

screening in the coming years. The inclusion in the reauthorization of a request for the National Academy of Science to evaluate our current screening system is timely and is likely to provide many relevant policy recommendations and/or identify areas of further study.

Once again, I thank you for the opportunity to provide testimony in support of the Newborn Screening Saves Lives Reauthorization Act of 2019. I look forward to your questions.

#### References

1. MMWR. 2012;61(21):390-393
2. <https://www.hrsa.gov/advisory-committees/heritable-disorders/rusp/index.html>
3. Pediatrics. 2019;143(2):e20182300
4. JAMA. 2014;312(7):729-738
5. JAMA. 2017;318(21):2111-2118

Ms. ESHOO. Thank you very much, Doctor. It's exciting to hear a first-hand report from someone on the—on the—is it a commission?

Dr. BOCCHINI. A committee. Yes. Thank you.

Ms. ESHOO. A committee?

Dr. BOCCHINI. Yes.

Ms. ESHOO. Wonderful. So now we will—we've concluded the testimony of the witnesses. I want to welcome Congressman Chris Smith, who has joined us. He has been an indefatigable leader on the issue of the Autism CARES Act and we are thrilled that you're here today and that we are taking up legislation.

Congressman Doyle was here earlier. So welcome to you and thank you for your wonderful work.

The Chair is going to recognize herself for 5 minutes to ask questions.

Dr. Hewitt, do we know what causes autism?

Dr. HEWITT. There isn't a single cause of autism. We know that there is an intersection between genetics. We know there's a genetic component, and the importance of the research that the CARES Act would fund would be to help us continue to explore what causation is but, more importantly, to make sure that we are identifying children earlier and getting them connected to services and supports in their community.

Ms. ESHOO. So now you mentioned your brother-in-law who is, what, you said, I think 43 years—

Dr. HEWITT. Forty-five.

Ms. ESHOO. Forty-five, and when was he diagnosed?

Dr. HEWITT. Unfortunately, Nathan wasn't diagnosed until he was 17.

Ms. ESHOO. And so what—in that gap of—what did he end up—

Dr. HEWITT. So had he been diagnosed earlier—

Ms. ESHOO. How was he held back, given the gap that you describe?

Dr. HEWITT. So for Nathan, he really received inappropriate educational services his entire 12 years of education. He ended high school without a high school diploma and if he had early intervention I think his life outcomes would have been substantially different than they are now.

Ms. ESHOO. Yes. So where do you think we are in terms of—how would you—what kind of score would you give the United States of America on the progress that we've made on autism both in terms of early detection and then the services that are needed? I think that's kind of the \$64,000 question to me.

[Laughter.]

Dr. HEWITT. It's a good question.

Ms. ESHOO. My sister teaches children with autism and she has taught me a lot.

Dr. HEWITT. Yes. I think we are doing much better at identifying children early. If you look at the ADDM data, it shows that we are inching towards identifying kids younger and then some states are doing better than other states. But we are making progress in early identification and getting kids connected to services.

Ms. ESHOO. Well, thank you for everything that you have done to move the needle.

Ms. KAGAN, I am struck by the statistic in your testimony that 85 percent of family caregivers of adults are not receiving any respite services whatsoever. In my previous life, before coming to Congress, I was a member of a county Board of Supervisors and established more than one adult day healthcare center so that the caregivers would have some rest.

And when I look at the dollars, and there is an increase in this, but for 50 States it's not even a million dollars for each state.

So we are, I think, on the right pathway but how many states did you say have absolutely no respite services whatsoever?

Ms. KAGAN. Well, there have been 37 States and the District of Columbia that have received at least one Lifespan respite grant. So we still have a large chunk of states that have never received a Lifespan grant.

There are other federal sources of funding for respite. But as I mentioned, Medicaid home and community-based waivers, for example, are often very narrowly targeted, don't exist across states in the same way, and have long waiting lists. Programs like National Family Caregiver Support Program also offer important respite but only primarily for the aging population—not only but primarily. So——

Ms. ESHOO. Well, Health Affairs found that by 2029 many seniors will be what they term in the forgotten middle where they won't qualify for Medicaid but also won't be able to afford to pay for long-term care.

So my question to you is how can family caregivers help address that problem and the larger question is what do you recommend Congress should be doing now to create a better system of support for the caregivers not only today but for tomorrow?

Ms. KAGAN. Absolutely. I think the Lifespan respite care program, of course, is an important first step because it not only helps pay for respite for families who don't qualify for these public programs——

Ms. ESHOO. Right.

Ms. KAGAN [continuing]. But have exorbitant expenses related to their care giving duties or had to give up employment in order to stay home and provide care. But Lifespan respite also allows states to use their funds to address the capacity issue.

We have a tremendous crisis in direct service worker shortages and Lifespan respite programs; most of the states are doing some kind of recruiting and training of respite workers as well as volunteers because we are just not going to have the bodies.

Ms. ESHOO. It's overwhelming—it really is—for the care.

Thank you to each one of you. I wish I had more time. I don't, and I now would like to yield 5 minutes to Dr. Burgess, the ranking member of the subcommittee, for his questions.

Mr. BURGESS. Thank you, Madam Chairwoman.

Ms. ESHOO. We need a doctor for the doctor. He doesn't feel well today.

Mr. BURGESS. Well, we went late in Rules Committee last night, so I used up all my vocal abilities last night.

So, Dr. Bocchini and Dr. Hewitt, you're sitting on opposite ends of this panel. But, Dr. Bocchini, maybe you want to develop an early screening method for the autism team and be able to provide Kim's therapy before they leave the newborn nursery. Is that—is that ever on your horizon?

Dr. BOCCHINI. I am not aware of it. Certainly, there are a number of known genetic changes that have been associated with autism and I am not sure of the total percentage of autistic cases that are associated with specific gene abnormalities.

But, there is a panel that can be used to diagnose some of the patients—some of the individuals with autism. Whether a newborn screening test would become an appropriate way to evaluate that I think is something to be considered for the future.

Mr. BURGESS. So when you went through your last—I mean, that's fascinating. I didn't realize severe combined immunodeficiency disease was one of those things that you can detect.

When I was in medical school, and it was a long time ago, but David the Bubble Boy, his doctor, was in Houston and we, through a rudimentary telecommunications hookup, got to interview David the Bubble Boy when he was still in—being protected from all things in the outside world.

But now you can detect that disease as part of newborn screening?

Dr. BOCCHINI. Yes, that is certainly one of the recent successes in newborn screening. Severe combined immunodeficiency is the disorder that the Boy in the Bubble had. It is a complete absence of an immune system and if those patients develop an infection, which they do quite early, it's typically very difficult to treat and is usually fatal.

If you find these children before they become infected and that's what newborn screening does in most cases, you can provide a reconstitution of the immune system by a bone marrow transplant or umbilical stem cell transplant or by enzyme replacement in some cases.

And the recent data from California and from other states have indicated that we are at a 90-plus percent recovery success rate in having those children live and, in many cases, with a fully reconstituted immune system.

So it's a very significant success story.

Mr. BURGESS. And thank you for sharing that with us. The spinal muscular atrophy, which is one of the things on your list, and the recent FDA approval of a new therapy that will be life-changing, I understand, for those kids, so the work that you do in identifying those children early is just so critical.

Dr. BOCCHINI. Yes, I agree. I think that there have been some remarkable advances in the treatment of spinal muscular atrophy and the committee in 2018 did recommend to the secretary and the secretary approved, including spinal muscular atrophy, on the RUSP in a number of states—I think it's up to 19—no, I am sorry, it's up to maybe about six states that are now screening. Many are also trying to work through the issues that are needed to implement the screening for it.

Mr. BURGESS. Sure. Well, it's a cost issue, and, clearly, that's one of the areas where we are focused as well. We delivered CURES

for the 21st Century a couple of Congresses ago but cures don't do any good if they're not available to the people, and now with breakthroughs like this we've got to figure out ways to make them available to the people.

Dr. Howard, thank you so much for your testimony today. I think your emergency nurses network helped me with the Mission Zero Act that we got added to the Pandemic All-Hazard Preparedness Act, so thank you for that, and that will be signed literally at any time. So it—

Ms. ESHOO. I think it was last night. Yes.

Mr. BURGESS. Oh, was it last night? OK. So it became law so good for us. We got a win on the board with that one, and thanks for your help on that.

As far as just developing the—your partnership grants for the interfacility transfer guidelines for pediatric patients but they're not completely universally accepted. Is that correct?

Dr. HOWARD. That is correct.

Mr. BURGESS. So what's the problem there?

Dr. HOWARD. Well, the problem is not every site has defined trauma systems, which is one of the bigger reasons we see interfacility transport. And so not every state has this same type of EMS system in place and that is a challenge.

Mr. BURGESS. So what—if we reauthorize this bill, are we going to get closer to achieving that goal?

Dr. HOWARD. I think that there is consistent work that is done as part of this reauthorization. One of the other big pieces is the pediatric readiness work that is being done, which I didn't talk about, which is really helping every emergency department be more pediatric ready, which is a key consideration because many are not.

Mr. BURGESS. OK. Thank you, Madam Chair. I will yield back.

Ms. ESHOO. The gentleman yields back.

Dr. Bocchini, let me just ask you very quickly, are you going to bring up at the committee the issue of autism? The screening and what might be available?

Dr. BOCCHINI. Yes, I have—I am no longer a member of the committee. I have completed my term. But I certainly can provide that information back to the committee. Thank you.

Ms. ESHOO. That would be wonderful. Thank you.

I now have the pleasure of recognizing the gentlewoman from California, Ms. Matsui, for her 5 minutes of questions.

Ms. MATSUI. Thank you very much, Madam Chair, and I want to thank the witnesses who are here today. Every one of you spoke to issues and concerns that affect every single one of us or our constituents, or our families.

Investment in public health programs and infrastructure is critical for our nation's health and well-being. The programs we are discussing today are designed to bolster communities' ability to cope with health problems and the special needs for at-risk subgroups and they have proven they can do just that if we fund and support them.

Autism is a lifelong disorder and for many families, there can be great uncertainty over how the needs of autistic children will be



met as they age out of school-based services and grow into adulthood.

I can tell you that in Sacramento, my district, we had parents come together to really develop an autism—the MIND Institute—which has been there for over 25 years and does great work, but it's parents and advocates that really did that because, you know, they're having access to a comprehensive range of services and strong systems of support that we all believe should be guaranteed for people of all disabilities for their entire lives.

Now, Dr. Hewitt, where do the greatest gaps in understanding autism still exist and how will this reauthorization support expanding key activities in areas of focus for autism research?

Dr. HEWITT. I think one of the largest gaps is understanding issues related to adults with autism and so CARES gets us moving in that direction by addressing issues across the Lifespan. Through LEND training programs, we are expected to teach and train the next generation of leaders across all different kinds of health and allied health disciplines about autism and the life course of a person with autism. The CDC's surveillance program is expanding in a few of its sites the surveillance up to 16-year-olds now. So I think CARES gets us, again, a little bit farther along the Lifespan and I think that's important.

Ms. MATSUI. But you're saying not far enough yet, really?

Dr. HEWITT. There's a lot of room to grow.

Ms. MATSUI. Right. Absolutely.

Dr. HEWITT. But it gets us moving in the right direction.

Ms. MATSUI. That's good. Now, we know that young people with autism can face significant mental and behavioral health challenges and that other autism-related health conditions like disrupted sleep cycles and painful GI disorders can contribute to crisis episodes.

Ms. Hewitt, how are providers addressing the special needs of the autism community? Are there mainstream evidence-based strategies for preventing and treating a mental health crisis for people with autism?

Dr. HEWITT. Sure. There is a number of—there's much—a body of research to help us, guide practitioners. We do that through our LEND programs, the developmental-behavioral pediatrician training programs.

That's the purpose is to connect practitioners to evidence-based practices that then they use in their community work.

Ms. MATSUI. OK.

Dr. HEWITT. So it's—

Ms. MATSUI. Right.

Dr. HEWITT [continuing]. We need to learn more. But we also need to get practitioners informed and educated about what we already do know so that they're using those interventions in their work.

Ms. MATSUI. OK. Dr. Howard, of the innovative research and training programs supported by the Emergency Medical Services for Children programs, are autism-tailored services a focus for improving overall pediatric emergency care? If not, how can we work to broaden the program's scope?

Dr. HOWARD. So I am not aware that there are autism-specific programs but I think that's a really right inclusion. There are programs for children with special healthcare needs and so that certainly would fall within that group where we tailor the treatments that we do differently for these children.

For example, we don't necessarily immobilize the child with a special healthcare need—

Ms. MATSUI. Right.

Dr. HOWARD [continuing]. The way we do with a child that doesn't have a developmental challenge. So, indeed, those are considerations that are worked with.

Ms. MATSUI. OK. Thank you.

Now, when discussing the needs of our nation's older Americans, we must ensure that policy reflects an inclusive focus on the need of caregivers and how aging impacts the entire family.

That's why I am really supportive of this increased funding for the Lifespan respite care program to really recognizing the incredible value of our family caregivers and give them greater access to the support and relief they need and many times, those are our only caregivers.

Ms. Kagan, how do disparate funding sources inhibit a state's ability to provide comprehensive and coordinated respite care programs?

Ms. KAGAN. Yes. States, because of their multiple funding streams and service avenues, it becomes very confusing to family caregivers to figure out how to access those services to figure out which programs they might qualify for.

For many caregivers, they don't even recognize what respite is and that there's a service available to them. So by giving the state the opportunity to identify all those funding streams and services in the state and put them in a format that they can then translate that information for family caregivers certainly helps them access the system to navigate that maze.

Ms. MATSUI. So you're saying better information is disseminated?

Ms. KAGAN. Better information, yes.

Ms. MATSUI. OK. Thank you, and I yield back.

Ms. ESHOO. The gentlewoman yields back.

It would be wonderful for doctors' offices to know so they could advise their—when the caregiver brings their loved one in, they can say, well, you need a break and here's something for you. I wish I had that but, you know, I mean, we all know what this is and if there's someone that doesn't, then it's what's in store for you.

Mr. WALDEN. Chairs of subcommittees may need that, too.

Ms. ESHOO. Yes. Exactly. Thank you.

Mr. WALDEN. And ranking members.

[Laughter.]

Ms. ESHOO. I know.

The Chair is happy to recognize the ranking member of the full committee, Mr. Walden, for his 5 minutes of questions.

Mr. WALDEN. Thank you, Madam Chair.

So, Ms. Kagan, I am, as you heard, a strong supporter of patients receiving the care they need in their homes if at all possible. Oregon led on this way back with Project Independence. I think we

still have a Medicaid waiver. It's been very good for families as well as, I think, the taxpayers.

How does respite care help keep a caregiver's loved one at home and out of a nursing home and how does respite care ultimately reduce costs to our federal health programs?

Ms. KAGAN. Yes, by—it's well documented that respite directly correlates with reduced stress and feeling the caregiver burden, and when we reduce the stress in caregiver burden of the family caregivers, their health is improved as well.

So they can continue to provide that care at home. Eighty percent of long-term services and supports are provided at home, especially for older individuals.

Mr. WALDEN. Yes.

Ms. KAGAN. And so we really need to support the family caregivers' health and well-being and that of their entire family so they can support that loved one at home.

Mr. WALDEN. So it's actually a savings to taxpayers in many ways?

Ms. KAGAN. Yes, absolutely. It can also help reduce use of emergency rooms.

Mr. WALDEN. Right.

Ms. KAGAN. We are increasingly seeing some family caregivers take their loved ones to the emergency room just for a break because they have no other option.

Mr. WALDEN. Oh, that's not what we want.

Ms. KAGAN. So that's a very costly alternative.

Mr. WALDEN. Yes. That's expensive, the most expensive portal into the healthcare delivery system right there.

So in your testimony you described the great work of states in leveraging Lifespan respite care program dollars and these dollars, we know, are used in a variety of ways.

Can you explain why allowing state grantees to innovate improves overall respite care services? These would be called softball questions, by the way. Just so you know.

[Laughter.]

Ms. KAGAN. By giving states the flexibility to innovate, we can continue to explore what works best for family caregivers and we know for sure that there's no one single respite model that works for all family caregivers.

Mr. WALDEN. Sure. Everybody's different.

Ms. KAGAN. Even over the course of a month a family caregiver may desire different forms of respite—in-home, out-of-home, volunteer companion services to help their loved one perhaps get out into the community and do something meaningful for them as well.

So by allowing us to explore these other options we not only help us figure out where we want to invest public dollars but it helps us identify where in the informal service sector what community activities already exist in terms of natural supports that can—

Mr. WALDEN. Sure.

Ms. KAGAN [continuing]. Help families identify that they can use for respite.

Mr. WALDEN. Because often they don't even know probably, right?

Ms. KAGAN. Exactly.

Mr. WALDEN. This comes on you or your spouse and there you are, and you have never even thought about it and now you own it and it's a challenge. It's a challenge, and the other spouse or whoever the caregiver is can really get worn down and then they have a problem—

Ms. KAGAN. Exactly.

Mr. WALDEN [continuing]. If you don't give them a little—

Ms. KAGAN. We are trying to protect the person with the health or disability having a meaningful healthy life but we also have to protect their caregiver and their family as well as support them.

Mr. WALDEN. That's right. Yes. Yes. I've seen it firsthand.

Dr. Howard, you mentioned that the EMSC program covers both pre-hospital EMS and emergency departments. Can you expand a little more on the improvements in the care for pre-hospital EMS and why those improvements can be critical in saving an injured child's life?

Dr. HOWARD. Well, pre-hospital is the first contact typically an injured child has. That is 911, and one of the challenges particularly across this country is that not every EMS system has the same resources. We still have many services across the United States that are volunteer-based.

Mr. WALDEN. Sure. My district.

Dr. HOWARD. And those services don't have the resources for the education or the specialized equipment needed to care for children.

And so Kentucky is one of those states that has some challenges, obviously, and we have taken PEPP, which is the Pediatric Education for Pre-Hospital Professionals, and the Emergency Nursing Pediatric Course both to these rural communities.

Mr. WALDEN. Good.

Dr. HOWARD. Actually help with that education and then the state partnership grants have allowed them to buy the specialized equipment they need to take care of those children.

And receiving those children in my emergency department I can tell you they're arriving in better condition.

Mr. WALDEN. Sure, they are. That makes a lot of sense. And can—you state in your testimony that pediatric patients are simply not little adults, as many people might assume, and they require very specific types of care and certainly specific equipment unique to children and dosages on medication.

Can you provide some examples of how diseases and injuries uniquely manifest themselves differently in children?

Dr. HOWARD. Absolutely. So there's—I will take injuries to start with. Number one, one of the things that's very different, if any of you have been in a car crash and you were pulled—taken out of your car and put on a board or some type of an immobilization device and you lay flat, children have a larger head and they can't do that. If you lay them flat on a board it will compromise their airway. So we have to put a pad under their shoulders so that their spine is maintained in a neutral position and their airway, which is very pliable and thin, unlike ours that's more rigid and cartilaginous, it will collapse. And so that's a perfect example there.

The other problem is in illnesses children can't tell you, particularly nonverbal small children, where their hurt is. They may cry if you touch it but they may not be able to tell you that they have

a sore throat or that their ear drum is bulging which, you know, untreated ear infections can lead to meningitis. So there are certainly many challenges that can occur.

Mr. WALDEN. Thank you very much, all of you, for the work you do and for your testimony today, and I yield back.

Ms. ESHOO. The gentleman yields back.

This is what's so wonderful about hearings. We just keep learning and learning from the experts in our country. We are so grateful to you.

I now would like to recognize the gentleman from North Carolina, Mr. Butterfield, for his 5 minutes of questioning.

Mr. BUTTERFIELD. Thank you very much, Madam Chair, and thank you to the four witnesses for your testimony today.

You know, the Chair is absolutely right. Every time we have a hearing like this we just learn more and more and more, and we go home and reach out to constituents and make community visits and we learn even more.

And so we just hear about examples after examples after examples. In our home districts the opioid has not limited itself to affecting only adults. We've all heard stories about student athletes, for example, who might be treated for a sports-related injury and find themselves caught in the grip of opioid abuse. Children and adolescents are not immune from the reach of addiction and substance abuse, which can sometimes lead to emergency situations where immediate care is needed.

So, Dr. Howard, let me stay with you, if I can. Dr. Howard, can you tell us about how the EMS has aided in helping emergency care providers identify adolescents for opioid or other substance abuse?

Dr. HOWARD. So PECARN that I mentioned earlier that does the research has actually looked at some of the programs in terms of being able to—how adolescents in particular present differently clinically than adults do with addiction. The symptoms and the presentation are not the same. So that's a very specific example of the work that this particular program has been able to do to make a difference for children and the opioid crisis.

Mr. BUTTERFIELD. And how does this identification improve follow-up care and treatment after these young people make it through the emergency?

Dr. HOWARD. Well, the first step to treatment is recognizing it and so being able to recognize it in the emergency department, which is not something even ten years ago we would have looked for.

So once we recognize it we can make sure they're connected to care, make sure that warm handoff occurs as is appropriate. We can't always assume that those that care for them are going to get them to that next step. So we have to make sure that those connections are made in the emergency department so that they can be safe.

Mr. BUTTERFIELD. Absolutely. There is no doubt that newborn screening is a vital preventive public health service that has led to better health outcomes for thousands, if not millions, of children.

The Newborn Screening Saves Lives Act has dramatically improved the capacity for states to expand newborn screening services

and I fully support its reauthorization. I was glad to see that the reauthorization bill that we are considering includes—it includes a study on how we can modernize newborn screening.

As our capabilities for treating and screening for conditions expand, I think it's important that our infrastructure also keeps pace.

Dr. Bocchini, let me ask you please, can you explain the role that public health labs play in the newborn screening program and how public health lab capacity plays a role in determining what conditions a state might be able to screen?

Dr. BOCCHINI. So the newborn screening program is a state-based public health program and so each state has the responsibility of putting together the laboratory that performs the testing that's necessary to screen and then, in many cases, do the diagnostic test to confirm that an individual has a specific diagnosis.

The capacity of state labs does vary from state to state and when we bring new conditions into the RUSP it does create the requirement that a state lab may have to modify its program. It may have to bring in new personnel. It may have to bring in new equipment. But, in addition, the state program not only has the lab requirement but it also has to develop the ability to not only identify the patients but get them to appropriate therapy for short-term follow-up and long-term follow-up.

So there is a variation in the capacity of individual states to provide the infrastructure that's needed. And so the grants that can come from HRSA and the efforts from the CDC can help individual state labs meet the requirements that are necessary for them to bring on a new condition.

Mr. BUTTERFIELD. That speaks to my next statement. In addition to lab capacity that we are talking about, we also want to make sure that a diagnosed child is able to receive adequate treatment and, as you know and I know, under the law HRSA is required to provide assistance to states on follow-up care once a newborn is diagnosed, right or wrong.

