This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

NEAL R. GROSS & CO., INC.

RPTS SHIPLE

HIF176140

REAUTHORIZING VITAL HEALTH PROGRAMS FOR AMERICAN FAMILIES

TUESDAY, JUNE 25, 2019

House of Representatives

Subcommittee on Health

Committee on Energy and Commerce

Washington, D.C.

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.

Members present: Representatives Eshoo, Engel, Butterfield, Castor, Sarbanes, Lujan, Schrader, Kennedy, Cardenas, Welch, Ruiz, Dingell, Kuster, Kelly, Barragan, Blunt Rochester, Rush, Pallone (ex officio), Burgess, Upton, Shimkus, Guthrie, Griffith, Bilirakis, Long, Bucshon, Brooks,

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

Mullin, Hudson, Carter, Gianforte, and Walden (ex officio).

Staff present: Mohammad Aslami, Counsel; Kevin Barstow, Chief Oversight Counsel; Billy Benjamin, Systems Administrator; Jacquelyn Bolen, Professional Staff; Jesseca Boyer, Professional Staff Member; AJ Brown, Counsel; Jeff Carroll, Staff Director; Jacqueline Cohen, Chief Environment Counsel; Sharon Davis, Chief Clerk; Luis Domingues, Health Fellow; Jennifer Epperson, FCC Detailee; Elizabeth Ertel, Office Manager; Adam Fischer, Policy Analyst; Jean Fruci, Energy and Environment Policy Advisor; Evan Gilbert, Press Assistant; Lisa Goldman, Counsel; Waverly Gordon, Deputy Chief Counsel; Tiffany Guarascio, Deputy Staff Director; Caitlin Haberman, Professional Staff Member; Alex Hoehn-Saric, Chief Counsel, C&T; Megan Howard, FDA Detailee; Zach Kahan, Outreach and Member Service Coordinator; Rick Kessler, Senior Advisor and Staff Directory, Energy and Environment; Saha Khaterzai, Professional Staff Member; Chris Knauer, Oversight Staff Director; Brendan Larkin, Policy Coordinator; Una Lee, Senior Health Counsel; Jerry Leverich, Counsel; Jourdan Lewis, Policy Analyst; Perry Lusk, GAO Detailee; Dustin Maghamfar, Air and Climate Counsel; John Marshall,

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

Policy Coordinator; Kevin McAloon, Professional Staff Member; Dan Miller, Policy Analyst; Jon Monger, Counsel; Elysa Montfort, Press Secretary; Phil Murphy, Policy Coordinator; Lisa Olson, FERC Detailee; Joe Orlando, Staff Assistant; Kaitlyn Peel, Digital Director; Mel Peffers, Environment Fellow; Alivia Roberts, Press Assistant; Tim Robinson, Chief Counsel; Chloe Rodriguez, Policy Analyst; Nikki Roy, Policy Coordinator; Samantha Satchell, Professional Staff Member; Andrew Souvall, Director of Communications, Outreach and Member Services; Sydney Terry, Policy Coordinator; Kimberlee Trzeciak, Senior Health Policy Advisor; Rick Van Buren, Health Counsel; Eddie Walker, Technology Director; Teresa Williams, Energy Fellow; Tuley Wright, Energy and Environment Policy Advisor; C.J. Young, Press Secretary; Jennifer Barblan, Minority Chief Counsel, O&I; Mike Bloomquist, Minority Staff Director; Adam Buckalew, Minority Director of Coalitions and Deputy Chief Counsel, Health; Robin Colwell, Minority Chief Counsel, C&T; Jerry Couri, Minority Deputy Chief Counsel, Environment & Climate Change; Jordan Davis, Minority Senior Advisor; Kristine Fargotstein, Minority Detailee, C&T; Margaret Tucker Fogarty, Minority Staff Assistant; Melissa Froelich, Minority Chief Counsel, CPAC; Theresa Gambo, Minority Human Resources/Office Administrator;

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

Caleb Graff, Minority Professional Staff Member, Health; Brittany Havens, Minority Professional Staff, O&I; Peter Kielty, Minority General Counsel; Bijan Koohmaraie, Minority Counsel, CPAC; Tim Kurth, Minority Deputy Chief Counsel, C&T; Ryan Long, Minority Deputy Staff Director; Mary Martin, Minority Chief Counsel, Energy & Environment & 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 Director; Kristen Shatynski, Minority Professional Staff Member, Health; Alan Slobodin, Minority Chief Investigative Counsel, O&I; Peter Spencer, Minority Senior Professional Staff Member, Environment & Climate Change; Natalie Sohn, Minority Counsel, O&I; Danielle Steele, Minority Counsel, Health; Everett Winnick, Minority Director of Information Technology; and Greg Zerzan, Minority Counsel, CPAC.

