OPPORTUNITIES TO IMPROVE HEALTH CARE

HEARING

BEFORE THE

SUBCOMMITTEE ON HEALTH

OF THE

COMMITTEE ON ENERGY AND COMMERCE HOUSE OF REPRESENTATIVES

ONE HUNDRED FIFTEENTH CONGRESS

SECOND SESSION

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OPPORTUNITIES TO IMPROVE HEALTH CARE

WEDNESDAY, SEPTEMBER 5, 2018

House of Representatives, SUBCOMMITTEE ON HEALTH, COMMITTEE ON ENERGY AND COMMERCE, Washington, DC.

The subcommittee met, pursuant to call, at 10:04 a.m., in room 2123, Rayburn House Office Building, Hon. Michael Burgess, M.D.

(chairman of the subcommittee) presiding.

Present: Representatives Burgess, Guthrie, Barton, Shimkus, Latta, Lance, Griffith, Bilirakis, Long, Bucshon, Brooks, Mullin, Hudson, Carter, Walden (ex officio), Green, Engel, Schakowsky, Matsui, Castor, Sarbanes, Schrader, Kennedy, Cárdenas, and Degette.

Also Present: Representatives Walberg, Welch, and Dingell. Staff Present: Mike Bloomquist, Staff Director; Samantha Bopp, Staff Assistant; Adam Buckalew, Professional Staff Member, Health; Daniel Butler, Legislative Clerk, Health; Karen Christian, General Counsel; Jordan Davis, Senior Advisor; Melissa Froelich, Chief Counsel, DCCP; Adam Fromm, Director of Outreach and Coalitions; Ali Fulling, Legislative Clerk, O&I, DCCP; Theresa Gambo, Human Resources/Office Administrator; Caleb Graff, Professional Staff Member, Health; Jay Gulshen, Legislative Associate, Health; Ed Kim, Policy Coordinator, Health; Ryan Long, Deputy Staff Director; James Paluskiewicz, Professional Staff, Health; Kristen Shatynski, Professional Staff Member, Health; Jennifer Sherman, Press Secretary; Austin Stonebraker, Press Assistant; Josh Trent, Chief Health Counsel, Health; Jacquelyn Bolen, Minority Professional Staff; Tiffany Guarascio, Minority Deputy Staff Director and Chief Health Advisor; Una Lee, Minority Senior Health Counsel; Rachel Pryor, Minority Senior Health Policy Advisor; and Samantha Satchell, Minority Senior Policy Analyst.

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

Mr. Burgess. I call the Subcommittee on Health to order. I am going to ask our guests to please take their seats. And, again, welcome to everyone for the first September hearing of the Health Subcommittee of the Energy and Commerce Committee, the most productive subcommittee in the United States House of Representatives.

So today we are joined by a panel of witnesses. I will recognize myself for 5 minutes for an opening statement. We are joined by a panel of witnesses who are going to provide us testimony on a

variety of topics and legislative ideas, ranging from initiatives to address drug pricing to reducing fraud at the Centers for Medicare and Medicaid Services to improving the care of children with complex medical conditions.

These bills cover different topics within healthcare, but there is a common thread that connects all. All of the bills in discussion drafts before us today have the aim to improve the access and the

quality of care for America's patients and their families.

So, first, I would like to commend Representative Buddy Carter of Georgia for his hard work on legislation to prohibit gag clauses in Medicare and private health insurance plans. Gag clauses prohibit pharmacists from informing patients that paying in cash will result in lower out-of-pocket costs than the insurer's cost-sharing arrangement unless the patient directly requests such information. The draft bill being discussed today is essential in both lowering drug costs for individuals and freeing the pharmacists to do what many consider would be the right thing, in fact, freeing the pharmacist to simply do their job. It would ban an employer and individual health insurance plans, in addition to Medicare Advantage and Medicare part D plans, from using gag clauses.