Dr. BOCCHINI. That is correct—both short-term and long-term follow-up. So we want to make sure that the child gets into the appropriate subspecialist if necessary and initiates the appropriate therapy but then maintains that so that we can look at what happens long term in terms of the effectiveness of the therapy and the ability to maintain that child in a program.

Mr. BUTTERFIELD. Thank you, Madam Chair. I yield back.

Ms. ESHOO. The gentleman yields back. The Chair now recognizes the gentleman from Illinois, Mr. Shimkus, for his 5 minutes of questioning.

Mr. SHIMKUS. Thank you, Madam Chairman, and welcome to you all. We are glad to have you here and I am going to follow up first with—I know Dr. Burgess touched on this issue with Dr. Bocchini but I want to turn to Dr. Hewitt on this same issue.

You know, I've worked on this genomic sequencing as a diagnostic tool for a couple years now and you noted that the prevalence of autism spectrum disorder diagnosis has risen dramatically over 600 percent in the past several decades. But it seems like we still lack a certain degree of precision when it comes to diagnosing autism spectrum disorder.

I realize that there are different schools of thought on the applicability of genetic diagnosis. But I am curious of your thoughts on the role this technology can play in two areas, first on the diagnostic end and secondly on the therapeutic side.

Dr. HEWITT. Certainly. That's a really good question and I would defer the answer to my colleagues who are doing that kind of research. I am not that—I am not a geneticist and I am not doing genetic research. So I would be happy to get you expert information about that at a later time.

Mr. SHIMKUS. OK. Great.

I am going to turn to Dr. Bocchini. You also mentioned genomic diagnostics has having the potential to significantly alter a newborn screening. So I would like to hear more on your thoughts on the role this technology can play.

A lot of us on this committee, based upon the 21st Century CURES—you know, this little rascal—his name is Max and he was, like, the number-one lobbyist for 21st Century CURES.

This is at the bill signing at the White House with Joel Pitts behind—Max is putting bunny ears behind my head and I am putting them behind his. His issue was a blood disorder that had they not delayed a tonsillectomy he could have bled to death, which was an undiagnosed bleeding disorder that could have been disastrous, as I had mentioned.

But as Max and millions of other children have told us, we shouldn't rely on luck or, quote, unquote, this diagnostic odyssey to ensure the best medical outcomes are achieved.

I would like, Dr. Kennedy, if you could expand. In your prepared statement in the end you say in addition to scientific advances the ability to utilize new technology such as genomic sequencing are evaluated additional research, ethical and clinical questions will need to be answered, and that's part of our internal debate of how we address this. These technical advances could significantly alter the approach to newborn screening in the coming years, and then you end.

So I would like for you to elaborate on that, as I think it's really timely and the things that we—I am trying to do in the public policy arena.

Dr. BOCCHINI. Well, thank you for that question. I think it's a very important one. Genomic sequencing can certainly identify a number of genetic changes that could be very specifically associated with underlying disorders and actually that's been recognized through the Hunter Kelly research program at NIH. There are three—and we don't know how it will ultimately affect newborn screening but we are in the process of determining how it might affect it.

The NIH, through the program, has three research projects underway now looking at, comparing the genomic screening, exome screening, to root current screening for infants in general population and in the population of infants in a NICU with critical illnesses.

Those studies will inform us on the potential benefit of moving towards genomic sequencing as part of newborn screening.

Mr. SHIMKUS. Thank you very much, and I am just going to end on here's a perfect example of kids being involved. I visited a school

called—it's pronounced—it's spelled Hoopeston but it's really pronounced Huptsten—and I had—after the event I had three high schoolers—Annalynne Schaumburg, Raven Rutherford, and Seth Mershon hand me a letter asking me to support this bill.

So that was true youth in action and I appreciate that and I want to give them credit because I then came back, looked at the bill, and got on it.

So with that, thank you for time, Madam Chairman, I yield back my nine seconds.

Ms. ESHOO. I will use part of that to say thank God for the advocates, right?

I now have the pleasure of recognizing the gentlewoman from Florida, Ms. Castor, for her 5 minutes of questioning.

Ms. CASTOR. Well, thank you, Chair Eshoo, for holding this hearing on this important package of bills and thank you to our experts for sharing your expertise with us.

I am pleased that we are taking up these bills and I am proud to be a co-sponsor of the Autism CARES Act and the Newborn Screening Saves Lives Reauthorization Act.

And I want to thank the Chair again for including my bill in this hearing, H.R. 776, the Emergency Medical Services for Children Program Reauthorization, which I introduced with Representatives Peter King, Representative Butterfield, Representative Chris Stewart.

Our bill will reauthorize the Emergency Medical Services for Children through 2024, and EMSC is vital because it is the only federal funding specifically focused on addressing the unique needs of children in the emergency services systems.

As Dr. Kunz Howard has stated very clearly, kids have specific healthcare needs and EMSC helps bring innovation in pediatric emergency care to each state.

In 2016, 22 percent—that's about two million—of emergency department visits in my home state of Florida were made by children. So we must reauthorize this initiative as soon as possible to ensure America's kids are getting the right care when they need it.

Florida is using its funds through the state partnership grant to work on a collaborative project with—it's called the Florida Pediatric Preparedness and Readiness program—PEDReady—for hospitals and the EMS. They're working with national and state groups including the National and Florida Emergency Nurses Association and the Florida College of Emergency Physicians.

Florida PEDReady is a quality improvement initiative with the goal of improving the readiness of medical facilities to care for children across the state with the focus on non-children's hospitals and the EMS agencies.

They did a needs assessment in 2018, so last year, and here are some of the findings from the survey. Pediatric equipment—most significant challenges include keeping the correct equipment or size stocked and knowing the most current pediatric equipment available on the market.

Medication—the most challenging pediatric medications are the vasopressor drips and emergency airway medications, and I believe you have mentioned those as well.



Top educational needs are emergencies, pediatric trauma, and burns.

Dr. Kunz Howard, you also talked a little bit about the importance of pre-hospital care. You have seen first hand how important ESMC or EMSC has been to providing better, more accurate care to our nation's kids.

Reiterate why it's important to have a kind of stand-alone funding that's specifically targeted back to our home communities to make sure that we are modern and kids stay well.

Dr. HOWARD. It's really critical that it be targeted back to the home communities because that is where the children are. We need children to receive the care no matter what location they are in across the United States.

We need to know that every area is going to be pediatric ready and that is really what EMSC is about is ensuring pediatric readiness.

And so it is critical that everyone everywhere across this country knows that if their child is ill or injured they don't have to think oh, gosh, I've got to get to the next county so that my child gets the care that they need.

That's not what they need to worry about. They need to worry about supporting their child and being there for them.

Ms. CASTOR. What are your hopes for this initiative, going forward, now that we've had a number of years of continuity and with this reauthorization local communities will be able to plan more?

Dr. HOWARD. Honestly, my hopes is that every emergency department will be pediatric ready because they are not. I mean, the survey showed us that not every emergency department is pediatric ready.

And so we worry about pre-hospital because their care is critical because if their job is not done right our job is much harder.

But we need that to be across that continuum of emergency care both pre-hospital readiness as well as emergency department readiness.

Ms. CASTOR. Thank you very much, and I yield back.

Ms. ESHOO. The gentlewoman yields back.

Please to recognize the gentleman from Kentucky, Mr. Guthrie, for his 5 minutes of questions.

Mr. GUTHRIE. Thank you very much, and thank you for all being here, particularly Dr. Howard. Thanks for coming up from the Commonwealth today to be with us and always enjoy having you in Washington, D.C., and bringing to attention the areas in which you focus on and it's always so important, particularly on the Emergency Medical Services for Children program.

I know that you're the educator for the—our Lexington division of fire and emergency services. I am close with our EMS folks down in Bowling Green Gary Madison. I know you know those guys down there that work hard.

Would you just explain how this program support courses that have saved children's lives and maybe some examples of how this program and your education of these great men and women in our emergency services have saved lives because of what you have done?

Dr. HOWARD. Well, you know, I've been very fortunate to be able to go across Kentucky because of the EMSC program and teach paramedics specifically as well as nurses and physicians what is appropriate for pediatric emergency care.

So we have been to Pikeville and we have been to Paducah. So we've been, you know, from one end of the state to the other to actually make sure that PEP is available because the Pediatric Education for Pre-Hospital Professionals is really a phenomenal course and one of the nicest things about that course is that it was developed collaboratively. The American Academy of Pediatrics, the Emergency Nurses Association, the American College of Emergency Physicians, and then some of the EMS agencies we all work together so that we would all talk the same language, because that is one of the challenges in care is the physicians will learn one thing, the nurses learn another, and the pre-hospital professionals learn something different. But we all use something called the Pediatric Triangle to do that initial assessment of the child to make that common language so that we all have the same starting place so we all recognize the same framework for how sick that child is. And so I think that's one of the best examples of the work that's been done as part of the EMSC is making sure we are all talking the same language about the ill or injured child.

Mr. GUTHRIE. All right. Thank you very much.

Dr. Bocchini, I got involved in early childhood or newborn screening when I was in the state legislature for hearing. We learned—Governor Patton, who was our governor at the time, championed that if a child just has hearing issues and you're able to find it at five years old and fix the issue or give them ability to hear better, they're going to lose things they can never recover like pronouncing certain words and things like that.

So we thought it was important to do that at early childhood—I mean, at newborn. And we all had groups that come here and talk about the issues and they're all important and they're all valuable and why we don't test for everything.

You know, one is the cost, as it moves forward. So could you kind of say for us—I know that six new conditions have been added for the recommended.

So when groups are pulling us, what should we be looking for? How this is something that we need to be screening for a child? How does that—as conditions change, as medicine changes so quickly, how do we know how to change this screening in a timely manner?

Ms. ESHOO. Your microphone.

Mr. GUTHRIE. Get the microphone, yes.

Dr. BOCCHINI. I am sorry. I turned it off.

The Advisory Committee has developed a very specific approach to bring conditions for evaluation. It starts off with working with advocacy groups, researchers, organizations that have a particular condition which they're interested in or have the development through research of a potential screening test or a therapy, and try to work with them to put together a nomination packet of information that would meet the standards for which the committee would review that condition for consideration of being placed on the RUSP.

Then the most important thing the committee does is when accepting that nomination for a condition, there is an independent evidence review committee that does a formal evaluation of all the evidence related to the condition and the benefits of treatment.

And so the goal of the committee is to look for a condition that we have a degree of certainty if it's added to the RUSP will provide a net benefit for the patient or for the child that is affected.

So we have a very formal way to bring people together and evaluate the condition and then, based on the evidence review, make a decision about whether the condition should be added to the RUSP. We make that recommendation to the secretary. The secretary of HHS has the final decision for acceptance of our recommendation.

Once the secretary accepts it, it becomes part of the RUSP. So it's a very significant evidence-based process that leads us to bring conditions forward.

We also are paying attention to where changes are being made, where breakthrough therapy might become available so that we can kind of look forward to bringing conditions on.

Mr. GUTHRIE. Thank you very much. My time has expired. I yield back. Thank you for your answers. I appreciate it.

Ms. ESHOO. The gentleman yields back.

The gentleman from Maryland, Mr. Sarbanes, is recognized for 5 minutes for his questions.

Mr. SARBANES. Thank you, Madam Chair. Thank you, all of you, for your testimony today on these very, very important public health programs and the need for us to maintain them.

I wanted to talk, Ms. Kagan, to you about the respite care issue; and I wondered if you could maybe pull us back a little bit and try to give us a sense of how the supply of these critical support services is meeting demand.

I know when I came in earlier you were, I think, talking with Congressman Eshoo a little bit about that and give us a sense, and I know it's hard to quantify this but try to describe what the gap is between the need for this and the demand—rather, the need for this and the supply for it.

I am also curious, in the same vein, if we looked five years ago and then ten years ago, just picking that time frame if that works, how much progress we've made in meeting the demand for these services. So if you could speak to that, then I have a couple follow-up questions.

Ms. KAGAN. Yes, absolutely.

I did include in my testimony and we don't have really great data on who needs respite and who's getting it. But there was the survey done by AARP and the National Alliance for Caregiving several years ago that demonstrated 85 percent of family caregivers of adults are not accessing respite and we know all of the reasons why: shortage of services, no ability to pay for services. But even when families have the dollars to pay for respite they cannot find the providers.

One great example of how this is being dealt with in Lifespan respite is in Maryland. They received a one-time grant in 2015 and they jumped right in to providing emergency respite services,

which were—they identified to be in critically short supply in the state.

But rather than just given families the voucher dollars to pay for emergency respite, because that doesn't do a family much good if they can't find a provider on short notice, so they also contracted statewide with a home health agency that would be available to provide those respite providers on less than 24 hours notice.

So we have to not only build up the system so that we can support family caregivers to pay for dollars, but address the provider shortage as well.

And it's not just individual providers. We need community and faith-based programs to step up as well—things I think you have asked over the last five to ten years.

In some ways it's gotten a little bit worse and then that's also because of the changing demographics. From my understanding of some of the AARP data, especially for older adults over age 85, currently there are seven people in the age range that can provide care to those over 85. In ten years or less, the ratio is going to be more like two to one. So to actually even have the physical bodies to provide this care, and it's not just in the respite field, of course. It's the direct service workforce across the board.

So we are facing bigger challenges but we are moving forward in terms of recruiting and training new providers.

States like North Carolina have partnered with Money Follows the Person programs or other programs to work on statewide direct service workforce issues.

So our programs are working in conjunction with those who are trying to deal with the crisis and provide—

Mr. SARBANES. So that kind of leads me to another question, which is, obviously, the flexibility of the grants that go to the states are allowing for a lot of different approaches to be tested.

Are there some best practices emerging? Some approaches that are the ones we should maybe be providing more support for as we go forward? Are we still really kind of in an experimental stage and there's a lot of different things being considered, all of which show promise or a substantial number of which show promise?

Or if you were kind of betting on what would emerge as the approach that's got the most promise, going forward, what would you say to that?

Ms. KAGAN. Again, that's a little bit of a difficult question because the respite needs of families are as varied as the models that should be out there for delivering it.

I think one successful model that most states have been using is use of the consumer-directed voucher that allows families to choose who they want for their provider, when they will hire them, how they will train them.

There's been some research that shows family caregivers are most satisfied with that approach if they have control over who they're hiring, when they're hiring, and how they use the respite services.

On the other hand, there are a lot of wonderful models that are helping us expand capacity through faith-based communities. In Rhode Island, they have developed a student respite initiative, which uses nursing students to provide respite services and in re-

turn for that they're getting course credit in clinical experience, and that's been so successful. In Rhode Island they've expanded this past year to two additional nursing programs, and there are several other states that are using these students to build respite services as well.

Mr. SARBANES. Right.

Ms. KAGAN. So that, along with volunteer respite opportunities. New York has trained over 100 companion respite volunteers that are serving families in 26 counties across the state.

So there are a lot of wonderful models. Some of these efforts right now are because the funding is so small the efforts are very tiny. But it's giving us a chance to see what families prefer and what they're willing to use as well.

Mr. SARBANES. Very helpful. Thank you. I yield back.

Ms. ESHOO. The gentleman yields back.

We went about a minute over but I wanted to hear every word you said so I didn't want to tap the gavel.

Now, you know, our subcommittee is blessed with having physicians as members of it. But we also have the only pharmacist in the—in the Congress that's part of our committee. He's the gentleman from Georgia, Mr. Carter, recognized for 5 minutes for his questioning.

Mr. CARTER. Thank you, Madam Chair, and thank all of you for being here. Certainly, these are important pieces of legislation that we need to take care of and we appreciate your help in helping us move them forward.

Dr. Hewitt, I want to start with you. I want to just say that I am very proud of the Children's Hospital of Atlanta's Marcus Center for Autism. I don't know if you have ever had the opportunity to visit. I have, and it's certainly, I think, just world class. I was so impressed. It has treated more than 40,000 children since it was opened, and it's one of the largest autism centers in the U.S., and we are just blessed to have it in Georgia and blessed to have the Marcus family as beneficiaries and helping us with that. They've done great things in the state of Georgia.

But the Marcus Center is one of five Centers of Excellence in the country. What constitutes—what makes it a Center of Excellence and what's the difference there?

Dr. HEWITT. Well, a big part of it is where the funding comes from. The Autism Centers of—and then the action that happens in those centers. So the Autism Centers of Excellence are known for research and that research varies. Some of it is very clinically oriented. Some of it is what we would call more bench science kinds of research. But the Center of Excellence concept is that you're doing important research that leads to changes in practice and policy.

Mr. CARTER. One of the things that I was impressed most with was their emphasis on early intervention. How important is that and what difference does that make?

Dr. HEWITT. The science is very clear that early intervention matters and children will have better educational outcomes. They'll have better lifetime outcomes the earlier in which they are—receive a diagnosis and get intervention.

And so that's why there is such an important focus in many of the Autism CARES programs around early intervention and treatment.

Mr. CARTER. I remember when I was there they showed me this new diagnosis, if you will, where they were measuring early detection devices that measured eye movements and that was to help screen for autism.

Are you familiar with that?

Dr. HEWITT. I am vaguely familiar with that.

Mr. CARTER. OK. What—just out of curiosity, what are some of the biggest breakthroughs that we've seen in autism? You know, it's such a problem and it's so difficult, I should say, to really break through. What are some of the big breakthroughs that we've seen?

Dr. HEWITT. I think one of the important things is just to remember that autism is complex and autism is unique for each individual.

An emerging breakthrough is really around what we are learning from brain imaging and being able to identify autism in very, very young children.

So and that, again, is an outcome of the research that CARES and other programs are investing in?

Mr. CARTER. So, obviously, research is extremely important in this and the funds that come from Autism CARES are extremely important in the research part of it?

Dr. HEWITT. They're extremely important. I think expansion into adult-related interventions is an important next horizon.

Mr. CARTER. Good.

Well, again, I just wanted to be able to tell and to speak about the Marcus Center because we are so proud of it in the state of Georgia and just the work that is being done there, as I say, I've witnessed it first hand and I've seen it and it's phenomenal.

We are very, very happy and very proud to have it in the state of Georgia.

Again, I thank all of you for being here. This is extremely important and I will yield back the remaining time.

Ms. ESHOO. The gentleman yields back.

I now would like to recognize the gentlewoman from New Hampshire, Ms. Kuster, for her 5 minutes of questioning.

Ms. KUSTER. Thank you, Chairwoman Eshoo, for holding this important hearing and for giving us the opportunity to discuss legislation critical to funding programs supporting newborns, children with autism spectrum disorder, and other intellectual disabilities, and family caregivers.

And just as an aside; I was a family caregiver with my father for my late mother, who had Alzheimer's disease, and we were very grateful for the respite care. Eventually, he just ran himself right into the ground. And I can remember friends coming up on the street saying, "is your father okay?", and I said, "no, he's not okay at all." He ended up needing hip surgery and he was just exhausted. But he didn't want to see a 53-year marriage—let it go and when I finally—he had to go to the hospital for the hip surgery; and we were going over her care during—in respite and he said, "wow, I am going to have a hard time taking care of her when I get home from surgery," and I said, "yes, I think that'll be impos-

sible.” So that was when we finally got him to get her into a nursing home care, and my heart is with all of the families that are working on this.

In my home state of New York, the Leadership Education Neurodevelopmental Disorders Program at Dartmouth-Hitchcock Medical Center provides Granite Staters with workforce training and family-centered services for patients with autism spectrum disorder and this funding is critical, as you can imagine, in a rural community to ensure patients’ and families’ access to support.

What we’ve heard today is a snapshot of how these different programs truly saved lives and I want to thank everyone on the committee for bipartisan legislation that’s noteworthy and important.

With that, I want to jump into the questions. Dr. Hewitt, you described a vast array of funding through CARES and we have many of those same programs.

Autism is in the name but the training and research touches people across the disability spectrum, and I think it’s important for us to understand how comprehensive the CARES program is.

Could you elaborate on how CARES serves families—patients with autism and intellectual abilities and the full spectrum?

Dr. HEWITT. Sure. The training programs that are funded through CARES—the LEND training programs, the developmental behavioral pediatrician programs—they’re really targeted to focus on the range of neurodevelopmental disabilities.

So autism is a part of that but they expand into many other categorical groups of disabilities—cerebral palsy, hydrocephalus, spina bifida, Tourette’s Syndrome. I could go on and on and on.

And so in our training programs, we are not charged with just developing leaders who are going to change services and practices and policy related specifically to autism. It’s an important focus of our programs. But autism is one of many neurodevelopmental disabilities on which our training programs focus.

Ms. KUSTER. So and key changes in the bill that we are discussing today address the needs of adults in geographically under-represented areas. How does CARES funding support the workforce so that there are enough properly trained providers to address the needs of this community?

Dr. HEWITT. I think that’s a really important step in the reauthorization. Specifically in the developmental behavioral pediatrics program there is a requirement that those training programs reach developmental behavioral pediatricians in rural communities.

In our LEND programs we are expected to reach our entire state. So, for example, our program is in metropolitan area—a large metropolitan area—but we are expected to be able to have a statewide reach throughout our entire state.

Ms. KUSTER. And can you speak to what might happen if continued federal support was not available?

Dr. HEWITT. I think a theme across all four of the people here to testify today has been workforce and in all of our areas of specialty we have workforce shortages and without reauthorization the specific training programs that help to evolve the expertise in nurses and occupational therapists, social workers, geneticists, on and on, it’s just not there. People don’t get that training in their

specific discipline, let alone an interdisciplinary perspective around these critical issues.

So I think one of the biggest drawbacks will be the lack of professional training that is targeted and specific on specific disability groups, specific genetic disorders, et cetera.

Ms. KUSTER. Well, my time is up. But I can certainly say in a state with 2.4 percent unemployment, this federal funding will be critical. So thank you. I yield back.

Ms. ESHOO. The gentlewoman yields back.

The Chair recognizes the gentleman from Oklahoma, Mr. Mullin. Mr. MULLIN. Thank you, Madam Chair.

Dr. Bocchini, I got just a couple questions for you. What is the process for adding a new test to the newborn screening?

Dr. BOCCHINI. So the test that—so a screening test would need to have the laboratory performance characteristics that would enable it to identify the majority of patients who have a disorder and not have a number of false positive tests that would create a need for evaluating a number of patients who do not have the disorder.

So that would mean that we need to know whether a screening test would perform adequately within a rapid high-performance newborn screening laboratory.

Mr. MULLIN. How long does that total time frame take?

Dr. BOCCHINI. Well, it takes pilot studies and one of the things that this committee—our advisory committee needs is adequate number of pilot studies.

Depending on the size of the pilot studies, it may take a year or more—multiple years—to prove that a test performs adequately to identify the patients that we need to so that there is not excess cost, excess number of false positives. That would potentially create harm for the patient.

Mr. MULLIN. What's the percentages that are acceptable? I mean, do you—when you say not—is it a five percent failure rate? Three percent? One percent?

Dr. BOCCHINI. Well, probably it varies from test to test. But the goal would be to have that down to as few as possible. So it would be probably much less than three percent.