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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 five minutes for an opening statement.

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 care givers. Very important--care givers. 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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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 care giver 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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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 one.

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 care givers 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 health care for every American.

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

The chair now has the pleasure of recognizing Dr.

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

Burgess, the ranking member of the subcommittee, for five minutes for his opening statement.

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 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 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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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 new born 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 10 states and Washington, D.C., required infant screening for the recommended disorders.

Since enactment of the Newborn Screening Saves Lives Act, all the states, Washington, D.C., 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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

Disease Control and Prevention, and the National Institute of Health to ensure that our newborn screening remains comprehensive and that our nation's health care 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 its 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, education at the NIH, the CDC, and HRSA.

And 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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

reauthorize funding for the Lifespan Respite Care Program through fiscal year 2024.

Respite care is critical--it is a critical resource for care givers 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 care givers across the United States, ensuring that we maintain access to respite care for our care givers 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.

Ms. Eshoo.= The gentleman yields back.

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

The Chairman.= Thank you, Madam Chair.

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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 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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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, and I want to thank Representative Roybal-Allard who has championed this program since it was first passed more than 10 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 witness 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 the get emergency care for a child, they should know their children will receive the medical care they need and this programs provide 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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

services and educational resources to family care givers 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 now 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.

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

gracious as has Chairman Pallone. I hope that we can move quickly to markup in 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.

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.

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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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, 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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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 health care 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 care givers.

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 care givers 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.

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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.

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, a national respite network and resource center of National Respite Coalition. Thank you to 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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

to you, Doctor, and a warm welcome.

At this time the chair is going to recognize each witness for five minutes to provide your opening statements. Bring the microphones 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, 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 five minutes.

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

?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=

Ms. 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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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 one in 59 children have autism and, roughly, one in six 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.

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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,

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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 report 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.

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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 Ms. Hewitt follows:]

**********INSERT 1**********

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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 five minutes for your testimony.

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

?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 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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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 health care 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 in 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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

reauthorize the program in a timely way.

Thank you very much.

[The prepared statement of Ms. Kagan follows:]

**********INSERT 2**********

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

Ms. Eshoo.= Thank you, Ms. Kagan.

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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

?STATEMENT OF KUNZ HOWARD=

Ms. 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 health care 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 Health Care, 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 health care 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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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 health care 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 health care professionals during an emergency requiring specific types of equipment and often different medication dosage regimens.

Nevertheless, this reality is that 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.

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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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 interfacility 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 that Pediatric Emergency Care Applied Research Network, or PECARN,

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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 health care 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 Ms. Howard follows:]

**********INSERT 3**********

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

Ms. Eshoo.= Thank you very much, Dr. Kunz Howard.

I know would like to recognize Dr. Bocchini. You have five 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.= Okay.

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

?STATEMENT OF DR. JOSEPH BOCCHINI=

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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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 are considered rare, one in approximately 300-- every 300 screened newborn infants is found to have a condition for which treatment is beneficial.

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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 benefits 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 immuno deficiency, critical congenital heart disease, Pompe disease, mucopolysaccharidoses type 1, adrenoleukodystrophy, and, most

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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 program 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 4 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 program 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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

testimony and support of this reauthorization act. I look forward to your questions.

Thank you.

[The prepared statement of Dr. Bocchini follows:]

**********INSERT 4**********

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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.= Mm-hmm.

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 a 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 five minutes to ask questions.

Dr. Hewitt, do we know what causes autism?

Ms. 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 CURES 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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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--

Ms. Hewitt.= Forty-five.

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

Ms. Hewitt.= Unfortunately, Nathan wasn't diagnosed until he was 17.

Ms. Eshoo.= And so what--in that gap of--what did he end up--

Ms. Hewitt.= So had he been diagnosed earlier--

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

Ms. 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 had he had early intervention I think his life outcomes would have been substantially different than they are now.

Ms. Eshoo.= Mm-hmm. 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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

services that are needed? I think that's kind of the $64,000 question to me.

[Laughter.]

Ms. Hewitt.= It's a good question.

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

Ms. Hewitt.= Mm-hmm. 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 health care 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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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.= --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 five minutes to Dr. Burgess, the ranking member of the subcommittee, for his questions.

Mr. Burgess.= Thank you, Madam Chairwoman.

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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 immuno deficiency disease was one of those things that you can detect.

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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 immuno deficiency 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.

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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.

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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? Okay. 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?

Ms. Howard.= That is correct.

Mr. Burgess.= So what's the problem there?

Ms. 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?

Ms. 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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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.= Okay. 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.= I have--yeah, 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 five 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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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, that 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?

Ms. 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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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?

Ms. Hewitt.= There's a lot of room to grow.