This bipartisan policy has been a shared priority for Mr. Carter and others on the committee for quite some time, and it was brought further to the forefront by the administration's drug pricing blueprint that many of us attended a Rose Garden ceremony in May. While the gag clauses are already prohibited in Medicare, it is important that we protect consumers by putting this in statute and sending this bill to the President's desk as soon as possible.

Today, we are also considering several Medicaid bills and discussion drafts that will further prevent and investigate fraud and abuse in addition to increasing access for certain beneficiaries.

abuse in addition to increasing access for certain beneficiaries. H.R. 3891, introduced by Representatives Walberg and Welch, will improve the authority of the State Medicaid Fraud Units, which currently investigate provider fraud and patient abuse only in healthcare facilities and care facilities. According to the Health and Human Service Office of the Inspector General, Medicaid Fraud Control Units recovered almost \$2 billion in fiscal year 2017. This legislation builds upon the success of these Fraud Control Units by broadening their authority to investigate and prosecute abuse and neglect of beneficiaries in noninstitutional or other settings. Another discussion draft before us today will codify the Health Fraud Prevention Partnership, which will further enable our public and private institutions to combat fraud within the healthcare system.

Health Subcommittee Vice Chairman Guthrie and Representative Dingell have introduced the EMPOWER Care Act, which will extend the Money Follows the Person Demonstration for an additional 5 years. This Medicaid demonstration, which was established in 2005, has enabled eligible individuals in States across our Nation, including Texas, to receive long-term care services in their homes or other community settings rather than in institutions such as nursing homes. Not only does this increase the comfort and quality of life for many Medicaid beneficiaries, but it has reduced hospital readmissions and saved money within the Medicaid pro-

gram.

The final Medicaid discussion draft, the ACE Kids Act, is introduced by full committee Vice Chairman Barton and Representative Castor of Florida and has received substantial feedback from stakeholders and has been revised to reflect this increased input. The goal of this legislation is to improve comprehensive care for medically complex children through a State option to create a Medicaid health home specific for children. The bill will also increase data collection and add a requirement for the Department of Health and Human Services to issue guidance on best practices for providing care for this unique and complex pediatric population.

I do want to thank the members whose legislation we are considering today. They have put in a lot of time and effort and certainly as has their staff. They put this into the development and fine-tuning of the language. I look forward to hearing from our witnesses and having a productive discussion on these important public health initiatives.

And now I yield back my time, and I want to recognize the ranking member of the subcommittee, Mr. Green of Texas, 5 minutes for an opening statement, please.

[The prepared statement of Mr. Burgess follows:]

Prepared Statement of Hon. Michael C. Burgess

Good morning, everyone. Today, we are joined by a panel of witnesses who are here to testify on a variety of topics and legislative ideas, ranging from initiatives to address drug pricing to reducing fraud at the Centers for Medicare and Medicaid Services, to improving the care of children with complex medical conditions.

While these bills cover different topics within health care, there is one common thread that connects them. All of the bills and discussion drafts before us today aim to improve the access to and quality of health care for American patients and their families.

First, I would like to commend Representative Buddy Carter of Georgia for his hard work on legislation to prohibit gag clauses in Medicare and private health insurance plans. Gag clauses prohibit pharmacists from informing patients that paying in cash will result in lower out of pocket costs than the insurer's cost-sharing arrangement, unless the patient directly asks. The draft bill being discussed today is essential in both lowering drug costs for individuals and in freeing pharmacists to do what many consider to be the right thing. It would ban employer and individual health insurance plans, in addition to Medicare Advantage and Medicare Part D Plans, from using gag clauses.

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I would like to thank the members whose legislation we are considering today for the time, effort, and thought that they have put into the development and fine-tuning of the language. I look forward to hearing from our witnesses and having a productive discussion on these important public health initiatives.

OPENING STATEMENT OF HON. GENE GREEN, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF TEXAS

Mr. Green. Thank you, Mr. Chairman, for holding today's hearing on these bipartisan drafts and legislation to improve the delivery cost of healthcare in our country. In particular, I am happy to see that our committee will be considering H.R. 3325, the Advancing Care for Exceptional Kids, or ACE Kids Act. I am grateful to Representatives Barton and Castor for their commitment to the children with complex medical needs and their quest to improve the system of care provided to our nation's most vulnerable population.