Mr. MULLIN. Much less than three. You mention in your testimony that six additional conditions were recommended for inclusion on the recommended uniform screening panel. Do we normally see savings in the Medicaid or CHIP system when we add tests?

Dr. BOCCHINI. Yes. Those—one of the advantages of having a public health system is that there would be no health disparities related to the ability to get tested and then there is really an important requirement that the treatment that is necessary for us to even consider a condition is available to everyone.

So that would include CHIP or Medicaid.

Mr. MULLIN. Some of the studies that we've seen is that the providers or primary care physicians they're not real familiar or real comfortable with recommending these tests or what to do with them when they have certain tests screened and where to send the individuals.

Are we looking at trying to educate the primary care person? How are we trying to educate, especially the individuals that are



maybe been in the field for a while versus ones that are entering the field?

Dr. BOCCHINI. Yes, that's a really good question because as things evolve primary care practitioners need to be much more aware of and how to deal with the genetic-related conditions that are being found in the newborn period.

So the advisory committee does have a education and training work group that addresses the education of everyone involved in newborn screening. That would be providers, the public, as well as the laboratorians that might need information.

So there is a significant effort to train or educate individuals. The American College of Medical Genetics has a series of statements that are available to state newborn screening programs that could be given to providers when a diagnosis—when the screening test is abnormal so that they could then have the information they need to advise parents of the next steps.

Mr. MULLIN. Is there an effort to include this training in some of their continued education that's required each year?

Dr. BOCCHINI. Yes. In fact, there are quality improvement projects, one from the American Academy of Pediatrics that is available to all primary care pediatricians as well as other programs as well in individual states.

Mr. MULLIN. Thank you. Thank you for your time. I yield back. Thank you.

Ms. ESHOO. The gentleman yields back. The Chair recognizes the gentlewoman from Illinois, Ms. Kelly, for her 5 minutes of questions.

Ms. KELLY. Thank you, Madam Chair, and thank you to all the witnesses.

Back to Hewitt, I just wanted to ask you, because something personal just happened in my life. My godson who is, like, a year and maybe three or four months his mom was just told that they think he has autism and I wondered, you know, what signs did he show that made them think that, because he seems like a healthy lively baby boy.

Dr. HEWITT. Sure. So one of the things about autism that's important for all of the subcommittee members to recognize is there isn't a blood test you can take. There isn't a genetic screening you can use right now to identify autism.

And so clinical staff, teachers, therapists are looking—they're observing for characteristics, and some of those common characteristics are related to communicate skills, social skills, behavioral interactions.

And so likely somebody saw some of those common characteristics related to communication, socialization, that were of concern.

Ms. KELLY. It's interesting we are having this hearing now because his mother is actually getting him tested today. So I was just curious.

Dr. HEWITT. And his mother is fortunate to be—for him to be the age he is and to be getting into a test—a diagnostic test so soon.

Ms. KELLY. And she's very—

Dr. HEWITT. That's really positive.

Ms. KELLY. So I know he'll be well taken care of. But thank you for your testimony.

Dr. Howard, can you illustrate for us what the scope of services would look like should Congress not act to protect the EMSC program?

Dr. HOWARD. It would be devastating. It would be very bad for many communities across the country. It would be challenging to smaller rural emergency departments that don't have a lot of resources. Where the resources are honestly needed the most is in the places where they have the fewest resources to start with.

It would mean that children would not arrive at referral facilities in quite as good of a condition as they're arriving in presently, and so it will compromise their outcomes.

And so it would be very devastating for the health and well-being of children across this country.

Ms. KELLY. And then even though we are here for the children—not only the children but the providers and the researchers.

Dr. HOWARD. Absolutely. The providers and all of the clinical care providers from pre-hospital, you know, through physicians, even, honestly, beyond the continuum of emergency care it even extends throughout that entire visit. It would be much more challenging for all and there would be a loss of training for those in the pre-hospital and emergency world, yes.

Ms. KELLY. You know, this is my first Congress on this committee. This committee has a long history of focussing on improving treatment and care for mental health including improving care for children.

And in your testimony you mentioned that the Pediatric Emergency Care Applied Research Network funded by the Emergency Medical Services for Children's program has improved mental health screening of children in emergency situations. Can you discuss how this mental health screening tool was developed and how it has helped care for children?

Dr. HOWARD. So, I don't know that I can talk about the specific tool. But what I can tell you is that we screen children in emergency departments now for behavioral health conditions which is not something that we always did because there's been some heightened awareness, part of it being through the EMSC program.

So we are much more cognizant of mental health screening for all ages of children. You know, for many years we didn't assess children for suicidality until they were 12 and now we assess at five years of age, and that can be complicated to talk to children and parents about do they have—have they expressed any desire to harm themselves or are they doing self-harm behaviors.

And so that's really important, and not everybody knows to do that without programs like EMSC.

Ms. KELLY. And there's still, even though we are in 2019, such a stigma still around mental health?

Dr. HOWARD. Unfortunately, yes, there is still a stigma. But the reality is that is an illness like every other illness we take care of. There should be no stigma. We don't stigmatize children for having pediatric cancer. We shouldn't stigmatize them for having pediatric mental health disorders.

Ms. KELLY. Right. I have a Master's in counselling. I totally agree with you.

I yield back the balance of my time.

Ms. ESHOO. The gentlewoman yields back.

And it's a pleasure for the Chair to recognize the gentlewoman from Indiana, Mrs. Brooks, for her 5 minutes of questions.

Mrs. BROOKS. Thank you, ma'am—Chairwoman—and thank you all so very, very much for your expertise, for your passion, for your patience, and for everyone that you're working with from the young to the older citizens among us.

Dr. Howard, I would like to ask you a couple questions about the interfacility transfer guidelines that, obviously, allow for the optimal selection of a hospital that can care for pediatric and transport of pediatric patients.

But yet, you have shared that only 50 percent of the hospitals in your written testimony have taken up these guidelines.

Can you talk with us? What are the barriers that might exist as to why more hospitals don't utilize the guidelines.

And why might—why aren't they appropriate for all hospitals?

Dr. HOWARD. Well, they actually are appropriate for all hospitals. You know, the main referral centers aren't really going to transfer children out, obviously.

These are going to be the places that are going to refer into us—into large academic centers that have all the resources available, and really one of the barriers still is knowledge, training, and education.

For as much as we have made great inroads in actually providing this information to places across the country, there still remain gaps in this knowledge and there are still some challenges.

Mrs. BROOKS. Excuse me. Can I ask a question about that?

Gaps in the knowledge—whose knowledge? Is it the physicians in other hospitals and nurses in other hospitals not knowing when to transfer a child? In Indiana, it might be the Riley Children's Hospital where I believe Dr. Hewitt trained.

I mean, why—how do physicians and/or nurses in a state not have that knowledge as to where a pediatric patient should be most appropriately treated?

Dr. HOWARD. Well, the reality is not every emergency physician is emergency medicine trained. Many facilities around the country, particularly smaller areas, have what we call locum tenens, emergency physicians, and so they may not be aware of the care network because they're there for a short time.

And so having those standardized programs and guidelines already set and in place by the facility is critical because if that standard work is there it makes a difference for when you have the revolving door because many of these small rural communities it's hard to get people to want to stay there and practice.

Mrs. BROOKS. And so when you refer to the arrangement these are without out-of-state physicians often coming in for periods of time and working in ERs. Is that correct?

Dr. HOWARD. That's—it's very common, particularly in—

Mrs. BROOKS. In rural—

Dr. HOWARD [continuing]. Small rural areas. I mean, that certainly happens in southeastern Kentucky. We have many locum tenens emergency physicians that are not vested in the community. They don't understand the networks. They don't have the relation-

ships with referral centers and they're just, like, well, send them to the next place.

Well, sending to the next place isn't really where they need to go because the next place might have more resources but they don't have all the resources.

Mrs. BROOKS. OK. Do you have any suggestions over what we can do improve the state partnership grants?

Dr. HOWARD. Well, I mean, my first recommendation would be that they, of course, could use more money. But I will just be happy if they reauthorize where they are today, because we all believe all of our passions could use more money to be able to allow for more training in education.

Mrs. BROOKS. Thank you.

Ms. ESHOO. Yes. Ask for more, don't say keep it the same.

Mrs. BROOKS. Dr. Hewitt, speaking of Riley Hospital and I want to talk a little bit about how do families find out about the LEND programs that you have been talking about? How does a family learn about it?

Dr. HEWITT. So LEND programs across our nation and in our territories have as a responsibility to have families as faculty. It's a unique component.

So as our training faculty we have family members and we have people with lived experience of disability, and we are partnering with family networks. So that could be Family Voices. It could be the ARC. It could be the parent-to-parent training centers in each and every state, and our Title V program.

So we are well networked in our partnerships to be able to reach through organizations that reach families, and then family to family by having faculty and trainees who are family members in our programs.

Mrs. BROOKS. You referred to your brother-in-law. What do the services look like for adults with autism spectrum disorder versus children?

Dr. HEWITT. It's a challenge. It varies by state—another theme that you have heard from us today.

Many states in their developmental disabilities systems have related conditions clauses which allows for somebody who has autism to be served in their developmental disability program.

Not all states have those clauses. So sometimes youth and adults with autism, once they're out of school, don't have access to developmental disabilities services.

Mrs. BROOKS. Any idea how many states don't have that clause?

Dr. HEWITT. I do know that data. I don't have it at the top of my head. But I will send it to you.

When there's a related conditions clause, most people with autism who are adults are served through the developmental disabilities system.

The challenge there is the primary program is home and community-based services, and as you may know there are waiting lists in most states for those services.

That's the primary mechanism. Some services through a vocational rehabilitation for employment.

Mrs. BROOKS. Thank you. I've exceeded my time. I am sorry, and I yield back.

Ms. ESHOO. The gentlewoman yields back.

The Chair now recognizes the gentlewoman from Delaware, Ms. Blunt Rochester, for 5 minutes of her questions.

Ms. BLUNT ROCHESTER. Thank you, Madam Chair.

I first want to thank all of the panellists.

You know, whenever issues come before us, I think it's important to put faces to those issues. And so as I thought about this opportunity to make sure that we highlight and support these important bills, I thought about faces in my life.

When you talk about Lifespan respite care, my mother's best friend for over 40 years is a caregiver to her daughter. When you talk about family navigation, I think about so many families that are challenged with trying to navigate sometimes very complex systems at a very stressful time in their lives.

When you talk about the LEND program, I think about the fact that my last job before coming to Congress I worked for the Institute for Community Inclusion at U. Mass Boston, which is also a USED, and just the hard work and the fact that people are trying to do things on a evidence based level, intra disciplinary and also focussing on parents and advocacy.

And so I just want everybody to take a minute to think about a face of a younger person of an older person that is touched by this very important legislation.

And so I thank you, Madam Chair, for the opportunity. Autism CARES has served as a catalyst for bringing people together in Delaware—critical stakeholders like service providers, families, clinicians, and students do discuss what's working, what's not working, and where we can go in the future.

One of the core pieces of autism CARES is support for early screening and identification of autism spectrum disorder which is also an important area of focus for my state of Delaware.

In 2013, we reported that the average age of diagnoses was 5.5 years old. But the American Academy of Pediatrics recommends screenings start as early as 18 months of age, and even more troubling are the existing disparities in access to diagnostic and early intervention services for ASD.

Because of a grant that funded autism CARES, stakeholders came together to focus on and target Latino families in Sussex County who are living in medically underserved areas with limited access to providers and appropriate services.

Dr. Hewitt, my first question is can you talk a little bit about the disparities that exist among the early diagnosis and screening for minority populations, why they exist and what kind of impact it would have?

Dr. HEWITT. Certainly. It's really an interesting topic because in some communities and in some states, children from diverse ethnic, racial linguistic backgrounds are under diagnosed. So a lot of times people make an assumption that the disparity is that children are over diagnosed. But in our state, you know, we are under diagnosing Latino children and Native American children as well as African-American children.

So part of it is that access to early identification, access to early intervention, those kinds of young child programs, one of our charges as LEND programs is to address those disparities.

So, for example, in our last cohort of LEND trainees one of our trainees' project was to be working in the mosques and trying to train the mosque families about autism.

So trying to get into faith communities to help in identifying and getting information about how kids should be identified and it shouldn't be a stigma to have autism. It should be considered like any other health issue where we identify it and get supports.

Ms. BLUNT ROCHESTER. I am going to turn to you, Doctor. Is it Bocchini or—Bocchini. OK.

Dr. Bocchini, could you just briefly—I have like 40 seconds, and it's a lot—describe the difference between testing and screening, and also you mentioned in your testimony about the fact that in addition to the health—the great health outcomes it is also cost savings. Can you share a little bit about those?

Dr. BOCCHINI. So many of the conditions that we screen for if untreated will cause developmental delays which then end up causing a significant amount to address and manage by early screening and a diagnosis before those permanent changes occur you reduce those costs?

So for many issues that's what happens.

Ms. BLUNT ROCHESTER. Thank you. Thank you so much.

Lastly, I will submit questions for the record, because I want to ask questions about the LEND program. I want to ask questions about the respite care. So I will do that.

But I want to thank you so much for all of your work on behalf of Americans. Thank you.

And I yield back.

Ms. ESHOO. The gentlewoman yields back.

The Chair now recognizes the gentleman from Florida, Mr. Bilirakis, for his 5 minutes of questions.

Mr. BILIRAKIS. Thanks you so very much.

Ms. ESHOO. And for all advocates that are here, Congressman Bilirakis's father preceded him in the Congress, and he was chair of this subcommittee. So the tradition continues. You are recognized.

Mr. BILIRAKIS. Oh, we care a great deal about these issues, Madam Chair, thank you, as you do to.

Thank you very much.

While I have some prepared questions, but I was looking into H.R. 2035 and I wanted to, for the benefit of the people listening back home, tell me what it encompasses. I am concerned specifically—is it Medicare-Medicaid patients who are severely—have severe illnesses. I am also specifically concerned. Do wounded warriors—I know it's mentioned in the bill with regard to wounded warriors—do they qualify for the respite care? In other words, their caregivers? That's so important as well. Please.

Ms. KAGAN. What's unique about Lifespan Respite program is that there are no stringent eligibility criteria. So this enables the state to identify where the biggest gaps are in services and try to target their limited dollars to those individuals.

So folks like wounded warriors and there is a VA program for respite but very often these individuals are either not qualifying for the VA program or there are not the types of respite options, espe-

cially the younger veterans where they're comfortable getting the respite services.

So we have continued to partner, especially at the state level—the state respite coalitions—have invited the VA caregiver coordinators to participate in their coalitions so that they can find additional respite resources for those individuals.

So, again, there's not a specific targeting. If a state is providing consumer-directed respite vouchers, they're very often targeting it to adults between the ages of 18 and 60 or with conditions like MS or ALS or spinal cord injuries or adults with intellectual developmental disabilities for whom no other respite services or public funding sources exist, people with mental health issues where it's very hard to find respite services or dollars to support that.

Families who are on Medicaid waiver waiting lists are often the first to be served under Lifespan programs too. So it's really—it's the gap filling program. It's those respite services. Families are eligible. If they're not getting services anywhere else from any other public program.

Mr. BILIRAKIS. Very good.

Yes, so it's basically up to the states. OK.

Dr. Bocchini, as lead sponsor of the congenital heart reauthorization act which is now law, and the co-chair of the rare disease caucus, I certainly understand the importance of early screening and the critical chance and hope that it affords patients and their care team.

What is the current state of newborn screening does it vary from state to state? I want to ask this question specifically. I know it covers hearing loss. In other words, the baby's screen for hearing loss.

How about visual impairment? Does it cover that as well?

Dr. BOCCHINI. Official impairment is not covered by newborn screening.

Mr. BILIRAKIS. We have to do something about that.

Dr. BOCCHINI. Well, there are a number of things that are considered to be practice parameters that all babies are screened for in the newborn period by physicians and are not part of by public health program.

The public health program for newborn screening is really dedicated to things that can be done in a public health laboratory as well as hearing, screening, and critical congenital heart disease screening, or point of care tests, and those are the only difference than—other than the blood heel stick blood test.

So certain things would be considered normal practice parameters and out of the public health realm.

Mr. BILIRAKIS. So you answered most of my questions here.

Screening with our proper follow-up actions is so very important. If you don't have the follow up actions it's basically moot.

After an initial newborn screening identifies a condition, patients, or the caregiver in this case, the education options and the resources become critical, especially in rural areas and low-income areas and medically underserved communities.

What does that handoff currently look like? Is that room—is there room for improvement to fall off? Because that's so important as well.

If you could maybe elaborate a little bit, sir. That's important that we follow up.

Dr. BOCCHINI. Thank you. It's a very important question.

Newborn screening is a program. It's really not a single test that's done in a laboratory. So it's very important that children who are identified are rapidly referred to the specialist or the individualist who can then manage that child's care. So we would call that short-term follow up.

And then once short-term follow up is assured, a diagnosis is made, and then the management is evolved, then long-term follow-up becomes really important so that that child is not lost to follow-up.

Yes, we can improve that. There are a lot of gaps that may exist in individual states based on resources, based on having enough subspecialty providers to take care of those patients, and then having the resources for the care that's needed surrounding that specific diagnosis.

So I think there is an opportunity with this reauthorization to have more funds go to states through the HRSA program to help improve short-term, long-term—especially long-term follow up of those patients.

Mr. BILIRAKIS. Very good. I yield back, Madam Chair. Thank you so much.

Ms. ESHOO. The gentleman yields back. The Chair recognizes Dr. Ruiz from California for his 5 minutes of questions.

Mr. RUIZ. Thank you, Madam Chair. I appreciate the opportunity. Thank you all of you for coming today and testifying.

The Emergency Medical Services for Children's program helps train providers on how to coordinate care for kids in the emergency department.

When I first ran I used to say, man, I don't care if it's a Republican idea or if it's a Democratic idea. I just care if it's a darn good idea and I am going to support it.

This bill is—has been introduced by a Republican, Representative King. It's a hell of a good idea. I support this bill 100 percent, and I believe Democratic Representative Castor is on it so it's a very good bipartisan bill. And I will back any good idea from a Republican any day any time.

As an emergency department physician, I can assure you that it is critical that there are protocols set specifically for the unique needs of children, and it is not just important for physicians.

My wife, Monica, is an emergency nurse and I know you have a doctorate in nursing, Dr. Howard, and she would say the same thing.

So Dr. Howard, what are some examples of the models that have been developed for pre-hospital and hospital use, and how did this program help to do that, especially in terms of the regional care—EMS care—for kids?

Dr. HOWARD. Well, there's a variety of different examples and I have alluded to the pediatric readiness a little bit earlier. In fact, one of the members actually talked a little bit about what had happened in their state.

But I think the pediatric readiness which is some of the work that's really actually occurring presently—all the different pediatric



readiness grants—is something that has really benefited all spectrums because it makes sure that not only is EMS ready but the emergency department is ready with not just the knowledge, training, and expertise but they also have dedicated physician and nurse champions for pediatric care, which is a little bit of a different focus than we've seen with some of the other EMSC programs. And so this pediatric readiness component I think is really critical.

Mr. RUIZ. Dr. Howard, you know as well as I do that when you're in a rural emergency department, or even an urban emergency department, that when a very sick kid comes to you everybody just tightens up a little and a lot of it is going to be quickly stabilize, resuscitate, and then transfer to a tertiary Children's Hospital.

And unfortunately, many locations in rural American they don't have nearby and therefore they have to call the medical flight physicians and nurses to come and transport that critically sick patient to get lifesaving care where they need it.

And having grown up in a rural impoverished community of Coachella, California, that's very underserved I've seen barriers to care that don't necessarily exist in nonrural settings and those hospitals face a unique set of needs.

I've also been a strong advocate for tribes and the Indian Health Service, and who often face even greater access issues since long before I came to Congress.

So, Dr. Howard, can you explain specifically how this program helps families living in underserved rural areas or tribal communities.

Dr. HOWARD. It specifically helps those areas because the EMSC partnership grants have taken services to those rural areas, and I will use my state for an example.

We only have two level one children's facilities in our entire state. So you either come to Louisville or Lexington.

Mr. RUIZ. What state is that again? I am sorry. What state is that?

Dr. HOWARD. Kentucky.

Mr. RUIZ. Kentucky only has two children's hospitals for the entire state?

Dr. HOWARD. Correct. And we are not geographically large but we are size wise. It takes a significant amount of time. So if you come from far eastern Kentucky by helicopter it's still almost an hour by flight. An hour when you're critically ill or injured and you have already had stabilization at another facility is challenging.

Mr. RUIZ. And that's why we got to protect the CHIP programs, the Medicaid programs for the children and families in Kentucky. You keep cutting those and putting on these work requirements you're going to decrease the people that are insured. It's going to make things worse for the residents of Kentucky.

So and we also have to make sure we fund those medical flights because without them time is tissue, right, in the emergency department. You don't get the appropriate timely care for strokes and heart attacks, you're done. It's going to be much more costly in the future than the cost of a medical flight because you're going to be paying for a lifetime of rehabilitation and loss of work.

So this program includes the EMSC data center which provides monetary data management.

Dr. Howard, what do we do with the data that we are collecting and how does it improve health outcomes for children in the emergency department setting?

Dr. HOWARD. So the PECARN network has been phenomenal in terms of providing best evidence and shared the best evidence, and one of the things I mentioned in my oral testimony earlier is I think of the best outcomes of that data, which is not getting a CAT scan on every child that presents to the emergency department for years if you had a minor head injury and a loss of consciousness, automatic CAT scan.

We don't do that now. We observe these children. We have parameters, and so we are not, number one, unnecessarily exposing them to radiation but we are also not spending dollars that we don't have to spend.

And so that makes a difference, and these children do very well.

Mr. RUIZ. Ms. Chair, I just want mention that she's absolutely correctly that they found that kids who get these CAT scans are at higher risk of getting leukemia, lymphomas, and other blood-borne cancers. And so now we are trying to really protect them from getting these CAT scans.

Ms. ESHOO. The gentleman yields back.

Mr. RUIZ. Yes.

Ms. ESHOO. I just want to—I can't help but add when you talked about air ambulances that we have to make sure that people don't suffer heart attacks when they get the bill for it.

The Chair now has the pleasure of recognizing the gentleman from Montana, Mr. Gianforte.

Mr. GIANFORTE. Thank you, Chairwoman Eshoo, and thank you for the experts in your testimony today. These are very important topics.

I am a proud sponsor of the Autism CARES Act. I know funding for this program has been used to identify thousands of kids who otherwise may not have been diagnosed as on the spectrum.

We have seen nearly a four-fold increase in the number of students with autism receiving special education services in Montana schools in the last ten years.

Montana families rely on the services and support outlined in this bill. Currently, Montana is one of only a handful of states without their own LEND training program.

But I know Montana is laying the groundwork to establish this training within our state. This program is especially important in rural areas where it could be difficult to find providers who can screen, diagnose, and help with the therapy needed.

Over the last 12 years Montanans have had to travel to Utah to participate in the LEND program. I know it would really help our state to have more—a more local LEND program.