Ms. Matsui.= Right. Absolutely.

Ms. 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?

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

Ms. Hewitt.= Sure. There are 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.= Okay.

Ms. Hewitt.= So it's--

Ms. Matsui.= Right.

Ms. Hewitt.= --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.= Okay. 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?

Ms. 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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

health care 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 health care need--

Ms. Matsui.= Right.

Ms. Howard.= --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.= Okay. 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 care givers 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.= States, because of their multiple funding

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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 care givers, 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 disseminated?

Ms. Kagan.= Better information, yes.

Ms. Matsui.= Okay. 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.

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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 five 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~~Reagan~~ led on this way back with Project Independence. I think we still have a ~~saw it in the~~ 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.

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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. 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 health care 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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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.= --help families identify that they can use for respite.

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

Ms. Kagan.= Exactly.

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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.= --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. Yeah. Yeah. 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?

Ms. 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.

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

Mr. Walden.= Sure. My district.

Ms. 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.

Ms. 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

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

injuries uniquely manifest themselves differently in children?

Ms. 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.

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

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 five 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.

This is a preliminary, unedited transcript. The statements within may be inaccurate, incomplete, or misattributed to the speaker. A link to the final, official transcript will be posted on the Committee's website as soon as it is available.

Howard, can you tell us about how the EMS has aided in helping emergency care providers identify adolescents for opioid or other substance abuse?

Ms. 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?

Ms. 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 10 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 for 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 five 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 gnomic 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.

Ms. 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. Okay. 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 school--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 five 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 health care needs and EMSC helps bring innovation in pediatric emergency care to each state.

In 2016, 22 percent--that's about 2 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 vasopresser 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.

Ms. 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?

Ms. 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 five 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?

Ms. 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 five 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 10 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 10 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 10

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 return 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 five 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?

Ms. 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?

Ms. 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?

Ms. Hewitt.= I am vaguely familiar with that.

Mr. Carter.= Okay. 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?

Ms. 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?

Ms. Hewitt.= They're extremely important. I think expansion into adult-related interventions is an important next horizon.

Mr. Carter.= Good. 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 five 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, yeah, I think that'll be impossible. So that was when we finally got him to get her into nursing home care, and my heart is with all of the families that are working on this.

In my home state of New Hampshire, 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, inn 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?

Ms. 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 underrepresented areas. How does CARES funding support the workforce so that there are enough properly trained providers to address the needs of this community?

Ms. 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?

Ms. Hewitt.= I think--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--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 5 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 3 percent.

Mr. Mullin.= Much less than 3. 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--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 in how to deal with the genetic-related conditions that are being in 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 rom Illinois, Ms. Kelly, for her five 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.

Ms. 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.

Ms. 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--

Ms. 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?

Ms. 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.

Ms. 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?

Ms. Howard.= So I don't know--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?

Ms. 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 five 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.

Ms. Howard.= Well--

Mrs. Brooks.= And why might--why aren't they appropriate for all hospitals?

Ms. 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?

Ms. 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?

Ms. Howard.= That's--it's very common, particularly in--

Mrs. Brooks.= In rural--

Ms. Howard.= --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 relationships 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.= Okay. Do you have any suggestions over what we can do improve the state partnership grants?

Ms. 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.= Shh. 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?

Ms. 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?

Ms. 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?

Ms. 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 five 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?

Ms. 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 it 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. Okay.

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 five 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, especially 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. Okay.

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 heal 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 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 five 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?

Ms. 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.

Ms. 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 it that?

Ms. Howard.= Kentucky.

Mr. Ruiz.= Kentucky only has two children's hospitals for the entire state?

Ms. 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 and 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 car 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?

Ms. 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 10 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?

Ms. 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?

Ms. 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?

Ms. Howard.= Absolutely.

Mr. Gianforte.= Okay. 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.

Ms. Howard.= Absolutely.

Mr. Gianforte.= I appreciate you making that point. At what age are children usually evaluated and diagnosed with autism?

Ms. 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?

Ms. Howard.= It is, and that's really because there aren't--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?

Ms. 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?

Ms. Howard.= Correct.

Mr. Gianforte.= Okay. 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?

Ms. 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.= Okay. 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 five 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 come 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?

Ms. 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 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?

Ms. 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?

Ms. 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.= Yeah, 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?

Ms. 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 health care organizations.

Ms. Eshoo.= So ordered.

[The information follows:]

**********COMMITTEE INSERT**********

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 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 five 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 the 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 10 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 an 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 follows:]

1 **********COMMITTEE INSERT**********

Ms. Eshoo.= And with that, the subcommittee is adjourned.

Thank you, everyone.

[Whereupon, at 12:37 p.m., the committee was adjourned.]