I am also proud to be a cosponsor of the ACE Kids Act. The ACE Kids Act aims to improve the delivery care for children with complex medical conditions served by Medicaid. It presents a great opportunity for us to implement better care delivery and payment

models to support children and their families.

The current discussion draft will establish a Medicaid health home State option, specifically targeting children with medically complex conditions, and require the Department of Health and Human Services to issue guidance regarding the best practices for using out-of-State providers for children with medically complex conditions. States who accept this new home health option for children with medically complex conditions will receive an enhancement 90 percent Federal medical assistance percentage, FMAP, for the first eight fiscal year quarters after the option is adopted.

The discussion draft seeks to achieve three primary goals: improve the coordination of care for children; address the problems of fragmented access, especially when the necessary care is only available out of State; gather national data to help researchers improve services and treatments for children with complex medical condi-

I also want to thank our stakeholders in my area in Houston, Texas, Children's Hospital-I am glad to have Dr. Cook on the panel I think today, no, anyway—and my colleagues for moving

this important legislation.

Children with medically complex conditions require a lot of healthcare and generate significant cost. One study found that children with complex medical conditions who account for just over 5 percent of all children in Medicaid account for 34 percent of all Medicaid spending for children.

While the data is compelling, it is important not to reduce these children and their families to statistics. We must do a better job to ensure that all of these exceptional children get the care they need.

Children with medically complex conditions often have multiple illnesses and disabilities and commonly need to see a number of physicians and specialists. The necessary care often requires these special children to travel across State lines to see one of the small number of pediatric specialists for their conditions.

Under our current system, parents of kids with complex conditions struggle to coordinate the intricate multistate care of their children. We need this legislation to make sure that this care is more coordinated and seamless for families. The discussion draft is

an important step forward.

We must ensure that final legislation is robust and meaningful in accomplishing our shared goals of improving care and removing barriers for children with complex medical conditions. The ACE Kids Act now has 99 cosponsors, evidence that the health of our children is an issue above partisanship and brings us all together. I look forward to working with my colleagues to move the legislation forward and give our children the bright futures they deserve.

I support the other four bills in discussion draft being considered today. Many of these bills, including H.R. 3891, will expand the authority of State Medicaid Fraud Control Units to investigate and prosecute Medicaid fraud and abuse at noninstitutional settings, and the discussion draft to codify the Health Fraud Prevention Partnership are comments and changes to current law and should

receive wide bipartisan support.

I also support the discussion draft to prohibit the use of the socalled gag clauses in Medicare and private health plans that prohibit pharmacists from informing consumers that their prescription can be purchased at a lower price. While I support the gag clause discussion draft, I hope the committee will consider a deeper examination for rising costs of prescription drugs and consider what Congress can do to help seniors struggling to afford their medica-

And like you, Mr. Chairman, I want to thank our colleague from Georgia for bringing this up. This is a major issue with the seniors in my district in Houston and Harris County, Texas. I thank our witnesses for joining us today and look forward to hearing their testimony. Again, Mr. Chairman, thank you, and I yield back the remainder of my time.

[The prepared statement of Mr. Green follows:]

PREPARED STATEMENT OF HON. GENE GREEN

Thank you, Mr. Chairman, for holding today's hearing on bipartisan legislation to improve the delivery and cost of health care in our country.

In particular, I am happy to see that our committee will be considering H.R. 3325, the Advancing Care for Exception Kids or "ACE" Kids Act.

I am grateful to Representatives Barton and Castor for their commitment to children with complex medical needs and their quest to improve the system of care provided to our nation's most vulnerable population.

I am a proud original co-sponsor of the ACE Kids Act.

The ACE Kids Act aims to improve the delivery of care for children with complex medical conditions served by Medicaid.

It presents a great opportunity for us to implement better care delivery and payment models to support children and their families.