Dr. Hewitt, what challenges to children with autism face in rural communities?

Dr. HEWITT. I was just in your state last week talking to them about gearing up for a LEND program. So they're definitely gearing up for it.

I think in answer to your question, the biggest challenge is having people with the training and the expertise where they live that can do the assessment—the diagnosis and the intervention.

And in our rural communities in nearly every state that's a real challenge. One of the things that many LEND programs are doing now is trying to use telehealth as an opportunity to get that expertise to rural communities.

Mr. GIANFORTE. Can you talk a little more about how telehealth is being used in the LEND program?

Dr. HOWARD. Sure. I will speak to our area. One of our big challenges in the metropolitan area, Minneapolis/St. Paul, we have a lot of programs. We have a lot of clinical services. We have a lot of trained professionals.

In Greater Minnesota, we don't, and so at our LEND program we have our LEND faculty who are through the internet, through secured way, and with training to the families, they're actually doing assessment diagnostic and intervention, and then monitoring that intervention from screen to screen in a family home.

Mr. GIANFORTE. So the LEND program, aspects of it, can be implemented effectively through telemedicine?

Dr. HOWARD. Absolutely.

Mr. GIANFORTE. OK. Great. And we can't have a specialist for every discipline in every rural town in the U.S. This is a really important part.

Dr. HOWARD. Absolutely.

Mr. GIANFORTE. I appreciate you making that point. At what age are children usually evaluated and diagnosed with autism?

Dr. HOWARD. That really varies. It varies based on state. It varies based on community. On average, it's just under five years of age when a child gets their first diagnosis.

But one thing we do know is that there were signs and there were comments from preschool teachers, from pediatricians, that identified perhaps characteristics of autism that go undiagnosed or get deferred until a child enters school.

Mr. GIANFORTE. Is that diagnosis delayed at all in rural areas?

Dr. HOWARD. It is, and that's really because there aren't—a clinical diagnosis often is delayed because there aren't experts to provide that intervention.

Mr. GIANFORTE. So what are the effects, if any, for children who are diagnosed with autism later in life versus earlier?

Dr. HOWARD. Well, we know that the earlier that you're identified the earlier that you get intervention, the better your communication skills are and the better your educational outcomes are, and overall in general your life, your work, your capacity to earn a living, all of those things matter.

Mr. GIANFORTE. So the path to a more productive life is benefited with an earlier diagnosis?

Dr. HOWARD. Correct.

Mr. GIANFORTE. OK. Thank you.

Ms. Kagan, is it more difficult to receive Lifespan respite care in rural communities?

Ms. KAGAN. As with any other program, especially when we are facing the direct service workforce shortage, of course it is harder.

Oklahoma, though, has had a wonderful program in place that they initiated with their initial Lifespan respite grant to do mobile respite where they partnered with state department of transportation to get a van that was no longer used by the state, and they transfer workers and volunteers from the more urban areas out to the rural areas to provide a day of respite for families in rural communities. It's a wonderful model.

Mr. GIANFORTE. Can you speak—can you speak briefly to the impact of the Lifespan Respite Care Reauthorization Act on rural communities?

Dr. HOWARD. Again, I think it's one of the few programs because it allows states to use funds to not only help families pay for respite but it allows them to build new services and test out these innovative models like the volunteer transportation.

Mr. GIANFORTE. OK. Thank you for your indulgence, Madam Chair.

I yield back.

Ms. ESHOO. You're most welcome. The gentleman yields back.

Now I would like to recognize the gentleman from Pennsylvania, Mr. Doyle, who's waiving onto the subcommittee. He's the chairman of the Communications and Technology Subcommittee of Energy and Commerce, and he and—we all need to thank both Mr. Doyle and Mr. Smith, who's also here and will follow him, because inside the Congress these are the two top advocates relative to autism, not only with their legislation but with the caucus that they have formed and I want to salute both of them.

So, Mr. Doyle, you have 5 minutes and take it away, and we are all really very grateful to you for your leadership, especially when it matters.

Mr. DOYLE. Thank you, Madam Chair.

Thank you, and I appreciate you allowing us to waive onto the subcommittee today to ask some questions.

And I want to recognize my good friend, Chris Smith.

About 20 years ago, Chris and I were members of the Veterans Affairs Committee and we were sitting down having a conversation and that's when the idea came up Chris was telling me about a spike in autism in Brick Township, New Jersey—that they thought maybe there was an environmental cause to this.

And I was relaying to him my experiences with a family back in Pittsburgh, the Torisky family—Dan Torisky, who eventually became the national president of the Autism Society of America, and that's where we come with the idea to start the caucus because a lot of members of Congress didn't know what autism was and not much was being done, and Chris has been a real pleasure to work with and a real champion for the cause. I couldn't have a better co-chair of the caucus than Chris Smith and I want people to know that.

Dr. Hewitt, we have heard a lot about early intervention. Can you share some of the information about the CDC's "Learn the Signs and Act Early" and some of the other resources that are available? And how can family use these resources to help them identify these signs?

Dr. HEWITT. Sure. As I said in my introduction, we have one of the “Learn the Signs Act Early” programs in Minnesota. We’ve been fortunate to have that.

We, as a program, have decided to use those resources to develop educational materials and outreach to communities—to various immigrant communities, so our Somali community, our Hmong community, our other East African community—as a way to get parent-to-parent information.

So we’ve developed brochures. We’ve developed talking, educational like in-person educational programs to work to train families so that they can go into their communities and train other families about what to look for in their child’s development and what concerns might arise and then what to—where to go if they identify something.

Mr. DOYLE. So Dr. Hewitt, we have a LEND program in Pittsburgh and it’s been invaluable to us. I am just curious. How do the LEND programs around the country interact with one another and could LEND programs improve interaction to create more of a national network?

Dr. HEWITT. That’s one of the great things about the LEND program. Through the Association of University Centers on Disability we have a network and we do work very closely together.

Next month we’ll come together for an Autism CARES national conference where the LEND directors and LEND staff get together and we share what we are doing in our various states, learn from one another about effective programs and then can take that back and replicate it.

Mr. DOYLE. Tell me, what are some of your experiences and concerns as a family member that are—that you feel are not being addressed in your research and research that’s taking place around the country?

Dr. HEWITT. Again, I’ve said it before in this hearing. But issues related to transition, youth transitioning to adulthood, and employment, so specialized employment programs that help support individuals who—with autism who are young adults and adults to find and keep their employment. It’s a big area.

Mr. DOYLE. Yes, I can’t tell you how many families that I talk to worry about as their kids are aging out of services and as we know the first person I met with autism is now a 50 some year old adult. It’s not a developmental disability that kills you, and families worry what happens to their children when they’re no longer around. And, as we know, the spectrum, depending on where you sit on that spectrum, that can be a real concern.

So it’s one of the things we are trying to address in the legislation.

Let me ask, in your opinion, what would be the benefits of CDC increasing a surveillance of adults with ASD?

Dr. HEWITT. I think it’s really important and, as I said, we are working toward that by adding a small number of states that will be looking at 16-year-olds.

We really just don’t have prevalence data about adults with autism in the United States, and what the prevalence data does is help policy makers at that local and state level plan for services and supports.

Mr. DOYLE. Madam Chair, I see my time is expiring.

I would like to seek unanimous consent to enter nine letters of support from the following organizations into the record: Autism Speaks, two letters from them, the Autism Society of America, Association of University Centers on Disabilities, American Academy of Pediatrics, the National Association of Councils on Developmental Disabilities, National Council on Severe Autism, Research America, and a letter of support from a diverse group of disability and healthcare organizations.

Ms. ESHOO. So ordered.

[The information appears at the conclusion of the hearing.]

Ms. ESHOO. And we just subtracted those I think successfully from my long list. But there's a real honor roll of organizations. I thank the gentlemen.

I now would like to ask for unanimous consent of the ranking member of our subcommittee, because Congressman Smith is with us.

But we have a rule at the committee that if you're not part of the full committee that you can't speak. But he's here and I think he deserves—I really want to recognize him so I ask for unanimous consent of Congressman Smith be able to participate now and recognize him for his 5 minutes of comments, questions.

Welcome, and thank you for your very fine work. We are all indebted to you for your leadership.

Mr. SMITH. Chairwoman Eshoo, thank you for not only your strong personal but your professional commitment to all of these important health issues including and especially the Autism CARES legislation, which is and continues to be historic. It is already making a difference but this new iteration, and Mike Doyle, you can't find a better friend and champion for combatting autism and helping across the board.

You know, one of the features of our new bill is to make it the Lifespan—the emphasis is no way diminished towards helping early childhood and children.

But we now know that about 50,000 people matriculate from the minor to adulthood, and there's so much that we don't know, so many needs that have to be met including housing.

Our last Autism CARES Act made it very clear that we wanted a full assessment from GAO. We did that by letter in the bill from the administration.

What is out there? What are the capabilities of local, federal, and state governments to meet this growing and really almost exponentially growing need that is largely unmet.

I want to thank Dr. Burgess, who has been a great friend on so many issues. I chaired for years—now I am ranking member—of the Africa Global Health Global Human Rights Committee, and had hearings on Ebola and neglected tropical diseases, Zika, HIV/AIDS, malaria, TB, autism, and Alzheimer's, and Dr. Burgess was at so many of those hearings I thought he was a member of the committee.

So I want to thank him for his expertise as well because—and his concern.

This bill is, I think, going to make a difference. It was written with close collaboration with those organizations that was just cited. Autism CARES and Speaks have been game changers.

It does provide a little over \$1.7 billion over five years. When I brought CDC to New Jersey in 1997, because we had a prevalence spike, we thought, that was just Brick Township.

CDC, to their shock and dismay, found when they did their data calls that other townships had similar prevalence increases that could not be explained.

You know what they were spending then for—at CDC? \$287,000 per year straight line for five years.

I even—I asked then, what does that buy, a desk? You can't even do a review of literature that's credible with that kind of puny spending.

So that has done up \$23 million for CDC per million now, \$53 million for HRSA and Mike is planning on offering an amendment that tracks our appropriations number of \$296 million per year for NIH.

If you look at all of the data—this is the way an NIH program and a CDC coordinated program should run, they have a strategic plan.

IIAC does a wonderful job—they're not perfect, but a wonderful job—and they ask questions and then they assign projects so there's less duplication and, hopefully, no duplication of effort.

We have 126 co-sponsors on this bill. Again, Mike and I have worked across the aisle. They say that bipartisanship is dead. Not here and not with my good friend from Pennsylvania.

So I want to thank him for that. We also have included on IIAC, what I think, what we think is so important. Labor, Justice, and HUD have now been included. So we get additional eyes and ears and buy-in from this whole of government approach.

So it's really a historic bill. It needs to pass early. We never know what's going to happen in the Senate. But we have had conversations with Lamar Alexander and I do believe he's likely to hold it at the desk.

Previous times we had holds galore on it. The Senate's arcane rules make it very hard to get important bills passed. And, you know, we are working it proactively to try to mitigate the possibility of different members putting a hold on it so that it hopefully gets to the president and then signed.

Mike and I—and this is one of the untold stories—the reason why NIH and CDC is up the way it is, we lobbied the daylights out of our friends and we are our friends, whether it be Tom Cole or others, when he was chairman of the Labor HHS bill to keep putting that number up because the need is overwhelming.

We don't have our arms around this yet, and as has been said—and Dr. Hewitt, thank you for your testimony and leadership—we are still expanding and it is global.

I have a bill that I've been unsuccessful in getting passed. That would be a global autism bill, because it's everywhere. It's all over Africa. It's all over Latin America, it's everywhere. And we have only made a small dent in that.

But the United States is leading. It is bipartisanship. Mike, thank you. You have been a great friend and a great champion.

I yield back. Thank you, Chairwoman Eshoo, for this time.

Ms. ESHOO. The gentleman yields back.

And we are so pleased that both of you were here today. It means everything to whomever is listening certainly to all of the advocates and all of the members of the subcommittee.

I think that we don't have any members here for any additional questions. So I want to thank this panel of witnesses.

I think you have been outstanding. You have answered the questions directly. We have learned from you. You have deepened our knowledge on the issues.

These are four bills that deserve to move on to being reauthorized. They're important for the American people.

And, you know, these are words that are written on paper but I always say, you know, you put legs, you put feet on those words they walk right into people's lives.

So thank you for testifying today. On behalf of all the members of the subcommittee we are really grateful to you.

And remind members—of course, there are only a couple of us left in the room now—that pursuant to committee rules each Member has ten days to submit additional questions for the record to be answered by the witnesses who have appeared.

So I ask each witness that you respond promptly to any of the questions that you may receive from members.

And I now would like for unanimous consent to enter into the record the following. It's a long list. These are the documents that I would like to place in the record:

The Coalition Letter in support of H.R. 2507, statement for the March of Dimes, in support of H.R. 2507, statement from the Aiden Jack Sager in support of 2507, a letter from AARP in support of 2035, a letter from the Consortium for Citizens with Disabilities in support of 2035, a letter from the American Speech Language Hearing Association in support of 1058, a letter from the Association of University Centers on Disabilities in support of 1058, Coalition letter in support of H.R. 1058, a letter from Research America in support of 1058, coalition letter in support of 776, and a statement from the American Academy of Pediatrics in support of 776.

Hearing no objections, so ordered.

[The information appears at the conclusion of the hearing.]

Ms. ESHOO. And with that, the subcommittee is adjourned.

Thank you, everyone.

[Whereupon, at 12:37 p.m., the committee was adjourned.]

[Material submitted for inclusion in the record follows:]

#### PREPARED STATEMENT OF HON. ELLIOT L. ENGEL

Madame Chairwoman Eshoo, thank you for holding today's important hearing on children's health care programs.

I want to commend Representatives Chris Smith (R-NJ) and Mike Doyle (D-PA) for their work on the Autism Collaboration, Accountability, Research, Education and Support (CARES) Act.

This bipartisan legislation will reauthorize funding for critical federal health programs that serve Americans with Autism Spectrum Disorder (ASD), including cutting-edge research at the National Institutes of Health. In fiscal year 2018, my home state of New York received about \$22 million from NIH for autism-related research. I am pleased that this legislation reauthorizes funding for this important work at the NIH.



The Autism CARES Act also includes provisions that will improve the Interagency Autism Coordinating Committee or IACC. This multidisciplinary panel has played a key role in helping shape and guide federal programs that support ASD research and treatment. The Autism CARES Act improves this panel by broadening its membership to include officials from different federal agencies, including the Department of Justice and Department of Labor. This bipartisan legislation will also elevate the individual's voice by enabling more Americans with ASD and their families to share their experiences with IACC.

I look forward to working with my colleagues on both sides of the aisle to advance the Autism CARES Act as well as the other important bills that we are considering today, including the Newborn Screening Saves Lives Reauthorization Act.

116TH CONGRESS  
1ST SESSION

# H. R. 776

To amend the Public Health Service Act to reauthorize the Emergency Medical Services for Children program.

---

## IN THE HOUSE OF REPRESENTATIVES

JANUARY 24, 2019

Mr. KING of New York (for himself, Ms. CASTOR of Florida, Mr. BUTTERFIELD, and Mr. STEWART) introduced the following bill; which was referred to the Committee on Energy and Commerce

---

## A BILL

To amend the Public Health Service Act to reauthorize the Emergency Medical Services for Children program.

1 *Be it enacted by the Senate and House of Representa-*  
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Emergency Medical  
5 Services for Children Program Reauthorization Act of  
6 2019”.

7 **SEC. 2. REAUTHORIZATION OF THE EMERGENCY MEDICAL**  
8 **SERVICES FOR CHILDREN PROGRAM.**

9 Section 1910(d) of the Public Health Service Act (42  
10 U.S.C. 300w–9(d)) is amended—

1           (1) by striking “2014, and” and inserting  
2           “2014,”; and

3           (2) by inserting before the period the following:  
4           “, and \$22,334,000 for each of fiscal years 2020  
5           through 2024”.

○

116TH CONGRESS  
1ST SESSION

# H. R. 1058

To reauthorize certain provisions of the Public Health Service Act relating to autism, and for other purposes.

---

## IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 7, 2019

Mr. SMITH of New Jersey (for himself and Mr. MICHAEL F. DOYLE of Pennsylvania) introduced the following bill; which was referred to the Committee on Energy and Commerce

---

## A BILL

To reauthorize certain provisions of the Public Health Service Act relating to autism, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*  
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Autism Collaboration,  
5 Accountability, Research, Education, and Support Act of  
6 2019” or the “Autism CARES Act of 2019”.

1 **SEC. 2. EXPANSION, INTENSIFICATION, AND COORDINA-**  
2 **TION OF ACTIVITIES OF NATIONAL INSTI-**  
3 **TUTES OF HEALTH WITH RESPECT TO RE-**  
4 **SEARCH ON AUTISM SPECTRUM DISORDER.**

5 Section 409C of the Public Health Service Act (42  
6 U.S.C. 284g) is amended—

7 (1) in subsection (a)(1)—

8 (A) by inserting after “and toxicology” the  
9 following: “, and interventions to maximize out-  
10 comes for persons with autism spectrum dis-  
11 order”;

12 (B) by inserting after “early” the fol-  
13 lowing: “and ongoing”; and

14 (C) by inserting after “treatment of autism  
15 spectrum disorder” the following: “, including  
16 dissemination and implementation of clinical  
17 care, supports, intervention, and treatment”;  
18 and

19 (2) in subsection (b)—

20 (A) by amending paragraph (2) to read as  
21 follows:

22 “(2) RESEARCH.—Each center under para-  
23 graph (1) shall conduct basic and clinical research  
24 into autism spectrum disorder. Such research should  
25 include investigations into the causes, diagnosis, and  
26 early and ongoing detection, prevention, and treat-

1       ment of autism spectrum disorder across the life-  
 2       span. The centers, as a group, shall conduct re-  
 3       search including in the fields of developmental  
 4       neurobiology, genetics, psychopharmacology, genom-  
 5       ics, and developmental, behavioral, and clinical psy-  
 6       chology.”; and

7               (B) in paragraph (3), by adding at the end  
 8       the following new subparagraph:

9               “(D) REDUCING DISPARITIES.—In award-  
 10       ing grants to applicants which meet the sci-  
 11       entific criteria for funding under this section,  
 12       the Director may consider, as appropriate, the  
 13       extent to which a center can demonstrate avail-  
 14       ability and access to clinical services for youth  
 15       and adults from diverse racial, ethnic, geo-  
 16       graphic, or linguistic backgrounds.”.

17   **SEC. 3. DEVELOPMENTAL DISABILITIES SURVEILLANCE**  
 18       **AND RESEARCH PROGRAM.**

19       Section 399AA(e) of the Public Health Service Act  
 20   (42 U.S.C. 280i(e)) is amended by striking “2019” and  
 21   inserting “2024”.

22   **SEC. 4. AUTISM EDUCATION, EARLY DETECTION, AND**  
 23       **INTERVENTION.**

24       Section 399BB of the Public Health Service Act (42  
 25   U.S.C. 280i–1) is amended—

1 (1) in subsection (a)(1), by striking “for chil-  
2 dren” and inserting “for individuals”;

3 (2) in subsection (b)—

4 (A) by redesignating paragraphs (4)  
5 through (6) as paragraphs (5) through (7), re-  
6 spectively; and

7 (B) by inserting after paragraph (3) the  
8 following new paragraph:

9 “(4) promote evidence-based screening tech-  
10 niques and interventions for individuals with autism  
11 spectrum disorder across their lifespans;”;

12 (3) in subsection (c)(1), in the matter preceding  
13 subparagraph (A), by inserting after “needs of indi-  
14 viduals with autism spectrum disorder or other de-  
15 velopmental disabilities” the following: “across the  
16 lifespan of such individuals”;

17 (4) in subsection (e), by adding at the end the  
18 following new paragraph:

19 “(4) PRIORITIZATION.—

20 “(A) IN GENERAL.—In awarding grants  
21 and agreements under paragraphs (1) and (2),  
22 the Secretary may prioritize awards to training  
23 programs described in paragraph (1) that are  
24 developmental-behavioral pediatrician training

1 programs located in rural areas or underserved  
2 areas.

3 “(B) UNDERSERVED AREA DEFINED.—In  
4 this paragraph, the term ‘underserved area’  
5 means—

6 “(i) an area described in section  
7 332(a)(1)(A); and

8 “(ii) a medically underserved popu-  
9 lation (as defined in section  
10 330(b)(3)(A)).”;

11 (5) in subsection (f), by inserting after “individ-  
12 uals with autism spectrum disorder or other develop-  
13 mental disabilities” the following: “across the life-  
14 span of such individuals”; and

15 (6) in subsection (g), by striking “2019” and  
16 inserting “2024”.

17 **SEC. 5. INTERAGENCY AUTISM COORDINATING COM-**  
18 **MITTEE.**

19 Section 399CC of the Public Health Service Act (42  
20 U.S.C. 280i-2) is amended—

21 (1) in subsection (b)—

22 (A) in paragraph (2), by inserting after  
23 “services and supports for individuals with au-  
24 tism spectrum disorder” the following: “across  
25 the lifespan of such individuals”; and



1 (B) in paragraph (5), by inserting after  
2 “individuals with an autism spectrum disorder”  
3 the following: “across the lifespan of such indi-  
4 viduals”;

5 (2) in subsection (e)—

6 (A) in paragraph (1)(D), by inserting after  
7 “the Department of Education” the following:  
8 “, the Department of Labor, the Department of  
9 Justice, the Department of Housing and Urban  
10 Development,”; and

11 (B) in paragraph (3)(A), by striking “one  
12 or more additional 4-year terms” and inserting  
13 “one additional 4-year term”; and

14 (3) in subsection (f), by striking “2019” and  
15 inserting “2024”.

16 **SEC. 6. REPORTS TO CONGRESS.**

17 Section 399DD of the Public Health Service Act (42  
18 U.S.C. 280i–3) is amended—

19 (1) in subsection (a)—

20 (A) in paragraph (1), by striking “of  
21 2014” and inserting “of 2019”; and

22 (B) in paragraph (2)—

23 (i) by striking “of 2014” each place it  
24 appears and inserting “of 2019”;

1 (ii) in subparagraph (G), striking  
2 “age of the child” and inserting “age of  
3 the individual”;

4 (iii) in subparagraph (H), by striking  
5 “and” at the end;

6 (iv) in subparagraph (I), by striking  
7 the period at the end and inserting “;  
8 and”; and

9 (v) by adding at the end the following  
10 new subparagraph:

11 “(J) information on how States use home  
12 and community-based services and other sup-  
13 ports to ensure that individuals with autism  
14 spectrum disorder or other developmental dis-  
15 abilities are living, working, and participating in  
16 the community.”; and

17 (2) by amending subsection (b) to read as fol-  
18 lows:

19 “(b) REPORT ON HEALTH AND WELL-BEING OF IN-  
20 DIVIDUALS WITH AUTISM SPECTRUM DISORDER.—

21 “(1) IN GENERAL.—Not later than 2 years  
22 after the date of enactment of the Autism CARES  
23 Act of 2019, the Secretary shall prepare and submit  
24 to the Committee on Health, Education, Labor and  
25 Pensions of the Senate and the Committee on En-

1 ergy and Commerce of the House of Representatives  
2 a report concerning the health and well-being of in-  
3 dividuals with autism spectrum disorder.