The current discussion draft would establish a Medicaid health home state option specifically targeted for children with medically complex conditions and require the Department of Health and Human Services to issue guidance regarding best practices for using out-of-state providers for children with medically complex conditions.

States that accept this new home health option for children with medically complex conditions will receive an enhanced 90 percent Federal Medical Assistance Percentage (FMAP) for the first eight fiscal year quarters after the option is adopted.

The discussion draft seeks to achieve three primary goals:

• Improve the coordination of care for children;

• Address problems with fragmented access, especially when the necessary care is only available out-of-state;

 Gather national data to help researchers improve services and treatments for children with complex medical conditions.

I want to thank our stakeholders, Texas Children's Hospital in particular, and my colleagues for moving this important legislation forward.

Children with medically complex conditions require a lot of health care and generate significant costs. One study found that children with complex medical conditions, who count for just over 5 percent of all children in Medicaid, account for 34 percent of all Medicaid spending for children.

While the data is compelling, it is important not to reduce these children and their families to statistics. We must do a better job to ensure that all of these exceptional kids get the care they need. Children with medically complex conditions often have multiple illness and disabilities, and commonly need to see a number of specialists and physicians. The necessary care often requires these special children to travel across state lines to see one of the small number of pediatric specialists for their conditions.

Under the current system, parents of kids with complex conditions struggle to coordinate the intricate, multi-state care of their children.

We need this legislation to make this care more coordinate and seamless for families.

This discussion draft is an important step forward.

We must ensure that the final legislation is robust and meaningful to accomplish our shared goals of improving care and removing barriers for children with complex medical conditions.

The ACE Kids Act now has 99 cosponsors, evidence that the health of our children is an issue that is above partisanship and brings us all together.

I look forward to working with my colleagues to move this legislation forward and give our children the bright futures they deserve.

I support the other four bills and discussion drafts being considered today.

Many of these bills, including H.R. 3891, which would expand the authority of state Medicaid Fraud Control Units to investigate and prosecute Medicaid fraud and abuse in non-institutional settings, and the discussion draft to codify the Health Fraud Prevention Partnership (HFPP), are commonsense changes to current law and should receive wide bipartisan support.

I also support the discussion draft to prohibit the use of so-called "Gag Clauses" in Medicare and private health insurance plans that prohibit pharmacists from informing consumers that their prescription can be purchased for a lower price out-of-pocket.

While I support the "gag clause" discussion draft, I hope that the committee while consider a deeper examination on the rising costs of prescription drugs and consider what Congress can do to help seniors struggling to afford their medication.

This is a major issue for seniors in my district in Houston and Harris County. I thank our witnesses for joining us today and look forward to hearing their testimony.

Thank you again, Mr. Chairman, and I yield the remainder of my time.

Mr. Burgess. The chair thanks the gentleman. The gentleman yields back.

The chair recognizes the gentleman from Oregon, the chairman of the full committee, Mr. Walden, 5 minutes for an opening statement, please.

OPENING STATEMENT OF HON. GREG WALDEN, A REPRESENT-ATIVE IN CONGRESS FROM THE STATE OF OREGON

Mr. WALDEN. Well, thank you, Mr. Chairman, and thanks for all your great work in this subcommittee, that and the members. Again, today we are taking up bipartisan issues that really matter for people's health and the cost of healthcare. So I think it is a real

another step forward.

So I traveled across Oregon over the last 5 weeks, covering 2,000 miles, 39 meetings, and 12 counties. These issues come up, especially about healthcare, the cost, the quality. Accessing affordable healthcare is a real important issue, and it is one we consistently try to tackle in this committee.

Today, we hope to build on the bipartisan achievements of the committee under the leadership of Chairman Burgess and Ranking Member Green and review yet another slate of bills that can help

improve our overall healthcare system.

Now, among those we will examine is the one we have heard about already pertaining to gag clauses, which have been front and center in the national debate on drug prices. Many patients who are struggling to afford costly prescription drug prices may not know that actually paying for their medications with cash is sometimes cheaper than using their health insurance. And with the high deductibles right now, you ought to be informed as a consumer. What is worse is some contracts prohibit pharmacists from telling their customers when this is the case.