4 “(2) CONTENTS.—The report submitted under  
5 paragraph (1) shall contain—

6 “(A) demographic factors associated with  
7 the health and well-being of individuals with au-  
8 tism spectrum disorder;

9 “(B) an overview of policies and programs  
10 relevant to the health and well-being of individ-  
11 uals with autism spectrum disorder, including  
12 an identification of existing Federal laws, regu-  
13 lations, policies, research, and programs;

14 “(C) proposals on establishing best prac-  
15 tices guidelines to ensure interdisciplinary co-  
16 ordination between all relevant service providers  
17 receiving Federal funding;

18 “(D) comprehensive approaches to improv-  
19 ing health outcomes and well-being for individ-  
20 uals with autism spectrum disorder, including—

21 “(i) community-based behavioral sup-  
22 ports and interventions;

23 “(ii) nutrition, recreational, and social  
24 activities; and

1 “(iii) personal safety services for indi-  
2 viduals with autism spectrum disorder re-  
3 lated to public safety agencies or the crimi-  
4 nal justice system; and  
5 “(E) recommendations that seek to im-  
6 prove health outcomes for individuals with au-  
7 tism spectrum disorder by addressing—  
8 “(i) screening and diagnosis of indi-  
9 viduals of all ages;  
10 “(ii) behavioral and other therapeutic  
11 approaches;  
12 “(iii) primary and preventative care;  
13 “(iv) communication challenges;  
14 “(v) aggression, self-injury, elope-  
15 ment, and other behavioral issues;  
16 “(vi) emergency room visits and acute  
17 care hospitalization;  
18 “(vii) treatment for co-occurring phys-  
19 ical and mental health conditions;  
20 “(viii) premature mortality;  
21 “(ix) medical practitioner training;  
22 and  
23 “(x) caregiver mental health.”.

1 **SEC. 7. AUTHORIZATION OF APPROPRIATIONS.**

2 Section 399EE of the Public Health Service Act (42  
3 U.S.C. 280i-4) is amended—

4 (1) in subsection (a), by striking “\$22,000,000  
5 for each of fiscal years 2015 through 2019” and in-  
6 serting “\$23,100,000 for each of fiscal years 2020  
7 through 2024”;

8 (2) in subsection (b), by striking “\$48,000,000  
9 for each of fiscal years 2015 through 2019” and in-  
10 serting “\$50,599,000 for each of fiscal years 2020  
11 through 2024”; and

12 (3) in subsection (c), by striking “there is au-  
13 thorized to be appropriated \$190,000,000 for each  
14 of fiscal years 2015 through 2019” and inserting  
15 “there are authorized to be appropriated such sums  
16 as may be necessary for each of fiscal years 2020  
17 through 2024”.

○

116TH CONGRESS  
1ST SESSION

# H. R. 2035

To amend title XXIX of the Public Health Service Act to reauthorize the program under such title relating to lifespan respite care.

---

## IN THE HOUSE OF REPRESENTATIVES

APRIL 2, 2019

Mr. LANGEVIN (for himself and Mrs. RODGERS of Washington) introduced the following bill; which was referred to the Committee on Energy and Commerce

---

## A BILL

To amend title XXIX of the Public Health Service Act to reauthorize the program under such title relating to lifespan respite care.

1 *Be it enacted by the Senate and House of Representa-*  
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Lifespan Respite Care  
5 Reauthorization Act of 2019”.

6 **SEC. 2. FINDINGS.**

7 Congress finds the following:

8 (1) There are an estimated 43,000,000 family  
9 caregivers nationwide that provide care for loved

1 ones with chronic, disabling health conditions across  
2 the lifespan.

3 (2) The economic value of uncompensated fam-  
4 ily caregiving to the United States economy was esti-  
5 mated at \$470,000,000,000 in 2013, more than  
6 total Medicaid spending of \$449,000,000,000, in-  
7 cluding both Federal and State contributions for  
8 medical and long-term care in the same year.

9 (3) While caring for the aging population re-  
10 mains a growing concern, more than half of care re-  
11 cipients are under age 75, and almost one-third are  
12 under age 50.

13 (4) Respite provides temporary relief to care-  
14 givers from the ongoing responsibility of caring for  
15 individuals of all ages with special needs.

16 (5) Respite care is one of the most commonly  
17 requested caregiver support services.

18 (6) Respite has been shown to provide family  
19 caregivers with the relief necessary to maintain their  
20 own health, balance work and family, bolster family  
21 stability, keep marriages intact, and avoid or delay  
22 more costly nursing home or foster care placements.

23 (7) Delaying nursing home, institutional, or fos-  
24 ter care placement of just one individual for several

1 months can save Medicaid, child welfare, or other  
2 government programs tens of thousands of dollars.

3 (8) The Lifespan Respite Care Act of 2006  
4 (Public Law 109–442) was originally enacted to im-  
5 prove the delivery and quality of respite care services  
6 available to families across all age and disability  
7 groups by establishing coordinated lifespan respite  
8 systems.

9 (9) Thirty-seven States and the District of Co-  
10 lumbia have received grants under the Lifespan Res-  
11 pite Care Act of 2006 to improve the availability and  
12 quality of respite services across the lifespan.

13 (10) For the Nation’s wounded servicemembers  
14 and veterans with traumatic brain injuries and other  
15 conditions, respite systems could be an integral life-  
16 line for families in their new roles as lifelong family  
17 caregivers.

18 (11) The Department of Veterans Affairs and  
19 Congress have both acknowledged the unique chal-  
20 lenges facing caregivers of returning servicemembers  
21 and veterans, as well as the need for increased care-  
22 giver services.

23 (12) The increased utilization of, and costs to,  
24 long-term care systems requires the continued devel-



1       opment of coordinated family support services like  
2       lifespan respite care.

3   **SEC. 3. REAUTHORIZATION OF LIFESPAN RESPITE CARE**  
4       **PROGRAM.**

5       (a) DATA COLLECTION AND REPORTING.—Section  
6   2904 of the Public Health Service Act (42 U.S.C. 290ii–  
7   3) is amended to read as follows:

8   **“SEC. 2904. DATA COLLECTION AND REPORTING.**

9       “Each eligible State agency awarded a grant or coop-  
10   erative agreement under section 2902 shall collect, main-  
11   tain, and report such data and records at such times, in  
12   such form, and in such manner as the Secretary may re-  
13   quire to enable the Secretary—

14       “(1) to monitor State administration of pro-  
15   grams and activities funded pursuant to such grant  
16   or cooperative agreement; and

17       “(2) to evaluate, and to compare effectiveness  
18   on a State-by-State basis, of programs and activities  
19   funded pursuant to section 2902.”.

20       (b) FUNDING.—Section 2905 of the Public Health  
21   Service Act (42 U.S.C. 300ii–4) is amended by striking  
22   paragraphs (1) through (5) and inserting the following:

23       “(1) \$20,000,000 for fiscal year 2020;

24       “(2) \$30,000,000 for fiscal year 2021;

25       “(3) \$40,000,000 for fiscal year 2022;

1 “(4) \$50,000,000 for fiscal year 2023; and

2 “(5) \$60,000,000 for fiscal year 2024.”.

○

116TH CONGRESS  
1ST SESSION

# H. R. 2507

To amend the Public Health Service Act to reauthorize certain programs under part A of title XI of such Act relating to genetic diseases, and for other purposes.

---

## IN THE HOUSE OF REPRESENTATIVES

MAY 2, 2019

Ms. ROYBAL-ALLARD (for herself, Mr. SIMPSON, Ms. CLARK of Massachusetts, and Ms. HERRERA BEUTLER) introduced the following bill; which was referred to the Committee on Energy and Commerce

---

## A BILL

To amend the Public Health Service Act to reauthorize certain programs under part A of title XI of such Act relating to genetic diseases, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*  
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Newborn Screening  
5 Saves Lives Reauthorization Act of 2019”.

6 **SEC. 2. IMPROVED NEWBORN AND CHILD SCREENING AND**  
7 **FOLLOW-UP FOR HERITABLE DISORDERS.**

8 Section 1109(a)(3) of the Public Health Service Act  
9 (42 U.S.C. 300b–8(a)(3)) is amended to read as follows:

1           “(3) to develop and deliver educational pro-  
2       grams (at appropriate literacy levels) about newborn  
3       screening counseling, testing, follow-up, treatment,  
4       specialty services, and long-term care to parents,  
5       families, and patient advocacy and support groups  
6       that assess the target audience’s current knowledge,  
7       incorporate health communications strategies, and  
8       measure impact;”.

9   **SEC. 3. ADVISORY COMMITTEE ON HERITABLE DISORDERS**  
10           **IN NEWBORNS AND CHILDREN.**

11       Section 1111 of the Public Health Service Act (42  
12   U.S.C. 300b–10) is amended—

13           (1) in subsection (b)—

14               (A) in paragraph (7) by striking “and” at  
15       the end;

16               (B) by redesignating paragraph (8) as  
17       paragraph (9); and

18               (C) by inserting after paragraph (7) the  
19       following:

20           “(8) develop, maintain, and publish on a pub-  
21       licly accessible website consumer-friendly materials  
22       detailing—

23               “(A) the uniform screening panel nomina-  
24       tion process, including data requirements,

1 standards, and the use of international data in  
2 nomination submissions; and

3 “(B) the process for obtaining technical as-  
4 sistance for submitting nominations to the uni-  
5 form screening panel and detailing the in-  
6 stances in which the provision of technical as-  
7 sistance would introduce a conflict of interest  
8 for members of the Advisory Committee; and”;  
9 and

10 (2) in subsection (g)—

11 (A) in paragraph (1) by striking “2019”  
12 and inserting “2024”; and

13 (B) in paragraph (2) by striking “2019”  
14 and inserting “2024”.

15 **SEC. 4. CLEARINGHOUSE OF NEWBORN SCREENING INFOR-**  
16 **MATION.**

17 Section 1112(c) of the Public Health Service Act (42  
18 U.S.C. 300b–11(c)) is amended by striking “and supple-  
19 ment, not supplant, existing information sharing efforts”  
20 and inserting “and complement other Federal newborn  
21 screening information sharing activities”.

22 **SEC. 5. LABORATORY QUALITY AND SURVEILLANCE.**

23 Section 1113 of the Public Health Service Act (42  
24 U.S.C. 300b–12) is amended—

25 (1) in subsection (a)—

1 (A) in paragraph (1)—

2 (i) by striking “performance evalua-  
3 tion services,” and inserting “development  
4 of new screening tests,”; and

5 (ii) by striking “and” at the end;

6 (B) in paragraph (2)—

7 (i) by striking “performance test ma-  
8 terials” and inserting “test performance  
9 materials”; and

10 (ii) by striking the period at the end  
11 and inserting “; and”; and

12 (C) by adding at the end the following:

13 “(3) performance evaluation services to enhance  
14 disease detection, including the development of tools,  
15 resources, and infrastructure to improve data anal-  
16 ysis, test result interpretation, data harmonization,  
17 and dissemination of laboratory best practices.”; and

18 (2) in subsection (b) to read as follows:

19 “(b) SURVEILLANCE ACTIVITIES.—The Secretary,  
20 acting through the Director of the Centers for Disease  
21 Control and Prevention, and taking into consideration the  
22 expertise of the Advisory Committee on Heritable Dis-  
23 orders in Newborns and Children established under sec-  
24 tion 1111, shall provide for the coordination of national  
25 surveillance activities, including—

1 “(1) standardizing data collection and reporting  
2 through the use of electronic and other forms of  
3 health records to achieve real-time data for tracking  
4 and monitoring the newborn screening system, from  
5 the initial positive screen through diagnosis and  
6 long-term care management; and

7 “(2) by promoting data sharing linkages be-  
8 tween State newborn screening programs and State-  
9 based birth defects and developmental disabilities  
10 surveillance programs to help families connect with  
11 services to assist in evaluating long-term outcomes.”.

12 **SEC. 6. HUNTER KELLY RESEARCH PROGRAM.**

13 Section 1116 of the Public Health Service Act (42  
14 U.S.C. 300b–15) is amended—

15 (1) in subsection (a)(1)—

16 (A) by striking “may” and inserting  
17 “shall”; and

18 (B) in subparagraph (D)—

19 (i) by inserting “, or with a high prob-  
20 ability of being recommended by,” after  
21 “recommended by”; and

22 (ii) by striking “that screenings are  
23 ready for nationwide implementation” and  
24 inserting “that reliable newborn screening

1 technologies are evaluated and ready for  
2 use”; and

3 (2) in subsection (b) to read as follows:

4 “(b) FUNDING.—In carrying out the research pro-  
5 gram under this section, the Secretary and the Director—

6 “(1) shall ensure that entities receiving funding  
7 through the program will provide assurances, as  
8 practicable, that such entities will work in consulta-  
9 tion with the appropriate State departments of  
10 health; and

11 “(2) may accept, use, and dispose of donations  
12 and bequests from private for-profit and non-profit  
13 entities, in accordance with Federal law.”.

14 **SEC. 7. AUTHORIZATION OF APPROPRIATIONS FOR NEW-**  
15 **BORN SCREENING PROGRAMS AND ACTIVI-**  
16 **TIES.**

17 Section 1117 of the Public Health Service Act (42  
18 U.S.C. 300b–16) is amended—

19 (1) in paragraph (1)—

20 (A) by striking “\$11,900,000” and insert-  
21 ing “\$31,000,000”;

22 (B) by striking “2015” and inserting  
23 “2020”; and

24 (C) by striking “2019” and inserting  
25 “2024”; and



1 (2) in paragraph (2)—

2 (A) by striking “\$8,000,000” and inserting  
3 “\$29,650,000”;

4 (B) by striking “2015” and inserting  
5 “2020”; and

6 (C) by striking “2019” and inserting  
7 “2024”.

8 **SEC. 8. INSTITUTIONAL REVIEW BOARDS; ETHICS GUID-**  
9 **ANCE PROGRAM.**

10 Section 12 of the Newborn Screening Saves Lives Re-  
11 authorization Act of 2014 (42 U.S.C. 289 note) is amend-  
12 ed to read as follows:

13 **“SEC. 12. INSTITUTIONAL REVIEW BOARDS; ETHICS GUID-**  
14 **ANCE PROGRAM.**

15 “Research on nonidentified newborn dried blood spots  
16 shall be considered secondary research (as that term is  
17 defined in part 4 of section 46.104 of title 45, Code of  
18 Federal Regulations) with nonidentified biospecimens for  
19 purposes of federally funded research conducted pursuant  
20 to the Public Health Service Act (42 U.S.C. 200 et seq.).”.

21 **SEC. 9. NAM REPORT ON THE MODERNIZATION OF NEW-**  
22 **BORN SCREENING.**

23 (a) STUDY.—Not later than 60 days after the date  
24 of the enactment of this Act, the Secretary of Health and  
25 Human Services shall seek to enter into an agreement

1 with the National Academy of Medicine (in this section  
2 referred to as “NAM”) (or if NAM declines to enter into  
3 such an agreement, another appropriate entity) under  
4 which NAM, or such other appropriate entity, agrees to  
5 conduct a study on the following:

6           (1) The uniform screening panel review and  
7           recommendation processes to identify factors that  
8           impact decisions to add new conditions to the uni-  
9           form screening panel, to describe challenges posed  
10          by newly nominated conditions, including low-inci-  
11          dence diseases, late onset variants, and new treat-  
12          ments without long-term efficacy data.

13          (2) The barriers that preclude States from add-  
14          ing new uniform screening panel conditions to their  
15          State screening panels with recommendations on re-  
16          sources needed to help States implement uniform  
17          screening panel recommendations.

18          (3) The current state of federally and privately  
19          funded newborn screening research with rec-  
20          ommendations for optimizing the capacity of this re-  
21          search, including piloting multiple prospective condi-  
22          tions at once and addressing rare disease questions.

23          (4) New and emerging technologies that would  
24          permit screening for new categories of disorders, or

1 would make current screening more effective, more  
2 efficient, or less expensive.

3 (5) Technological and other infrastructure  
4 needs to improve timeliness of diagnosis and short-  
5 and long-term follow-up for infants identified  
6 through newborn screening and improve public  
7 health surveillance.

8 (6) Current and future communication and edu-  
9 cational needs for priority stakeholders and the pub-  
10 lic to promote understanding and knowledge of a  
11 modernized newborn screening system with an em-  
12 phasis on evolving communication channels and mes-  
13 saging.

14 (7) The extent to which newborn screening  
15 yields better data on the disease prevalence for  
16 screened conditions and improves long-term out-  
17 comes for those identified through newborn screen-  
18 ing, including existing systems supporting such data  
19 collection and recommendations for systems that  
20 would allow for improved data collection.

21 (b) REPORT.—Not later than 18 months after the ef-  
22 fective date of the agreement under subsection (a), such  
23 agreement shall require NAM, or such other appropriate  
24 entity, to submit to the Secretary of Health and Human

1 Services and the appropriate committees of jurisdiction of  
2 Congress a report containing—

3           (1) the results of the study conducted under  
4       subsection (a);

5           (2) recommendations to modernize the proc-  
6       esses described in subsection (a)(1); and

7           (3) recommendations for such legislative and  
8       administrative action as NAM, or such other appro-  
9       priate entity, determines appropriate.

10       (c) AUTHORIZATION OF APPROPRIATIONS.—There is  
11   authorized to be appropriated \$2,000,000 for the period  
12   of fiscal years 2020 and 2021 to carry out this section.

○



June 25, 2019

The Honorable Frank Pallone  
Chairman, House Committee on Energy and  
Commerce  
2125 Rayburn House Office Building  
Washington, DC 20515

The Honorable Anna Eshoo  
Chairwoman, Subcommittee on Health  
House Committee on Energy and Commerce  
202 Cannon House Office Building  
Washington, DC 20515

The Honorable Greg Walden  
Ranking Member, House Committee on Energy  
and Commerce  
2322 Rayburn House Office Building  
Washington, DC 20515

The Honorable Michael Burgess  
Ranking Member, Subcommittee on Health  
Subcommittee on Health  
House Committee on Energy and Commerce  
2161 Rayburn House Office Building  
Washington, DC 20515

Dear Chairman Pallone, Ranking Member Walden, Chairwoman Eshoo, and Ranking Member Burgess:

Thank you for holding this important hearing today and for your support of individuals with autism and their families. Autism Speaks strongly supports the Autism Collaboration, Accountability, Research, Education, and Support Act of 2019 (Autism CARES Act of 2019). We are grateful for your commitment to moving this bill towards passage in the Committee, House of Representatives and, ultimately, into law. Today's hearing is a vital step forward in that process.

As you know, the Autism Collaboration, Accountability, Research, Education, and Support Act of 2014 (Autism CARES Act of 2014) is the primary authority for funding autism research, services, training, and monitoring. Unless action is taken, parts of the Autism CARES Act of 2014 will expire on September 30, 2019. The Autism CARES Act of 2019 would continue programs authorized under the Autism CARES Act of 2014, ensuring sustained funding to better support people with autism across the spectrum and at every stage of life.

Under the authority of the Autism CARES Act of 2014 and predecessor legislation, over \$3.1 billion have been dedicated to the National Institutes of Health (NIH), Centers for Disease Control and Prevention (CDC) and Health Resources and Services Administration (HRSA). This funding has supported autism research grants awarded by NIH, prevalence monitoring by the CDC, training of healthcare professionals, as well as efforts to develop treatments for medical conditions often associated with autism.

Autism CARES authorizes funding at NIH for programs and research across the country that advance the understanding of autism and address the needs of people affected by it. Through research, the age at which autism can be reliably diagnosed has gone down from 3 years to between 18 and 24 months. Advances in behavioral and biomarker research may make it possible within the next decade to diagnose autism before 15 months. NIH Autism Centers of Excellence grants foster collaboration within and among research centers and increase the power and efficiency of their research.



Autism CARES authorizes critical funding for HRSA programs that benefit individuals with autism and their families. Collaborative programs under the Autism Intervention Research Network on Physical Health (AIR-P) help translate research into improved care and tangible resources for families and clinicians. The 52 Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND) sites and 12 Developmental Behavioral Pediatric Training Programs help to prepare future leaders and professionals to deliver high-quality care and services for the autism and developmental disability communities.

Autism CARES has enabled the CDC to advance our understanding of the prevalence of autism. About 1 in 59 children were identified with autism among a 2014 sample of 8-year-olds. The data, which showed that prevalence varies by geographic region, by sex, and by race and ethnicity, can help inform efforts to improve identification and close gaps where there are disparities.

Autism CARES authorizes the Interagency Autism Coordinating Committee (IACC), a federal advisory committee composed of government officials and public stakeholders, which serves as a public square on issues of importance to the autism community. The IACC provides advice and recommendations to the Secretary of Health and Human Services on issues related to autism and annually updates the strategic plan for autism spectrum disorder research.

The Autism CARES Act of 2014 mandated a report to Congress on young adults with autism and the challenges they face in transitioning to adulthood. Continuing the focus on the needs of individuals with autism across the life span, the Autism CARES Act of 2019 would mandate a report to Congress on the health and well-being of individuals with autism.

Thank you for supporting and advancing the Autism CARES Act of 2019. By building on the advances that have already been made in science and services with a heightened focus on life span research and disparities, the Autism CARES Act of 2019 is essential legislation for the autism community. Thank you again for holding this hearing and for your support. We look forward to working with you to get the bill signed into law.

Sincerely,

A handwritten signature in black ink, appearing to read "Angela Geiger".

Angela Geiger  
President and CEO



4340 East West Highway, Suite 350  
Bethesda, MD 20814  
Phone: 301.657.0881  
Fax: 301.657.0869  
Email: [info@autism-society.org](mailto:info@autism-society.org)  
Web site: [www.autism-society.org](http://www.autism-society.org)

February 7, 2019

The Honorable Mike Enzi  
United States Senate  
Washington, DC 20510

The Honorable Mike Doyle  
U.S. House of Representatives  
Washington, DC 20515

The Honorable Bob Menendez  
United States Senate  
Washington, DC 20510

The Honorable Chris Smith  
U.S. House of Representatives  
Washington, D.C. 20515

Dear Senators Menendez and Enzi and Representatives Smith and Doyle,

The Autism Society of America is writing to thank you for your leadership introducing a bill to reauthorize and improve the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act. Since its enactment in 2006, this law has significantly increased research, public education, and training of professionals to assist individuals and families on the autism spectrum. While we celebrate these accomplishments, much more needs to be done to help individuals reach their full potential.

The bipartisan bill introduced on February 7 will reauthorize the law for five years (through 2024); further expand the mission to include individuals with autism and other developmental disabilities *across the lifespan*; expand the interagency autism coordinating committee (IACC) to include agencies that provide services and supports to individuals in the community; and authorizes a report to research ways to increase their health and well-being.