So banning these so-called "gag clauses" has gained tremendous bipartisan support, rightly so, with these bills in both the Senate Finance and Senate Health Committees advancing without objection. We will review the draft legislation banning group health plans offered by employers and individual health plans as well as Medicare Advantage and Medicare part D plans from limiting a pharmacist's ability to inform a consumer about the lower cost out-

of-pocket price for their prescription.

Now, another practical bill will give the administration additional authority to better detect and stop fraud and abuse in the healthcare system. This has been an area of interest for both the Obama and Trump administrations, and it is supported by the committee's ranking member, Mr. Pallone, as well as myself. I look

forward to our continued bipartisan work in this space.

We will also consider three bills in the Medicaid space that will help ensure the beneficiaries who are receiving the support and care they deserve in the setting that works best for them. Mr. Guthrie and Ms. Dingell's bill, H.R. 5306, for example, extend funding for the Money Follows the Person Demonstration Program, that is MFP Demonstration, in Medicaid. The MFP Demonstration provides additional resources for State Medicaid programs to help ensure Medicaid patients needing long-term care are served in their communities or in their homes instead of at institutions. By many measures, the MFP Demonstration has been successful.

We will also consider a bill offered by Mr. Walberg and Mr. Welch, H.R. 3891, that will help improve the authority of State Medicaid Fraud Control Units, or MFCUs. Currently, MFCUs are only allowed to investigate cases of provider fraud and patient abuse in healthcare facilities or board and care facilities. This legislation would broaden that authority so that these units could investigate and prosecute abuse and neglect of Medicaid beneficiaries in noninstitutional or other settings. Practically speaking, this bill will improve the ability of MFCUs to help protect vulnerable Medicaid patients from harm, while reducing the program's resources

diverted by fraud.

And, finally, we will consider an amendment in the nature of a substitute to a familiar bill authored by our full committee vice chair, Mr. Barton, and Representative Castor. That is H.R. 3325. Under current law, a health home State plan amendment cannot target by age or be limited to individuals in a specific age range. The Centers for Medicare and Medicaid Services has reported that States have identified this inability to target health home services as an operational challenge. This bipartisan bill seeks to address that challenge by giving States a new option through the existing health home model to coordinate care for children with medically complex conditions.

So further discussion of this report and bill, I would yield the balance of my time to full committee vice chair, Mr. Barton, and

thank our witnesses for joining us today.

[The prepared statement of Mr. Walden follows:]

Prepared Statement of Hon. Greg Walden

Today's hearing is another step forward to improve patient health care. As I traveled across Oregon over the last 5 weeks, I continued to hear from constituents about health care, particularly regarding the cost and quality of care. Today we hope to build on the bipartisan achievements of this subcommittee, under the leadership of Chairman Burgess and Ranking Member Green, and review yet another slate of bills that can help improve our health care system.

Among the bills we will examine today is one pertaining to gag clauses, which have been front and center in the national debate on drug prices. Many patients who are struggling to afford costly prescription drug prices may not know that paying for their medications with cash can sometimes be cheaper than using their health insurance. What's worse is some contracts prohibit pharmacists from telling

their customers when this is the case.

Banning these so-called "gag clauses" has gained tremendous bipartisan support, with bills in both the Senate Finance and Senate HELP committees advancing without objection. We'll review draft legislation banning group health plans offered by employers and individual health insurance plans—as well as Medicare Advantage and Medicare Part D plans—from limiting a pharmacist's ability to inform a cus-

Another practical bill will give the administration additional authority to better detect and stop fraud and abuse in the health care system. This has been an area of interest for both the Obama and Trump administrations, and it's supported by the committee's Ranking Member, Mr. Pallone, as well as myself. I look forward to our continued binartisan work in this space.

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By many measures, the MFP demonstration has been successful.