The Autism Society of America, the nation's largest and oldest grassroots organization representing people with autism across the lifespan, strongly supports this bill. Due to a sunset provision, the law must be reauthorized by September 30, 2019. We pledge our full support to move this bill quickly through Congress.

Thank you for all you continue to do on behalf of those with autism. Please contact the Autism Society of America ([kmusheno@autism-society.org](mailto:kmusheno@autism-society.org) or 800-328-8476) for more information and assistance.

Sincerely,

Executive Director and CEO  
Autism Society of America



February 6, 2019

The Honorable Mike Doyle  
United States House of Representatives  
Washington, DC 20501

Dear Congressman Mike Doyle,

On behalf of the Association of University Centers on Disabilities (AUCD), this letter is to thank you for your outstanding work and leadership on behalf of individuals with autism spectrum disorders and related developmental disabilities. AUCD strongly supports your bipartisan bill, the Autism Collaboration, Accountability, Research, Education, and Support Act of 2019, which will prevent the sunset or expiration in September of this year of Autism CARES.

The prevalence of autism is growing. According to the Centers for Disease Control and Prevention Autism and Developmental Disabilities Monitoring (ADDMM) Network, autism now affects one in every 59 children. The Autism CARES Act has shown significant progress in increasing the capacity of professionals to screen, diagnose, treat and support individuals with Autism Spectrum Disorders (ASD). However, substantial gaps still remain, which is why it is so critical to reauthorize the Autism CARES Act and sustain the momentum of the work that has begun under this law.

The membership of AUCD includes a national network – serving every state and territory – of 67 University Centers for Excellence (UCEDD), 52 Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs, and 14 Intellectual and Developmental Disabilities Research Centers (IDDRC). Together, these programs provide a direct national impact through direct services, the development of new professionals, and the use of new knowledge generated from our research.

Again, AUCD applauds your commitment to individuals with autism and other developmental disabilities and will do all that we can to help to move this legislation quickly through Congress to continue these vital activities.

Sincerely,

Andrew Imparato  
Executive Director

Amy Hewitt  
President

1100 Wayne Avenue, Suite 1000  
Silver Spring, MD 20910  
t: 301-588-8252  
www.aucd.org

Amy Hewitt, PhD, MSW  
President

Sachin Pavithran, PhD  
President-Elect

Bruce L. Keisling, PhD  
Past-President

Carol Salas Pagan, PsyD  
Secretary

Stephan Viehweg, MSW  
Treasurer

Jack M. Brandt, MS  
Council on Leadership and Advocacy

Angela Martin, LMSW  
Council on Leadership and Advocacy

Ronda Jensen, PhD  
Council on Research and Evaluation

Jacy Farkas, MA  
Multicultural Council

Derrick Willis, MPA  
Multicultural Council

Megan Orsag, PhD  
Community Education and  
Dissemination Council

Eileen McGrath, PhD  
National Training Directors Council

Daniel Armstrong, PhD  
Member at Large

Maria Mercedes Avila, PhD  
Member at Large

Tawara Goode, MA  
Member at Large

Scott Pomeroy, MD, PhD  
Member at Large

Marc J. Tassé, PhD  
Member at Large

Sheida Raley, MEd  
Trainee Representative

Andrew J. Imparato, JD  
Executive Director





**Testimony for the Record**

On Behalf of the American Academy of Pediatrics

**Before the U.S. House of Representatives**

Health Subcommittee of the Committee on Energy and Commerce

**"Reauthorizing Vital Health Programs for American Families"**

**June 25, 2019**



February 11, 2019

Sen. Lamar Alexander, Chairman  
Committee on Health, Education, Labor and Pensions  
428 Senate Dirksen Office Building  
Washington, DC 20510

Sen. Patty Murray, Ranking Member  
Committee on Health, Education, Labor and Pensions  
428 Senate Dirksen Office Building  
Washington, DC 20510

Rep. Frank Pallone, Chairman  
Committee on Energy and Commerce  
2125 Rayburn House Office Building  
Washington, DC 20515

Rep. Fred Upton, Ranking Member  
2322 Rayburn House Office Building  
Washington, D.C. 20515

Re: National Association of Councils on Developmental Disabilities (NACDD) Support for Autism CARES Act 2019.

Dear Senators Alexander and Murray and Congressmen Pallone and Upton:

On behalf of the National Association of Councils on Developmental Disabilities (NACDD), I write to express strong support for the recently introduced legislation which would reauthorize the Autism Collaboration, Accountability, Research, Education and Support Act of 2019 (Autism CARES Act). Congress must reauthorize this legislation prior to the sunset or expiration date of September 2019 to prevent endangering critical research and programs necessary to address the needs of individuals with Autism Spectrum Disorder (ASD) and other developmental disabilities.

The Autism CARES Act expands research and coordination, increases public awareness and surveillance, and facilitates interdisciplinary health professional training to identify and support individuals with ASD and their families. NACDD is grateful that Autism CARES Act of 2019 maintains support for interdisciplinary diagnostic services for hundreds of thousands of children, training for tens of thousands of graduate students, and important research being conducted around the nation via Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs.

The Autism CARES Act of 2019 introduced by Sen. Robert Menendez (SB 427) and Rep. Christopher Smith (HR 1058) were referred to your respective committees. SB 427 and HR 1058 build upon the current law by maintaining investment in research, early detection, and development of new treatments and therapies for those with ASD while adding language to address the needs of individuals well into adulthood and across their lifetime. We feel strongly that these provisions must be maintained and, if possible, strengthened in the committee process.

We urge you to bring this legislation to your committees for consideration as soon as possible and press for a final vote on these bills in time to reauthorize and expand existing programs before the statutory sunset or expiration date.

Sincerely,

Erin M. Prangle  
Director, Public Policy  
National Association of Councils on Developmental Disabilities

cc: Sen. Robert Menendez and Rep. Christopher Smith

(202) 506-5813 | WWW.NACDD.ORG  
1825 K STREET NW, SUITE 600, WASHINGTON, DC 20006



PO Box 26853  
San Jose, CA 95159

info@ncsautism.org  
[ncsautism.org](http://ncsautism.org)

February 14, 2019

Senator Bob Menendez  
528 Hart Senate Office Building  
Washington, DC 20510

Representative Chris Smith  
2373 Rayburn House Office Building  
Washington, DC 20515

Senator Mike Enzi  
379A Russell Senate Office Building  
Washington, DC 20510

Representative Mike Doyle  
306 Cannon House Office Building  
Washington, DC 20515

**Re: NCSA support for the reauthorization of The Autism Collaboration, Accountability, Research, Education, and Support ("CARES") Act**

Dear Senators Menendez and Enzi and Representatives Smith and Doyle:

The National Council on Severe Autism (NCSA) joins Autism Speaks and Autism Society of America in supporting the reauthorization of The Autism Collaboration, Accountability, Research, Education, and Support Act of 2019 ("Act"), which has been introduced in the Senate as S 427 and in the House of Representatives as H.R. 1058. The Act would continue the activities authorized under the Autism CARES Act of 2014, placing a new emphasis on improving lifespan services and reducing disparities.

Over the past 30 years, our country has experienced a staggering, if inexplicable, increase in serious neurodevelopmental disorders that fall under the umbrella of autism. Based on California developmental services data, the **population of adults with developmental disability-type autism will nearly quintuple over the next 20 years. And our country is woefully unprepared to meet their needs.** Though we may wish otherwise, we cannot alter the fact that these individuals will have limited means to care for themselves or earn a living, and will depend in large part on public programs for long-term supports and services.

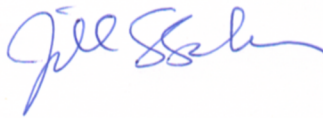
The Act will serve as a precursor to needed system reform to properly and humanely address the needs of this unprecedented population of disabled adults with severe cognitive and functional limitations. It is our hope that the groundwork laid by CARES research and reporting on lifespan needs **will help enable the crafting of legislation to open the floodgates to the wide array of programs, services and residential options that will be needed for many decades to come to support this vulnerable population.**

The steep increase in autism, now affecting nearly 2% of our children, represents **one of our country's greatest public health and social services challenges**. We thank you for your continued attention to America's escalating autism crisis. It is urgent that, now 30 years into this crisis we finally identify causes of autism, find therapeutics to improve the well-being of individuals disabled by autism, and provide adequate long-term supports for those too disabled to care for themselves. This is why we strongly support your legislation.

NCSA represents the needs of growing population of individuals with autism and related disorders who cannot speak for themselves, and their families and caregivers. We support your efforts to address the needs of this community and hope that as new policy takes shape that we can be included in background discussions, to ensure the voiceless have a voice in the issues that affect them most deeply.

We thank you for your support of CARES and look forward to working with you on system reforms that respond to the growing and acute community needs.

Very truly yours,

A handwritten signature in blue ink, appearing to read "Jill Escher", with a stylized, flowing script.

Jill Escher  
President



April 18, 2019

**OFFICERS**

The Hon. Michael N. Castle, Chair  
 The Hon. John Edward Porter, Chair Emeritus  
 The Hon. Kweisi Mfume, Vice Chair  
 Mary Woolley, President  
 E. Albert Reece, MD, PhD, MBA, Secretary  
 Sudip S. Parikh, PhD, Treasurer

**BOARD MEMBERS**

Tenley E. Albright, MD  
 Georges C. Benjamin, MD  
 Nancy Brown  
 Susan Dentzer  
 Victor J. Dzau, MD  
 Suzan Fitzpatrick, PhD  
 Jay A. Gershen, DDS, PhD  
 The Hon. Bart Gordon  
 William N. Halt, MD, PhD  
 Larry Hausner, MBA  
 Mary J.C. Hendrix, PhD  
 Martha N. Hill, PhD, RN  
 Rush D. Holt, PhD  
 Elizabeth Baker Keffer  
 Debra R. Lappin, JD  
 Alan L. Loebner, PhD  
 James L. Madara, MD  
 Lucinda Maine, PhD, RPh  
 Mark McClellan, MD, PhD  
 Herbert Pardes, MD  
 Harold L. Paz, MD, MS  
 Guillermo Prado, PhD  
 Amy Comstock Rick, JD  
 Laing Rogers  
 Larry J. Shapiro, MD  
 Laing Rogers Sisto  
 Gregory Sorenson, MD  
 Jack T. Watters, MD  
 Keith R. Yamamoto, PhD  
 Elias A. Zerhouni, MD

241 18th Street South  
 Suite 501  
 Arlington, VA 22202

P 703.739.2577

F 703.739.2372

E [info@researchamerica.org](mailto:info@researchamerica.org)

The Honorable Lamar Alexander  
 Chair  
 Committee on Health, Education,  
 Labor and Pensions  
 Washington, DC 20510

The Honorable Frank Pallone  
 Chair  
 Committee on Energy & Commerce  
 Washington, DC 20515

The Honorable Patty Murray  
 Ranking Member  
 Committee on Health, Education,  
 Labor and Pensions  
 Washington, DC 20510

The Honorable Greg Walden  
 Ranking Member  
 Committee on Energy & Commerce  
 Washington, DC 20515

Dear Chair Alexander, Ranking Member Murray, Chair Pallone and Ranking Member Walden:

On behalf of Research!America, the nation's largest not-for-profit advocacy and public education alliance working to promote faster medical and public health progress, we are writing to ask that you consider The Autism Collaboration, Accountability, Research, Education, and Support Act of 2019 (Autism CARES Act of 2019), which has been introduced in the Senate as S. 427 and in the House of Representatives as H.R. 1058.

The Autism CARES Act of 2019 would continue the activities authorized under the Autism CARES Act of 2014, while placing new emphasis on lifespan services and reducing disparities. Since its passing, the Autism CARES Act of 2014 has advanced research in and our understanding of autism, supported training programs to improve the health of children living with neurodevelopmental and other related disabilities, and empowered fellows in developmental-behavioral pediatrics with essential skills.

The Autism CARES Act of 2019 is also designed to address the challenges individuals living with autism face when transitioning from school-based to adult services and ensure issues of importance to the community are reflected in strategic research plans. This focus is emblematic of the evolving nature of research and the need to respond to new challenges that can have a significant impact on the health and wellbeing of those living with autism.

We hope that Congress and the White House treat the Autism CARES Act of 2019, emblematic of the value research and research-based advances delivers, with

the priority merited by need and beneficial impact. Thank you for your consideration, and please accept our gratitude for your hard work and that of your respective staff members.

Sincerely,

A handwritten signature in cursive script, appearing to read "Mary Woolley".

Mary Woolley  
President and CEO



June 24, 2019

The Honorable Frank Pallone, Chairman  
Committee on Energy & Commerce  
U.S. House of Representatives  
Washington, D.C. 20515

The Honorable Greg Walden, Ranking Member  
Committee on Energy & Commerce  
U.S. House of Representatives  
Washington, D.C. 20515

Dear Chairman Pallone and Ranking Member Walden:

On behalf of the 25 to 30 million Americans with one of the over 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) writes to express support for the *Newborn Screening Saves Lives Reauthorization Act of 2019* (H.R. 2507).

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the over 270 organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

Started in the 1960s, newborn screening has proven to be one of the most successful public health programs. Each year, approximately four million babies are screened using blood from a heel prick. Of that four million, screening identifies over 12 thousand infants with a disorder that, left undiagnosed and untreated, could cause severe developmental disability or death.

While administered at the state level, newborn screening programs depend heavily on the Federal Government for support. With support from the Federal Government, states have been able to expand the number of conditions they screen for and do so in a responsible manner, meaning that, among other things, the tests are appropriately calibrated for the population in order to avoid a high rate of false positives or negatives and there are follow-up programs in place to ensure necessary care. State programs have come a long way, but, with fewer than five states screening for all recommended conditions, there is still considerable work to be done.

The *Newborn Screening Saves Lives Act of 2008* authorized the Centers for Disease Control and Prevention, the National Institutes of Health, and the Health Resources and Services Administration to implement critical programs that have helped fund improvements in training and follow-up, operated vital research programs to advance newborn screening, established laboratory quality standards, increased public awareness and education, and grown the list of recommended conditions for states to screen (the Recommended Uniform Screening Panel or RUSP). This legislation was reauthorized in 2014 and, in order for these agencies to continue their lifesaving work, it must be reauthorized again by the end of September 2019.

1779 MASSACHUSETTS AVENUE NW, SUITE 500, WASHINGTON, DC 20036  
T 202-588-5700 ■ F 202-588-5701 ■ [rarediseases.org](http://rarediseases.org) ■ [orphan@rarediseases.org](mailto:orphan@rarediseases.org)

NORD® and icon are registered trademarks of the National Organization for Rare Disorders. NORD is a registered 501(c)(3) charity organization.

In addition to reauthorizing the agencies' work, H.R. 2507 would make focused improvements, such as increasing the funding available to states to expand and refine their programs. The legislation would also better facilitate the ability of the National Institutes of Health to accept private funding within the Hunter Kelly program, a research program established by the *Newborn Screening Saves Lives Act*, with the goal of amplifying the program's ability to carry out pilot studies involving multiple stakeholders. Enhancing the capacity of the Hunter Kelly program in this manner will help alleviate the growing need for pilot studies, particularly within disease communities that do not have the resources to carry them out on their own.

H.R. 2507 would help save the lives of thousands of babies who might otherwise be gravely harmed by an untreated rare disease. NORD appreciates your efforts to advance this legislation, and we look forward to working with you to ensure its successful passage.

Sincerely,

/s/

Rachel Sher  
Vice President, Policy and Regulatory Affairs



June 24, 2019

The Honorable Lucille Roybal-Allard  
United States House of Representatives  
2083 Rayburn House Office Building  
Washington, DC 20515

The Honorable Michael Simpson  
United States House of Representatives  
2084 Rayburn House Office Building  
Washington, DC 20515

The Honorable Katherine Clark  
United States House of Representatives  
2448 Rayburn House Office Building  
Washington, DC 20515

The Honorable Jaime Herrera Beutler  
United States House of Representatives  
2352 Rayburn House Office Building  
Washington, DC 20515

Dear Reps. Roybal-Allard, Simpson, Clark and Herrera Beutler,

On behalf of the undersigned organizations committed to the success of our nation's newborn screening system, we thank you for your leadership in introducing the *Newborn Screening Saves Lives Reauthorization Act of 2019* and offer our endorsement of this important legislation.

For almost 60 years, newborn screening has been saving and improving the lives of children across the United States through early identification of diseases that cause permanent disability or death if not treated early. It is one of the most successful public health programs of our time, positively impacting hundreds of thousands of children and their families. The Federal Government plays a crucial role in supporting state newborn screening programs: investing in research to advance newborn screening science; providing states with funds and technical assistance to improve their newborn screening programs; facilitating the sharing of best practices among states; educating providers, patients, and the public about newborn screening; and maintaining a recommended list of conditions that states should include on their newborn screening panels. These activities were authorized in the original *Newborn Screening Saves Lives Act of 2008* (P.L. 110-204) and reauthorized in 2014. Since passage of the 2008 bill, states have made a number of improvements to their programs with assistance from federal programs, including increasing the number of conditions on newborn screening panels to align with federal recommendations and decreasing the time it takes for the providers and families of infants with conditions identified through newborn screening to be notified and for babies to receive follow-up care.

The *Newborn Screening Saves Lives Reauthorization Act of 2019* will ensure essential federal newborn screening programs at the Centers for Disease Control and Prevention, the National Institutes of Health, and the Health Resources and Services Administration continue for the next five years. It makes targeted improvements, including increasing funding for those activities, ensuring federal agencies have the flexibility to address emerging technologies and new conditions, and improving surveillance activities. The bill also commissions the National Academy of Medicine to issue a report on the modernization of newborn screening and make appropriate recommendations.

Our organizations thank you for introducing legislation to support and advance our nation's newborn screening system. We stand ready to help you in your efforts to quickly pass the *Newborn Screening Saves Lives Reauthorization Act of 2019*. For additional information, please contact Rebecca Abbott, Deputy Director of Federal Affairs for Public Health at March of Dimes (202.292.2750 or [rabbott@marchofdimes.org](mailto:rabbott@marchofdimes.org)).

Sincerely,

1,000 Days

Aidan Jack Seeger Foundation

American Academy of Allergy, Asthma & Immunology

American Academy of Pediatrics

American Association for Clinical Chemistry

American Association on Health and Disability

American College of Medical Genetics and Genomics

American Public Health Association

American Society of Hematology

Asian & Pacific Islander American Health Forum

Association of Maternal & Child Health Programs

Association of Public Health Laboratories

Association of University Centers on Disabilities

Caring America

Children's National Health System

Cystic Fibrosis Foundation

EveryLife Foundation for Rare Diseases

First Focus Campaign for Children

Hydrocephalus Association

Immune Deficiency Foundation

Lakeshore Foundation

March of Dimes

Mississippi Urban League

MLD Foundation

Muscular Dystrophy Association

National Association of County Health Officials

National Birth Defects Prevention Network

National Organization for Rare Disorders

Newborn Foundation

Parent Project Muscular Dystrophy (PPMD)

Pathways for Rare and Orphan Studies

Prevent Blindness



**Statement for the Record Submitted by**  
**Rahul Gupta, MD, MPH, MBA, FACP; Senior Vice President and Chief Medical and Health**  
**Officer; March of Dimes**  
**Hearing of the Health Subcommittee of the Committee on Energy and Commerce**  
**“Reauthorizing Vital Health Programs for American Families”**  
**Tuesday, June 25, 2019**

March of Dimes, a unique collaboration of scientists, clinicians, parents, members of the business community, and other volunteers representing every state, the District of Columbia and Puerto Rico, appreciates this opportunity to submit testimony for the record for the hearing, “Reauthorizing Vital Health Programs for American Families.” March of Dimes commends you for holding this hearing examining the vital role the federal government plays in supporting state newborn screening programs and the urgent need to renew those programs by passing the *Newborn Screening Saves Lives Reauthorization Act of 2019* (H.R. 2507).

Each day, thousands of newborns across the country will receive screening tests for medical conditions that, while not apparent at birth, have the potential to cause death or permanent disability if not treated early. For more than 12,000 families each year, newborn screening will be life-altering and, in many cases, life-saving.<sup>1</sup> Newborn screening allows babies with identified conditions to receive timely treatment allowing them to grow up healthy and thrive. Since newborn screening began in the United States almost 60 years ago, it has saved or improved the lives of hundreds of thousands of infants.

In the United States, newborn screening is a collaboration between federal and state governments. Each state runs its own newborn screening program by determining which conditions to include on its panel of tests, collecting specimens, performing screening tests, and developing follow-up systems to identify and treat infants who screen positive for a disorder on the panel. The federal government supports state programs by providing technical assistance, facilitating collaboration across states, and allocating financial resources to implement screening for new disorders and improve the quality of programs, among other activities. The federal government also convenes the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC), which is responsible for making recommendations to the Secretary of Health and Human Services (HHS) on opportunities to improve the nation’s newborn screening system. These recommendations include which conditions should be on the federal Recommended Uniform Screening Panel (RUSP), a list of disorders the HHS Secretary recommends for states to screen as part of their newborn screening panels.

Federal programs and investments are essential to nation’s newborn screening systems. The **Centers for Disease Control and Prevention (CDC)** is the world’s expert on newborn screening laboratory technology, providing quality assurance materials and technical assistance to

laboratories responsible for newborn screening in the United States and around the world. CDC also develops laboratory tests for new conditions eligible for newborn screening and provides financial support to state laboratories to implement screening tests for new conditions. The **Health Resources and Services Administration (HRSA)** improves the overall newborn screening system by facilitating collaboration and sharing of best practices across states; supporting the development of educational tools that states can use for patients, providers, and other stakeholders; assisting states to implement new conditions to state screening panels, and addressing emerging issues. The **National Institutes of Health (NIH)** advances the field of newborn screening by researching new screening technologies and new treatments. NIH also funds pilot studies to gather the necessary data to determine if a condition is an appropriate candidate for state newborn screening panels.

Activities administered by CDC, HRSA and NIH are both vital to improving that nation's newborn screening system and would not be undertaken by states without federal support. That is why it is essential that Congress reauthorize these programs before they expire at the end of the fiscal year by passing the *Newborn Screening Saves Lives Reauthorization Act of 2019*. March of Dimes strongly supports H.R. 2507 and its important provisions, including:

- Reauthorization of HRSA grants to help states expand and improve their screening programs, educate parents and health care providers, and improve follow-up care for infants with a condition detected through newborn screening.
- Reauthorization of CDC's Newborn Screening Quality Assurance Program, the only comprehensive program devoted to ensuring the accuracy of newborn screening tests.
- Reauthorization of the NIH's Hunter Kelly Newborn Screening program, which funds research aimed at identifying new treatments for conditions that can be detected through newborn screening and developing new screening technologies.
- Reauthorization of the ACHDNC, which provides states with the RUSP to help ensure every infant is screened for conditions which have a known treatment.
- Directing the National Academy of Medicine to develop policy recommendations to modernize the nation's newborn screening system.