We will also consider a bill authored by Mr. Walberg and Mr. Welch, H.R 3891, that will improve the authority of state Medicaid Fraud Control Units—or MFCUs. Currently, MFCUs are only allowed to investigate cases of provider fraud and patient abuse in health care facilities or board and care facilities. This legislation would broaden the authority of these units to investigate and prosecute abuse and neglect of Medicaid beneficiaries in non-institutional or other settings. Practically speaking, this bill will improve the ability of MFCUs to help protect vulnerable Medicaid patients from harm, while reducing the program resources diverted by fraud.

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To further discuss this important bill, I would like to yield the remainder of my time to the Vice Chairman of the Full Committee, Mr. Barton, and thank our witnesses for joining us here today.

Mr. BARTON. Well, thank you, Mr. Chairman. Every now and then, we have a day when it reminds us why we ran for Congress. Today is one of those days. As Mr. Green in his opening statement just itemized, the ACE Kids Act, all the good things that it will do. So I don't need to go through that.

But we are going to have a hearing on that bill today among the other four bills, and hopefully, on Friday, we are going to mark it up. ACE Kids is a bill that has been in some shape or form before this subcommittee for about 6 years. The bill, the draft discussion today, is one of those rare things. It is totally bipartisan. Half of the cosponsors are Republican; half are Democrat. On this subcommittee, Mr. Latta, Mr. Lance, Mr. Guthrie, Mr. Bilirakis, Mr. Long, and Mr. Carter are Republican cosponsors. Mr. Green, Ms. Eshoo, Mrs. Dingell, Ms. DeGette, Ms. Castor, Mr. Kennedy, and Mr. Cárdenas are Democratic cosponsors. We have half the subcommittee cosponsor this bill. It doesn't expand coverage; it doesn't increase spending. It makes it better, Mr. Chairman. It allows families to choose. It allows the care providers to coordinate, and you can go across State lines.

This is a really, really good bill. I hope we have a great hearing. I want to thank Rick Merrill from Fort Worth, Texas, for testifying in its favor, and I look forward to the discussion and the questions.

With that, I yield back, Mr. Chairman.

Mr. Burgess. The chair thanks the gentleman. The gentleman yields back.

The ranking member of the full committee has not yet arrived,

so we will delay his opening statement until his arrival.

But I do want to welcome and thank our witnesses for being here and taking time to testify before the subcommittee on these pending pieces of legislation. Each witness will have the opportunity to give an opening statement, and this will be followed by questions from members.

So, today, in order, we are going to hear from Mr. Hugh Chancy, Owner, Chancy Drugs, and Member of the Board of Directors of the National Community Pharmacists Association; and Mr. Curtis Cunningham, Vice President, National Association of States United for Aging and Disabilities, and Assistant Administrator, Long-Term Care Benefits and Programs, Division of Medicaid Services, Department of Health Services from the State of Wisconsin; Mr. Matt Salo, the Executive Director of the National Association of Medicaid Directors; Mr. Rick Merrill—always have to have a Texan on the panel, so welcome and thank you for joining us today—Mr.

Rick Merrill, who is the President and CEO of Cook Children's Health Care System in beautiful downtown Fort Worth, Texas; Mr. Derek Schmidt, the Attorney General for the State of Kansas; and Dr. David Yoder, Executive Director of Member Care and Benefits, Blue Cross Blue Shield Association's Federal Employee Plan.

Again, thanks to all of you. We appreciate you giving of your time today to testify. Mr. Chancy, you are now recognized 5 minutes to summarize your opening statement, please.

STATEMENTS OF HUGH M. CHANCY, RPH, OWNER, CHANCY DRUGS. HAHIRA. GEORGIA. AND MEMBER. BOARD OF DIREC-TORS, NATIONAL COMMUNITY PHARMACISTS ASSOCIATION; CURTIS CUNNINGHAM, VICE PRESIDENT, NATIONAL ASSO-CIATION OF STATES UNITED FOR AGING AND DISABILITIES (NASUAD), AND ASSISTANT ADMINISTRATOR, LONG-TERM CARE BENEFITS AND PROGRAMS, DIVISION OF MEDICAID SERVICES, DEPARTMENT OF HEALTH SERVICES, STATE OF WISCONSIN; MATT SALO, EXECUTIVE DIRECTOR, NATIONAL ASSOCIATION OF MEDICAID DIRECTORS; RICK MERRILL, PRESIDENT AND CEO, COOK CHILDREN'S HEALTH CARE SYSTEM, FORT WORTH, TEXAS; DEREK SCHMIDT, J.D., AT-TORNEY GENERAL, STATE OF KANSAS; AND DAVID YODER, PHARM.D., M.B.A., EXECUTIVE DIRECTOR OF MEMBER CARE AND BENEFITS, BLUE CROSS BLUE SHIELD ASSOCIATION'S FEDERAL EMPLOYEE PLAN

STATEMENT OF HUGH M. CHANCY, RPH

Mr. Chancy. Chairman Burgess, Ranking Member Green, members of the subcommittee, thank you for conducting this hearing. My name is Hugh Chancy. I have been practicing community pharmacy since 1988. I am currently an owner of five community pharmacies in the southern part of Georgia, and I am here on behalf of the National Community Pharmacy Association. I currently serve as NCPA board of directors. NCPA represents America's community pharmacists, including owners of more than 22,000 independent community pharmacies. I am here today as a healthcare provider and a small business owner to present my experience with restrictive contractual language, often called gag clauses, that may result in patients being charged inflated prices for their medications.

My first experience with so-called gag clauses occurred in 2015, when one of my pharmacies served several patients on the city's employment-sponsored insurance, including the city mayor. The city had just changed insurance providers, and many of my patients experienced a rise in their prescription copays. Specifically, the mayor's copay of his medication went from roughly \$7 to \$26.

When I noticed this difference, I informed the mayor that it would be cheaper if he paid cash for his prescription or off of his insurance. The mayor was fortunate to have the political wherewithal to contact the right people in charge of the city's insurance plan and to complain about the changes and the oddities of paying more for the prescription on insurance than off. It goes without saying that many of the patients do not have similar avenues to voice their concerns about prescription drug coverage.

After the mayor contacted the plan, the plan consulted with their PBM, who issued us a verbal warning to my pharmacy for talking to the patient about the drug cost. The PBM stated that we are in violation of our contract for disparaging the plan when we discuss the cost of the drug off insurance. We were told that if our pharmacy were to do so again, there would be consequences and possibly exclusion from the PBM's network.

The common denominator in all community pharmacies' experiences with gag clauses is a strained relationship with PBMs. When a patient comes to the pharmacy and presents insurance, the pharmacy is bound by the terms of the patient's insurance and the PBM's rules. Put simply, pharmacists do not play a role in determining the patient's financial responsibility for prescription medications that they access through any prescription drug coverage.

If a patient does not present insurance or if a patient inquires directly, however, pharmacies can tell the patient alternative means to purchase a drug. When a PBM is involved, however, communication with the patient becomes murky, because pharmacies are contractually required to charge the patient what the PBMs

say when the prescription is processed.

I am often asked what gag clauses look like in contracts, but the answer to that question is not as simple as it may seem. The expression "gag clauses" is a misnomer, because what is most often being referred to are multiple contract provisions or requirements embedded in lengthy PBM provider manuals that include overly broad confidentiality requirements and nondisparagement clauses. Some PBMs have even included provisions that can be interpreted as prohibiting communication with news media, policymakers, and even elected officials.

Ultimately, these provisions have the effect of chilling a range of pharmacist communications with patients for fear of retaliation by the PBM. For this reason, the gag clause issue goes well beyond drug price disclosures. Further, community pharmacies like mine have very little negotiating power to strip these provisions out of their contracts.

As a solution to this problem, community pharmacies need a place to point into law that will allow for the free flow of information between them and the patients. NCPA supports the discussion draft that is the focus of this hearing. The draft is legislation to prohibit gag clauses in Medicare and private insurance by banning health plans from restricting a pharmacy's ability to inform customers about the lower cost, the out-of-pocket price for their prescription.