Newborn screening is one of the greatest public health successes of the 20th century. Advancing medical and laboratory technologies, new therapies, and accelerated rare disease research promise continued success in the 21st Century, but only if state newborn screening programs can keep pace with the rapidly changing landscape. That is why it is essential to maintain and expand federal programs that will help states modernize their newborn screening programs and continue to save infants lives in the years to come.

March of Dimes again thanks you for holding this important hearing and stands ready to help you in advancing the *Newborn Screening Saves Lives Reauthorization Act of 2019* before the end of the fiscal year.

---

<sup>1</sup> CDC. CDC Grand Rounds: Newborn screening and improved Outcomes. Morbidity and mortality weekly report 2012;61(21);390-393.

House Energy and Commerce Committee  
 Subcommittee on Health  
 Hearing on H.R. 2507, the Newborn Screening Saves Lives Act of 2019  
 Statement of Elisa Seeger  
 Executive Director, Aidan Jack Seeger Foundation  
 June 25, 2019

Chairwoman Eshoo, Ranking Member Burgess, Chairman Pallone, Ranking Member Walden, and Members of the Subcommittee, thank you for giving me the chance to provide testimony regarding H.R. 2507, the Newborn Screening Saves Lives Act. I currently serve as the Executive Director of the Aidan Jack Seeger Foundation, an organization that I founded following the death of my son Aidan from the disease adrenoleukodystrophy (ALD).

ALD is a demyelinating disease which leads to the loss of all neurological functioning. Due to a late diagnosis, Aidan had irreparable damage to his brain. Aidan received a bone marrow transplant and spent the last 10 months inpatient at Duke and NY. If Aidan would have been diagnosed at birth, he would be alive today. ALD does not present before the age of 4 – giving these boys the chance to be monitored and treated before the onset of symptoms.

In 2013, following the work of many people, including myself, New York State passed and the Governor signed “Aidan’s Law” to implement ALD newborn screening in that state. Testing began December 30, 2013, and in four years New York State identified 90 babies with disease, not counting siblings and other family members. ALD was added to the federal RUSP in 2016 but as of December 2018 only ten states had implemented ALD screening. Yes, over 250 babies have been diagnosed, not counting siblings and other family members, but think of how many babies could have been saved if a quarter, or half, or all 50 states had implemented the screening. Today, only 13 of the 50 states have implemented routine screening for ALD, with two states undertaking limited pilot projects.

I have fought for newborn screening for five years, along with many others in the patient community, but the current system where states have issues implementing newborn screening for RUSP approved conditions, primarily due to funding – one that has caused needless deaths and disability. It is unacceptable, and I ask that the Committee find a solution to this situation where a child born in one zip code lives and a child born in a different zip code dies. This should not happen in America.

Consider the case of Jalen. Even though they live in New Jersey, Anthony and Kelly had their second son born in New York State because of Kelly’s job. Jalen, age 6, was only diagnosed because his brother Kylar, age 2, was born in New York in 2018. Right after Kylar’s diagnosis, his brother Jalen was tested and also tested positive for ALD. Jalen has been monitored for the last 2 years and recently there were changes to his MRI. Jalen is now undergoing lifesaving treatment at the right time: the earliest stage of the disease. Their story could have been very different if Anthony and Kelly did not decide to have their second child in New York, as New Jersey is not testing for ALD.

I would urge the Committee to use this reauthorization to end “death by zip code” and establish a dedicated funding stream to give direct support to the States to implement newborn screening for all RUSP approved conditions. The reason is simple: the longer people dither, the more babies are lost unnecessarily. As I have spent the last several years speaking in states’ newborn screening committee

meetings, I realize the primary issue is the states do not have the funds necessary. Funds that are so minimal, just a few dollars per test, yet need to be fought for on the state level, in competition with every other need in that particular state, leading to the unnecessary passing of valuable time and lives lost. Imagine if we could cut down the time for all states to implement from 10 years to 5, saving countless lives and millions of dollars in healthcare costs caring for a child with disabilities which could have been prevented.

The current reauthorization calls for a study of the entire newborn screening system, the results of which this committee will not see for years. We need not wait. I know from my conversations that Congress is reluctant to mandate states to follow the RUSP. If that is the case, the very least Congress can do is agree that it does no good to praise or blame states for where they are at, but simply provide resources to them so we know, as a country, that all states are implementing newborn screening for those conditions that have already met the evidence review standard of the RUSP. If we have the political will to end "death by zip code," we will save at least 1,000 lives which are lost to the current gaps in the system.

I am thankful to Congresswoman Clarke and Congressman Zeldin for their leadership on newborn screening, as well as Congresswoman Roybal-Allard and Congressman Simpson, and look forward to working with the Committee to make this important policy change in America.



601 E Street, NW | Washington, DC 20049  
 202-434-2277 | 1-888-OUR-AARP | 1-888-687-2277 | TTY: 1-877-434-7598  
[www.aarp.org](http://www.aarp.org) | [@aarp](https://twitter.com/aarp) | [facebook.com/aarp](https://facebook.com/aarp) | [youtube.com/aarp](https://youtube.com/aarp)

June 25, 2019

The Honorable Anna G. Eshoo  
 Chairwoman  
 House Committee on Energy and  
 Commerce  
 Health Subcommittee  
 2125 Rayburn House Office Building  
 Washington, DC 20515

The Honorable Michael C. Burgess, M.D.  
 Ranking Member  
 House Committee on Energy and  
 Commerce  
 Health Subcommittee  
 2125 Rayburn House Office Building  
 Washington, DC 20515

Dear Chairwoman Eshoo and Ranking Member Burgess:

AARP, on behalf of our nearly 38 million members and all older Americans nationwide, thanks you for holding a hearing on the bipartisan Lifespan Respite Care Reauthorization Act (H.R. 2035). AARP has endorsed this legislation to help support family caregivers caring for loved ones of all ages.

Family caregivers help make it possible for older adults, veterans, and people with disabilities of all ages to live independently in their homes and communities. About 40 million family caregivers provide about \$470 billion in unpaid care annually. Most of us are, have been, or will be a family caregiver or we will need help to live independently. While many family caregivers find caregiving to be an enriching experience and a source of deep satisfaction, family caregivers also take on physical, emotional, and financial challenges in their caregiving roles. About 30 percent of family caregivers provide, on average, 62 hours of care weekly and some family caregivers provide care 24 hours a day, 7 days a week.

Respite care provides family caregivers with vital temporary relief from their caregiving responsibilities and is one of the most commonly requested caregiver support services. Respite care can allow a family caregiver much needed time to go see their own doctor, run errands, go to work, and take care of themselves (ultimately helping them to better assist their loved one). The Lifespan Respite Care Program helps family caregivers caring for loved ones regardless of age or disability, including by providing respite services, training respite workers and volunteers, providing information about and assistance in accessing services, and better coordinating services. Respite can extend the time an individual is cared for at home, potentially delaying costly institutional care.

Alabama | Alaska | Arizona | Arkansas | California | Colorado | Connecticut | Delaware | District of Columbia | Florida | Georgia | Hawaii | Idaho | Illinois | Indiana | Iowa | Kansas | Kentucky | Louisiana | Maine | Maryland | Massachusetts | Michigan | Minnesota | Mississippi | Missouri | Montana | Nebraska | Nevada | New Hampshire | New Jersey | New Mexico | New York | North Carolina | North Dakota | Ohio | Oklahoma | Oregon | Pennsylvania | Puerto Rico | Rhode Island | South Carolina | South Dakota | Tennessee | Texas | Utah | Vermont | Virgin Islands | Virginia | Washington | West Virginia | Wisconsin | Wyoming



and saving taxpayer dollars. The Lifespan Respite Care Reauthorization Act would reauthorize the Lifespan Respite Care Program through Fiscal Year 2024, authorize increased funding for the program, and add new reporting requirements.

We appreciate the Subcommittee on Health holding this hearing and look forward to working with Members on both sides of the aisle to advance this legislation to support our nation's family caregivers. If you have any further questions, please feel free to call me or have your staff contact Rhonda Richards of our Government Affairs staff at [rrichards@aarp.org](mailto:rrichards@aarp.org) or 202-434-3770.

Sincerely,

A handwritten signature in black ink, appearing to read "David Certner", with a stylized flourish at the end.

David Certner  
Legislative Counsel & Legislative Policy Director  
Government Affairs



June 24, 2019

The Honorable Anna G. Eshoo  
Chairman  
Energy and Commerce Committee  
Health Subcommittee  
United States House of Representatives  
Washington, DC 20515

The Honorable Michael C. Burgess  
Ranking Member  
Energy and Commerce Committee  
Health Subcommittee  
United States House of Representatives  
Washington, DC 20515

Re: Lifespan Respite Care Reauthorization Act of 2019 (H.R. 2035)

Dear Chairman Eshoo and Ranking Member Burgess,

Thank you for holding a hearing on "Reauthorizing Vital Health Programs for American Families" which includes the Lifespan Respite Care Reauthorization Act. We, the undersigned members of the Developmental Disabilities, Autism and Family Support Task Force of the Consortium for Citizens with Disabilities (CCD) are writing to express our strong support for the Lifespan Respite Care Reauthorization Act. CCD is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.

More than 65 million Americans provide care for a loved one who has a disability, is chronically ill, or is elderly and spend an average of 20 hours per week providing care. For caregivers of people with intellectual and developmental disabilities (I/DD), the levels of responsibility are not only greater, but frequently lifelong. There are approximately 3 million family caregivers of persons with I/DD in the U.S. According to The Arc's Family and Individual Needs for Disability Supports (FINDS) survey, the majority of these family caregivers provide more than 40 hours of care per week.

Respite services are desperately needed to help family members continue to provide this level of care in the community instead of more costly and unwanted institutions. Unfortunately, changing demographics are placing even greater demands on extremely limited respite services. The aging of the baby boom generation is resulting in an increasing number of people with I/DD living with aging caregivers who have greater need for respite to address their own physical and mental health care needs.

The grants provided under the Lifespan Respite Care Act give states resources they need to improve their system of respite care. These grants can be used to train respite care providers, implement marketing campaigns to inform families of available respite care options, or implement a respite voucher program, among other options. Furthermore, states are able to give priority to family caregivers who are caring for individuals with disabilities and chronic

820 First Street, NE Suite 740 • Washington, DC 20002 • PH 202-567-3516 • FAX 202-408-9520 •  
Info@c-c-d.org • www.c-c-d.org

illness of all ages who are not currently eligible for existing public programs, on Medicaid waiver waiting lists, or for whom finding qualified providers is especially difficult. This population includes individuals between the ages of 18-60; grandparents raising grandchildren; rural family caregivers; culturally diverse groups and others identified as having unmet needs.

Thank you for your leadership in supporting our Nation's caregivers and we look forward to working with you to help ensure the reauthorization of the Lifespan Respite Care Act.

Sincerely,

American Network of Community Options and Resources (ANCOR)  
American Therapeutic Recreation Association  
Autism Society  
Easterseals  
Family Voices  
National Association of Councils on Developmental Disabilities  
National Respite Coalition  
The Arc of the United States



June 21, 2019

The Honorable Chris Smith  
2373 Rayburn House Office Building  
Washington, DC 20515

The Honorable Michael Doyle  
306 Cannon House Office Building  
Washington, DC 20515

Dear Representative Smith and Representative Doyle:

On behalf of the American Speech-Language-Hearing Association, I write to express support for H.R. 1058, the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2019.

The American Speech-Language-Hearing Association (ASHA) is the national professional, scientific, and credentialing association for 204,000 individuals who are audiologists; speech-language pathologists; speech, language, and hearing scientists; audiology and speech-language pathology support personnel; and students. ASHA members work regularly with individuals with autism to address a wide range of communication disorders and comorbidities related to the condition.

Audiologists and speech-language pathologists (SLPs) play a central role in addressing the needs of individuals with autism. Research in audiology confirms that autism spectrum disorder (ASD) and hearing impairment can occur in the same individual.<sup>1,2,3</sup> The similarities in communication and socialization deficits between hearing impairment and ASD populations, along with the possibility of dual diagnosis, make early and differential diagnosis essential. Most newborns are screened and often diagnosed first for hearing loss, which may sometimes delay the separate diagnosis for ASD. SLPs contribute to the independence and productivity of individuals with ASD by ensuring effective functional communication systems or approaches (including Augmentative and Alternative Communication [(AAC)]) that allow them to attain and maintain maximum levels of functional communication.

ASHA applauds you for your steadfast leadership in this area and for working with the autism community in crafting this critical legislation. ASHA supports its passage to ensure the continuation of important autism research and coordination of initiatives. If you or your staff have any questions or if we can help you in your efforts to improve access to care for individuals with autism, please contact Jerry White, ASHA's director of federal affairs, health care, at [jwhite@asha.org](mailto:jwhite@asha.org).

Sincerely,

Shari B. Robertson, PhD, CCC-SLP  
2019 ASHA President

<sup>1</sup> Easterbrooks, S. R., & Handley, C. M. (2005). Behavior change in a student with a dual diagnosis of deafness and pervasive development disorder: A case study. *American Annals of the Deaf*, 150(5), 401–407.

<sup>2</sup> Malandraki, G. A., & Okalidou, A. (2007). The application of PECS in a deaf child with autism: A case study. *Focus on Autism and Other Developmental Disabilities*, 22(1), 23–32.

<sup>3</sup> Szymanski, C., & Brice, P. J. (2008). When autism and deafness coexist in children: What we know now. *Odyssey: New Directions in Deaf Education*, 9(1), 10–15.

June 25, 2019

Senator Bob Menendez  
528 Hart Senate Office Building  
Washington, DC 20510

Representative Chris Smith  
2373 Rayburn House Office Building  
Washington, DC 20515

Senator Mike Enzi  
379A Russell Senate Office Building  
Washington, DC 20510

Representative Mike Doyle  
306 Cannon House Office Building  
Washington, DC 20515

Dear Senators Menendez and Enzi and Representatives Smith and Doyle:

We are writing to express our support for The Autism Collaboration, Accountability, Research, Education, and Support Act of 2019 (Autism CARES Act of 2019), which has been introduced in the Senate as S. 427 and in the House of Representatives as H.R. 1058. The Autism CARES Act of 2019 would continue the activities authorized under the Autism CARES Act of 2014, placing a new emphasis on improving lifespan services and reducing disparities.

Under the authority of the Autism CARES Act of 2014 and predecessor legislation, more than \$3.1 billion has been dedicated to autism activities at the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), and the Health Resources and Services Administration (HRSA). Funding has supported NIH research, including center and network grants through the [Autism Centers of Excellence program](#); [developmental disabilities surveillance and research](#) at CDC; and [training, research, and state implementation and planning](#) at HRSA. The HRSA-supported programs include 52 [Leadership Education in Neurodevelopmental and Other Related Disabilities \(LEND\) training programs](#), which builds the capacity of providers across health and related disciplines to deliver high-quality services, as well as 12 [Developmental Behavioral Pediatrics training programs](#), which support fellows in developmental-behavioral pediatrics and provide practitioners, residents, and medical students with essential clinical, research, and other leadership skills.

The Autism CARES Act of 2019 continues the [Interagency Autism Coordinating Committee \(IACC\)](#), which coordinates federal efforts and provides advice to the Secretary of Health and Human Services on issues related to autism. The IACC's responsibilities include monitoring research, services, and supports across the federal government. Another important responsibility of the committee is developing a [strategic plan for the conduct and support of autism research](#). The [periodic meetings of the committee](#) are open to the public and serve as a forum on issues important to the community.

The Autism CARES Act of 2019 calls for the preparation of a report on the health and well-being of individuals with autism. This report would follow upon the [report prepared under the Autism CARES Act of 2014 on young adults and transitioning youth with autism](#), which highlighted the challenges young people with autism face in transitioning from school-based services to adult services.

We applaud your staff for listening to the autism community in crafting the Autism CARES Act of 2019. As you are aware, prompt congressional action on the Autism CARES Act of 2019 is essential, as parts of the Autism CARES Act of 2014 will sunset after September 30, 2019. We will work with your offices to pass the Autism CARES Act of 2019 and continue the vital programs that it supports.

Sincerely,

American Academy of Neurology  
 American Academy of Pediatrics  
 American Association on Health and Disability  
 American Psychological Association  
 American Speech-Language-Hearing Association  
 American Therapeutic Recreation Association  
 Association of Maternal & Child Health Programs  
 Association of Special Children and Families  
 Association of University Centers on Disability  
 Autism New Jersey  
 Autism Science Foundation  
 Autism Society of America  
 Autism Speaks  
 Children's Hospital Association  
 Council on Exceptional Children  
 Easterseals  
 EveryLife Foundation  
 Family Voices  
 Family Voices New Jersey  
 Family Voices North Dakota  
 Lakeshore Foundation  
 Madison House Autism Foundation  
 Maine Parent Federation  
 Marcus Autism Center  
 National Alliance on Mental Illness  
 National Association of Councils on Developmental Disabilities  
 National Association of Pediatric Nurse Practitioners  
 National Association of State Directors of Developmental Disabilities Services  
 National Center for Learning Disabilities  
 National Council on Severe Autism  
 National Down Syndrome Congress  
 National Down Syndrome Society  
 National Fragile X Foundation  
 Network of Jewish Human Service Agencies  
 SPAN Parent Advocacy Network  
 TASH  
 The Independence Center  
 The Jewish Federations of North America  
 Thompson Center for Autism & Neurodevelopmental Disorders

April 30, 2019

The Honorable Peter King  
U.S. House of Representatives  
339 Cannon House Office Building  
Washington DC, 20515

The Honorable Kathy Castor  
U.S. House of Representatives  
2022 Rayburn House Office Building  
Washington, DC 20515

The Honorable Chris Stewart  
U.S. House of Representatives  
323 Cannon House Office Building  
Washington DC, 20515

The Honorable G.K. Butterfield  
U.S. House of Representatives  
2080 Rayburn House Office Building  
Washington, DC 20515

Dear Representatives King, Castor, Stewart, and Butterfield:

As organizations that care deeply about the health and safety of children, we offer our strong support for H.R. 776, the *Emergency Medical Services for Children Program Reauthorization Act of 2019*. The EMSC program has made landmark improvements to the emergency care delivered to children all across the nation. As the only federal program dedicated to improving emergency care for children, EMSC has brought vital attention and resources to this important population.

Just this year, 30 million children will visit the emergency department, and emergencies involving children can occur anytime, anywhere. The EMSC program is designed to ensure that all children and adolescents – no matter where they live, attend school, or travel – receive appropriate care in a health emergency. Through EMSC, all states and territories have received state partnership grants to expand and improve their capacity to reduce and respond to emergencies. EMSC funding is used to ensure that hospitals and ambulances are properly equipped to treat pediatric emergencies, to provide pediatric training to paramedics and first responders, and to improve the systems that allow for efficient, effective pediatric emergency medical care.

EMSC has been successful in improving care for children. Emergency departments and pre-hospital EMS personnel have more appropriate medication, equipment, training, and systems in place to treat children. For example, doctors and nurses are better able to manage pediatric emergencies such as traumatic brain injuries, pediatric seizures, and bronchiolitis. The majority (90%) of EMS agencies in the US have consistent availability to online medical direction when treating a pediatric patient and 85% have off-line medical direction that includes protocols inclusive of pediatric patients. In the hospital setting, almost two thirds (67%) of hospitals have interfacility transfer agreements and 50% have interfacility transfer guidelines that incorporate recommended pediatric components. Looking ahead, EMSC aims to ensure all EDs are ready to care for children through the implementation of the National Pediatric Readiness Project, a national quality improvement initiative to ensure EDs have the essential guidelines and resources in place.

H.R. 776 would reauthorize the EMSC program to continue its vital work for an additional five years. We thank you for your leadership in authoring this critical legislation for children and appreciate your long-standing commitment to the quality of the emergency care children receive. We look forward to working with you in support of enactment of this legislation.

Sincerely,

Academic Pediatric Association  
 American Academy of Pediatrics  
 American Ambulance Association  
 American College of Emergency Physicians  
 American College of Surgeons  
 American Pediatric Society  
 American Pediatric Surgical Association  
 Association of Maternal & Child Health Programs  
 Association of Medical School Pediatric Department Chairs  
 Children's Health Fund  
 Children's Hospital Alliance of Tennessee  
 Children's Hospital Association  
 Children's Hospital Association of Texas  
 Children's Hospital at Erlanger  
 Children's Hospital of Philadelphia  
 Children's Hospital of Wisconsin  
 Children's Mercy Hospital, Kansas City  
 Cincinnati Children's Hospital Medical Center  
 Danny's Dose Alliance  
 East Tennessee Children's Hospital  
 Emergency Nurses Association  
 Family Voices  
 First Focus  
 International Trauma Life Support  
 Le Bonheur Children's Hospital  
 March of Dimes  
 Monroe Carell Jr. Children's Hospital at Vanderbilt  
 National Association of County and City Health Officials  
 National Association of Emergency Medical Technicians  
 National Association of EMS Physicians  
 National Association of Pediatric Nurse Practitioners  
 National Association of State Emergency Medical Services Officials  
 National EMS Management Association  
 Nemours Children's Health System  
 New Mexico Pediatric Society  
 Niswonger Children's Hospital  
 Norton Children's Hospital



Pediatric Policy Council  
Rhode Island Parent Information Network  
Seattle Children's  
Society for Pediatric Research  
The Paramedic Foundation  
University of New Mexico Health Sciences Center  
UPMC Children's Hospital of Pittsburgh  
Wisconsin Chapter of the American Academy of Pediatrics

## American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™



February 26, 2019

345 Park Blvd  
Itasca, IL 60143  
Phone: 630/928-8000  
Fax: 847/434-8000  
E-mail: kidsdocs@aap.org  
www.aap.org

The Honorable Chris Smith  
United States House of Representatives  
2373 Rayburn House Office Building  
Washington, DC 20515

The Honorable Mike Doyle  
United States House of Representatives  
306 Cannon House Office Building  
Washington, DC 20510

Dear Representatives Smith and Doyle:

**Executive Committee**

**President**  
Kyle E. Yasuda, MD, FAAP

**President-Elect**  
Sara H. Goza, MD, FAAP

**Immediate Past President**  
Colleen A. Kraft, MD, FAAP

**Secretary/Treasurer**  
Anthony D. Johnson, MD, FAAP

**CEO/Executive Vice President (interim)**  
Mark Del Monte, JD

**Board of Directors**

**District I**  
Wendy S. Davis, MD, FAAP  
Burlington, VT

**District II**  
Warren M. Selig, MD, FAAP  
Brooklyn, NY

**District III**  
Margaret C. Fisher, MD, FAAP  
Long Branch, NJ

**District IV**  
Jane M. Foy, MD, FAAP  
Winston-Salem, NC

**District V**  
Richard H. Tuck, MD, FAAP  
Zanesville, OH

**District VI**  
Dennis M. Cooley, MD, FAAP  
Topeka, KS

**District VII**  
Anthony D. Johnson, MD, FAAP  
Little Rock, AR

**District VIII**  
Martha C. Middemist, MD, FAAP  
Centennial, CO

**District IX**  
Yasuko Fukuda, MD, FAAP  
San Francisco, CA

**District X**  
Lisa A. Cosgrove, MD, FAAP  
Meritt Island, FL

On behalf of the American Academy of Pediatrics (AAP), an organization of 67,000 primary care pediatricians, pediatric medical sub-specialists, and pediatric surgical specialists dedicated to the health, safety, and well-being of infants, children, adolescents, and young adults, I write to express our strong support for H.R. 1058, the *Autism CARES Act of 2019*.

Autism Spectrum Disorder (ASD) is one of our nation's top health priorities and as the CDC recently reported, ASD now affects 1 in 59 children in the United States, with males more than four times as likely as females to be identified with ASD. Autism affects all ethnic and socioeconomic groups, but minority groups still tend to be diagnosed later and less often. It is imperative that we continue the important work being done as a result of the programs authorized by *Autism CARES Act* by enacting this reauthorization legislation by September 30, 2019.

Reauthorizing the *Autism CARES Act* is a needed step to advance research in early detection, intervention and understanding of autism spectrum disorders. Children with ASD have unique needs that don't stop when they become adults. The bill addresses this continuation of care by encouraging research and services across the lifespan, and by providing support for training more developmental behavioral pediatricians, with a particular focus on training providers in under-served areas.

The *Autism CARES Act of 2019* builds upon the previous versions of the legislation, last reauthorized in 2014, which have enhanced our country's understanding of ASD through expansion of research at the National Institutes of Health (NIH), increased surveillance, awareness, and outreach at the Centers for Disease Control and Prevention (CDC), and training of health care professionals through the Health Resources and Services Administration (HRSA), particularly its Leadership in Neurodevelopmental and Related Disabilities (LEND) and Developmental Behavioral Pediatrician (DBP) training programs.

We are pleased to support the *Autism CARES Act of 2019*, and we applaud your efforts and leadership by introducing this legislation. We thank you for your commitment to this important issue and we look forward to working with you and the rest of Congress to ensure the bill becomes law. Thank you for all you do for our nation's children.

Sincerely,

Kyle E. Yasuda, MD, FAAP  
President

KEY/pmj

Thank you for the opportunity to provide written testimony in support of H.R. 776, the Emergency Medical Services for Children (EMSC) Program Reauthorization Act of 2019 and to commend Representatives Peter King, Kathy Castor, G.K. Butterfield, and Chris Stewart for their bipartisan leadership on this legislation. The American Academy of Pediatrics (AAP) is a non-profit professional membership organization of 67,000 primary care pediatricians and medical and surgical pediatric subspecialists dedicated to health and well-being of all infants, children, adolescents, and young adults. Ensuring appropriate pediatric emergency medical care is a central component of this mission. Since it was signed into law in 1984, EMSC has supported pediatric specific emergency medical and trauma research as well as mobilized resources to provide the right care, in the right place, at the right time for every child. The AAP has been a leading champion of the EMSC program since its inception.

The EMSC program has made landmark improvements to the emergency care delivered to children all across the nation. As the only federal program dedicated to improving emergency care for children, EMSC has brought vital attention and resources to this important population. Just this year, 30 million children will visit the emergency department. The EMSC program is designed to ensure that all children and adolescents – no matter where they live, attend school, or travel – receive appropriate care in an emergency.

EMSC has been successful in improving care for children. Through EMSC, all states and territories have received state partnership grants to expand and improve their capacity to reduce and respond to emergencies. EMSC funding is used to ensure that hospitals and ambulances are properly equipped to treat pediatric emergencies, provide pediatric training to paramedics and first responders, and improve the systems that allow for efficient, effective pediatric emergency medical care. For example, doctors and nurses are better able to manage pediatric emergencies such as traumatic brain injuries, pediatric seizures, and bronchiolitis.

The majority (90%) of EMS agencies in the U.S. have consistent availability to online medical direction when treating a pediatric patient and 85% have off-line medical direction that includes protocols inclusive of pediatric patients. In the hospital setting, almost two thirds (67%) of hospitals have interfacility transfer agreements and 50% have interfacility transfer guidelines that incorporate recommended pediatric components. Looking ahead, EMSC aims to ensure all Emergency Departments are ready to care for children through the implementation of the National Pediatric Readiness Project, a national quality improvement initiative to ensure Emergency Departments have the essential guidelines and resources in place.

EMSC drives research through the Pediatric Emergency Care Applied Research Network (PECARN)--the first and only federally funded network for research in pediatric emergency medicine in the United States. Serving approximately 1.1 million pediatric patients, this network conducts rigorous institutional research into the prevention and management of acute illness and injuries in children across the continuum of emergency medicine health care. Since its inception in 2001, PECARN has had 36 research studies funded, published 126 peer-reviewed manuscripts and provided more than 170 national scientific presentations. PECARN has mentored more than 95 new investigators, increasing the number of future researchers trained in pediatric emergency medicine.

In addition, two clinical guidelines, based on the findings of PECARN studies are published (1) when it is appropriate to do computed tomography (CT) scans for children with minor head injuries (reducing unnecessary scans); and (2) the common use of steroids does not improve outcomes or reduce hospitalizations for infants with bronchiolitis. Recently, PECARN examined the impact of giving fluids intravenously to children with diabetic ketoacidosis (DKA), a clinical intervention that was often avoided for fear of causing brain injury. The study found that fluid hydration can be safe for children with DKA, allowing clinicians to administer the fluids on an individualized basis, which may prevent cognitive impairment and decrease the risk of other complications in these children.

EMSC promotes a continual process of quality improvement by funding the EMSC Innovation and Improvement Center (EIIIC) and the EMSC Data Center. The EIIIC uses improvement science as the basis for collaborative efforts to improve outcomes for children in emergency situations. Their collaboratives are networks designed for shared learning, driven by an evidence base and known gaps to facilitate rapid translation of research into clinical practice. EIIIC supports these collaboratives through varied learning systems, coaching, project management, information technology infrastructure, data management, and analytics.

As you can see, EMSC has a track record of working for children. It ensures supplies, training, and continued research that is necessary to caring for our nation's children in times of emergency. Thank you for the opportunity to provide written testimony on the importance of the EMSC program. We appreciate your long-standing commitment to the quality of pediatric emergency care and urge you to take up and pass this important legislation before September 30, 2019.

Dr. Amy Hewitt

**Attachments—Additional Questions for the Record**

**Subcommittee on Health  
Hearing on  
“Reauthorizing Vital Health Programs for American Families”  
June 25, 2019**

**Amy Hewitt, Ph.D.**

**The Honorable Jan Schakowsky (D-IL)**

1. *Adults make up the majority of autistic people alive today, but many programs remain focused primarily on children. Similarly, though autism impacts Americans across different racial and ethnic groups and all gender identities, the public perception of an autistic individual is often that of a young, white man. By law, LEND program trainees are required to receive training in cultural and linguistic competence using a family-centered approach. How are the LEND programs addressing the needs of adults and of diverse populations? And what areas of improvement, if any, do you believe are necessary for better identifying and serving the needs of autistic adults and autistic people of color?*

We know from Centers for Disease Control (CDC) research through Autism CARES funding that approximately 1 in 59 children are diagnosed with an autism spectrum disorder (ASD). As these children grow to become adults, LEND programs play a critical role in training professionals to serve the needs of autistics across the lifespan. Through didactic trainings, our trainees learn about the life course perspective, or life course theory (LCT), which is a multidisciplinary approach to understanding the mental, physical and social health of individuals. LCT incorporates both life span and life stage concepts that determine the health trajectory. We've seen LEND programs such as the University of Illinois LEND establish a new partnership with the Rush Autism, Assessment, Research, Treatment and Services Center, which expanded opportunities for trainees to engage in clinical work with transition-aged young adults and young children with ASD/DDs. Additionally, LEND trainees and faculty at the University of Minnesota have developed and evaluated a new intervention called “Autism Mentorship Program (AMP),” which provides youth with autism transition-related mentoring that is delivered by autistic adults. They also facilitate treatment groups called “Transitioning Together” and “Working Together” intervention groups. MNLEND faculty and staff have also studied eligibility criteria in state developmental disabilities systems to determine if these systems have “related clause” language in their criteria and thus allow for individuals (children, youth and adults) with autism to receive lifelong services through Home and Community Based Services. There are many states that include autism in their eligibility criteria and many that do not. Some states allow for eligibility of children only. To learn about specific state eligibility requirements, you may want to review the enclosed/attached paper entitled, “A Systematic National Review of Medicaid 1915(c) Home and Community-Based Services for People with Autism Spectrum Disorder.”

In regard to addressing diverse populations, between 2014 and 2016, on average, at least 1 in 5 long-term LEND and Developmental Behavioral Pediatrics (DBP) trainees was a racial minority, and approximately 1 in 10 long-term trainees was Hispanic. Enrolling trainees and fellows from a range of racial, ethnic and cultural groups extends grantees' reach into underserved areas and creates opportunities for professionals to communicate more effectively with families from a wide range of backgrounds. It's also important to mention that LEND and

Dr. Amy Hewitt

Developmental Behavioral Pediatrician (DBP) curricula are driven by the Maternal and Child Health (MCH) leadership competencies, one of which is cultural and linguistic competency. All programs address this explicitly (through lectures, discussions, reflective practice exercises, etc.) in training but also implicitly. For example, the LEND program at the University of California, Los Angeles, created the first family autism resource center focused on developmental screening and educational access for underrepresented groups. Additionally, LEND fellows in Minnesota worked with various community members to develop a series of short educational videos in several languages (e.g. Spanish, Somali, Hmong) that share information about the signs of autism and where to go for early identification and support. These short videos entitled, “On the Autism Spectrum” can be found here –

[https://www.youtube.com/playlist?list=PLKdIRbjdmxgdMeagQaED8T52YCUC\\_3HyD](https://www.youtube.com/playlist?list=PLKdIRbjdmxgdMeagQaED8T52YCUC_3HyD)

Many LEND programs have trainees who are autistic. This provides a unique opportunity for LEND fellows to learn from and with people who have lived experience with autism. Individuals with autism learn about current policy, practice and research and they develop leadership skills through a cohort model. Many LEND programs also include self-advocates who are autistic on their community faculty as instructors. This ensures that LEND trainees learn from people who know best about the lives of people with autism.

Through this work we know the value and importance of including the voices of autistic adults and autistic people of color in our LEND trainee program. Improvements can be made in ensuring that we are addressing health equity through training and clinical work that includes family members and individuals with ASD from diverse populations.

2. *What impact do you feel the inclusion of self-advocates has, if any, on your research and training activities?*

LEND programs incorporate family-centered care and self-advocacy in their programs in various ways, having significant impact on training the next generation of professionals. Many training programs integrate principles of family-centered care in their didactic curriculum by recruiting trainees with disabilities and family members of children, adolescents, and adults with ASD/DDs. At Georgia State University LEND, as part of a course on systems of care, trainees identified best practices for early intervention, the transition from pediatric to adult healthcare, and natural supports for children with special healthcare needs (CSHCN) and their families. They then interviewed family members, self-advocates, and service providers to gather information on their experiences and perspectives with these systems and subsequently developed a resource for families on how to navigate the healthcare system. By including self-advocates in our research and training activities, we are better able to deliver services and to transform systems that best serve the very people who are navigating them.

#### **The Honorable Nanette Barragan (D-CA)**

3. *Part of the Autism CARES Act aims to reduce disparities. For instance, I saw that while Autism Spectrum Disorder can typically be diagnosed around age 4, African American children may be diagnosed around a year and a half later. Can you expand on how the bill tackles the issue of minority health disparities, what research and work has been done on this issue, and what progress has been made since the bill was first passed in reducing disparities for people of color?*

Through Autism CARES funding, we have been able to research minority health disparities in relation to autism. The University of Massachusetts was able to complete a study titled, “Addressing Health Disparities in Autism Diagnosis, Service Utilization, and School

Dr. Amy Hewitt

Engagement Among Young Children Living in the Circle of Promise (CoP).” Health disparities in ASD diagnosis have grave implications for children in the CoP, 98 percent of whom are children of color. In this study, routine, early, multistage screening and assessment were implemented in CoP-serving early intervention agencies. The goal of this intervention was to increase ASD diagnosis and reduce disparities in diagnosis and service use outcomes by providing universal access to the diagnostic process to all early intervention-enrolled children. Results provide evidence that in the context of an early intervention-based, multistage screening protocol for ASD, rates of ASD detection among early intervention-participating children were increased (from 2.6 percent to 12.9 percent of the served populations). Evidence of reduced disparities was apparent with children diagnosed through the program being significantly more likely to be English learners, to be parent-identified as racial minorities, or to qualify for public insurance (as a proxy for income level). Additional findings outline areas for further systemic improvement at multiple points along the pipeline from screening to diagnosis to receipt of post-diagnostic intervention services.

Autism CARES funds the Autism and Developmental Disabilities Monitoring (ADDM) program through the CDC. Through its network of states that collect data, ADDM identifies the age of diagnosis and monitors prevalence among various racial and linguistic groups. This enables us to monitor variations and improvements in disparities of identification and diagnosis. In Minnesota, our ADDM project gathers data on specific immigrant populations to assist us in understanding prevalence, preparing better outreach programs and in planning personnel training programs to ensure these communities have needed support.

Dr. Patricia Kunz Howard  
Page 3

**Attachment—Additional Questions for the Record**

**Subcommittee on Health  
Hearing on  
“Reauthorizing Vital Health Programs for American Families”  
June 25, 2019**

**Patricia Kunz Howard, Ph.D.**

**The Honorable Nanette Barragan (D-CA)**

1. The Emergency Medical Services for Children Program is incredibly vital in helping meet the needs of children who receive emergency care. In 2015 alone, there were 30 million emergency department visits of children aged 18 or under. I believe that this discussion comes at a good time. This committee is currently working on other legislation related to services obtained in emergency rooms, and the surprise bills that patients may receive as a result. This unconscionable practice harms those requiring care, with patients receiving a surprise bill one in six times they are taken to an emergency room or checked into the hospital. I am very worried about the impact that surprise bills have on families when a child gets emergency treatment.

- a. Do you know how often children who go to the emergency room receive a surprise bill?  
National statistics are not readily available describing the rates at which pediatric patients (or their families) are receiving surprise bills from emergency care providers.

One study conducted by Stanford University and published in the Journal of the American Medical Association identified that patients presenting at the emergency department in 2016 received surprise bills about 43 percent of the time. The study can be found here:  
<https://jamanetwork.com/journals/jamainternalmedicine/article-abstract/2740802>

- b. Do you have any views on the current surprise billing debate, and do you support any of the current legislative solutions that have been offered?

ENA has a robust legislative agenda on advocating for legislative and regulatory issues affecting emergency nurses and the care provided to their patients. We support measures to ensure high-quality patient care, as well as for a safe and



Dr. Patricia Kunz Howard  
Page 4

healthy working environment for the 180,000 nurses working in emergency departments across the country. These priorities include enhancing the quality of pediatric emergency care, reducing preventable death from traumatic injury, responding to ED-specific issues arising from the opioid crisis to improve patient care, supporting the mission of poison control centers and reducing the impact of violence on emergency departments and their staff.

Surprise billing is certainly an important issue facing hospitals, certain health care providers and patients. Emergency nurses generally do not bill patients for their services. Therefore, ENA has not taken a position regarding the federal legislative proposals regarding the issue of surprise or balance billing. Our organization is focusing its resources on continuing work on issues that have a direct impact on the quality of emergency care received by patients and the working environment affecting nurses in the emergency department.

Dr. Joseph Bocchini  
Page 1

**Attachments—Additional Questions for the Record**

**Subcommittee on Health  
Hearing on  
“Reauthorizing Vital Health Programs for American Families”  
June 25, 2019**

**Joseph Bocchini, MD**

**The Honorable Nanette Barragan (D-CA)**

1. The Newborn Screening Saves Lives Act is an incredible piece of legislation, which helps infants receive the treatments they require to combat serious illnesses. Many of the diseases that are screened have large disparities for people of color. For instance, Sickle Cell Disease occurs among 1 out of every 365 African American births. Additionally, a study found that between 1991 and 2010 Hispanics with Cystic (SIS-TICK) Fibrosis (F-EYE-BRO-SIS) were almost three times as likely to die as non-Hispanic CF patients.

- a. Is there a racial disparity when it comes to newborn screening? Do babies of color get screened at the same rate as other babies?

*There is no racial disparity in newborn screening. All newborns in the United States are offered newborn screening whether they are born in a hospital, a birthing center or at home. Every state public health program develops a system whereby specimens are collected from infants and transported to the laboratory, and results of testing are sent to the infant's provider. A system is also established for confirmatory testing and treatment. Parents have the right to opt out of the newborn screening program. Each year, >98% of the approximately 4 million infants born in the United States are screened (MMWR 2012;61(21):390-393).*

- b. How many children have been screened as a result of the Newborn Screening Saves Lives Act? What will the impact on newborns be if this program is not reauthorized?

*Universal newborn screening is now a well-established state-based public health program. Thus, almost all newborns in the United States undergo newborn screening. The Newborn Screening Saves Lives Act established an evidence-based approach to include a condition in a newborn screening panel. Thus, through this Act a Recommended Uniform Screening Panel (RUSP) was established. This has led to a standardization of the panel of tests performed by most states so that the majority of infants born in the United States receive screening for all of the conditions on the RUSP, regardless of the state in which they were born. The impact has been remarkable. A CDC review (MMWR 2012;61(21):390-393) demonstrated that each year about*

Dr. Joseph Bocchini  
Page 2

*12,500 newborn infants were being identified with one of the conditions included in the RUSP and that all 50 states by 2009 were screening for all of the 29 originally recommended conditions. Therefore, approximately 1 in 300 newborns with a treatable condition are being identified by newborn screening each year in the United States.*

*Since then, six additional conditions have been added to the Routine Newborn Screening Panel (RUSP) which has increased the number of affected babies identified by this program before they develop symptoms or permanent sequelae. Examples of the frequency of the conditions added since 2010 include: critical congenital heart disease (~ 2 in 1,000 infants), Severe Combined Immune Deficiency and related disorders (~ 1 in 58,000 infants), Pompe disease (~ 1 in 28,000 infants), X-linked adrenoleukodystrophy (~ 1 in 20-50,000), Mucopolysaccharidosis Type 1 (severe form ~1 in 100,000) and spinal muscular atrophy (1 in 6-10,000).*

*Today, all of the 53 state and US territory newborn screening programs are screening for critical congenital heart disease and 52 are screening for Severe Combined Immune Deficiency. For the conditions most recently added to the RUSP, 16 programs are screening for X-linked adrenoleukodystrophy, 18 are screening for mucopolysaccharidosis Type 1, 20 are screening for Pompe disease and 11 are screening for spinal muscular atrophy.*

*If the Newborn Screening Saves Lives Act is allowed to sunset, Federal support for this highly successful, rapidly evolving, newborn screening system will no longer exist. The Act supports states through a variety of mechanisms including educational and training activities, research, technical assistance and infrastructure development. As I indicated in my testimony, this Act provides Federal support for: the Advisory Committee on Heritable Disorders in Newborns and Children and its activities, which include an evidence-based, transparent approach to evaluating conditions for inclusion on the RUSP and national oversight of newborn screening activities (including, for example, evaluating the effectiveness of screening, laboratory functions and follow-up programs, and timeliness of reporting of results), with approval of ACHDNC recommendations by the Secretary of the Department of Health and Human Services (HHS) which standardizes RUSP recommendations for states to consider; research supported by the National Institute of Health (NIH); state laboratory improvement resources and other efforts by the Centers for Disease Control and Prevention; and funding to help improve state screening programs from the Health Resources and Services Administration (HRSA) directed to provide support for individual state newborn screening activities depending on the needs of individual states.*

**The Honorable Gus M. Bilirakis (R-FL)**

Dr. Joseph Bocchini  
Page 3

1. Are states struggling with newborn screening, and if so, how?
  - a. Can you briefly share some best practices and lessons learned from the states regarding newborn screening?

*A good example of best practices and lessons learned is related to efforts to improve timeliness of blood spot specimen collection, transport of the blood spots to the screening laboratory, completion of testing by the laboratory and reporting of time-sensitive results to providers. The ACHDNC updated its recommendations on the appropriate time range for each of these components of the newborn screening system to be completed, so that states could achieve maximum efficiency and the morbidity and mortality of serious conditions which can present early after a child is born, could be minimized. The Committee requested an evaluation of performance by states in meeting these timeliness goals. A national survey was conducted through HRSA which revealed that a number of programs were not meeting these recommended time ranges. Potential barriers were identified. A best practice continuous quality improvement program was set up through the Association of Public Health Laboratories with the establishment of a Collaborative Innovation Network, and offered to states. Best practice approaches were developed thorough face to face and teleconference participation with participants who shared ideas, information and solutions for identified barriers. Significant improvement was achieved by participants in many of the outcome measures. Additional activities are underway following the completion of the first cohort of states and timeliness improvement activities are a continued focus of the ACHDNC, HRSA, and state newborn screening programs.*

*Many states use the CDC Newborn Screening Quality Assurance Program to help maintain and enhance the quality of newborn screening test results. This is a voluntary program which provides quality assurance and proficiency testing for states. Interactions between states and CDC lead to better outcomes for individual state programs. CDC also provides training for new technologies required for implementation of screening.*

- b. Can you describe some of the current limitations to newborn screening?

*Each state public health program must develop the funding needed to maintain its newborn screening program and to implement a screening program for a newly recommended condition. Newborn screening is part of the overall public health program and budget in each state. Thus, it often takes a number of years for some states to identify resources to bring on a new condition or improve its newborn screening infrastructure while maintaining all other needed public health activities. For inclusion of a new condition, states must create laboratory capacity (equipment, supplies,*

Dr. Joseph Bocchini  
Page 4

*personnel), and resources for the short-term and the long-term follow-up programs required for identified infants before initiating screening.*

*In addition, incorporating health information technology for reporting results and coordinating follow-up is a problem for many states at the present time.*

- c. While ACA requires most health plans to cover the federal Recommended Uniform Screening Panel of newborn screening tests with no cost sharing, state newborn screening programs vary widely in both the number of mandated tests and their funding mechanisms, including a combination of state laboratory fees, third-party billing, and other federal and state funding.
  - i. As we move forward with addressing the issue of surprise billing, is newborn screening another area that patients could receive a surprise bill for?

*No. Although the cost of newborn screening is covered differently by individual states, it is covered by private health insurance plans, and under the Children's Health Insurance Program (CHIP) and Medicaid for those who are eligible. Therefore, a parent will not receive a separate surprise bill for newborn screening.*

*However if a parent chooses to have supplemental screening done through a private laboratory, that testing is not covered by the fees charged by each state for its recommended newborn screening panel, and parents are likely to be charged by the laboratory that performs those tests.*