Additionally, NCPA appreciates the work that Congressmen Buddy Carter and Peter Welch have done in introducing legislation that would also meaningfully address contract provisions that prohibit or penalize a pharmacist from communicating different cost

options to their patients.

Also, I was pleased to hear that CMS recently sent a letter to plan sponsors and Medicare explaining that any form of gag clauses in contracts is unacceptable. In addition, 25 States have passed legislation prohibiting gag clauses. These actions give pharmacists the ability to point to laws and rules that prevent PBMs from restricting free flow of information.

In conclusion, as Congress demands increased transparency in the prescription drug marketplace, this committee can provide a much needed stake in the ground to allow pharmacists to freely discuss drug costs with their patients. Providing the free flow of this kind of information is a step in the right direction to meaningfully addressing drug costs for Americans. Thank you.

[The prepared statement of Mr. Chancy follows:]



United States House of Representatives Energy and Commerce Committee

Subcommittee on Health Hearing

"Opportunities to Improve Health Care"

Written Testimony of:

Hugh Chancy, R.Ph., Chief Executive Officer, Chancy Drugs

On Behalf of the National Community Pharmacists Association (NCPA)

September 5, 2018

Chairman Burgess, Ranking Member Green, and Members of the Subcommittee:

Thank you for conducting this hearing that focuses on egregious contract clauses that PBMs impose on pharmacies and providing me the opportunity to share how these clauses have impacted the relationship between my patients and me. My name is Hugh Chancy, and I have been a community practice pharmacist since 1998 and currently am a pharmacist-owner of five community pharmacies located in southern Georgia. I am here on behalf of the National Community Pharmacists Association (NCPA) where I currently serve on NCPA's Board of Directors. NCPA represents America's community pharmacists, including the owners of more than 22,000 independent community pharmacies. I am here today as a healthcare provider and small business owner to present my experience with restrictive contractual language (often referred to as gag clauses) that may result in patients being charged inflated prices for their medications.

THE VOICE OF THE COMMUNITY PHARMACIST®

(703) 683-8200 PHONE
(703) 683-3619 FAX

My first experience with so called gag clauses occurred in 2015 when one of my pharmacies in a rural city in southern Georgia served several patients on the city's employer-sponsored insurance, including the city's mayor. The city had just changed insurance providers and many of my patients experienced a rise in their prescription co-payments. Specifically, the mayor's co-payment for one medication went from roughly \$7 to \$26. When I noticed this difference, I informed the mayor that it would be cheaper if he paid for his prescription off his insurance. The mayor was fortunate to have the political wherewithal to contact the right people in charge of the city's insurance plan to complain about the change changes and the oddity that paying for the prescription off insurance was a better deal. It goes without saying that other patients do not have similar avenues to voice their concerns about their prescription drug coverage.

What happened next has become a common story. After the mayor contacted the plan, the plan consulted with their PBM who then issued a verbal warning to my pharmacy for talking to patients about their drug costs. The PBM stated we were in violation of our contract for disparaging the plan when we discussed the cost of a drug off insurance. We were told that if our pharmacy were to do so again, there would be consequences, including exclusion from PBM networks.

The common denominator in all community pharmacies' experiences with gag clauses is a strained relationship with the PBMs. When a patient comes to the pharmacy and presents insurance, the pharmacy is bound by the terms of that patient's insurance and the PBM's rules. Put simply, pharmacists do not play a role in determining a patient's financial responsibility for

prescription medications that they access through any prescription drug coverage. If a patient does not present insurance or if a patient inquires directly, however, pharmacies can tell the patient alternative means to purchase a drug. When a PBM is involved, however, communication with the patient becomes murky because pharmacies are contractually required to charge the patient what the PBM says when the prescription is processed.

I am often asked what gag clauses look like in contracts but the answer to that question is not as simple as it may seem. The expression "gag clauses" is a misnomer because what is most often being referred to are multiple contract provisions or requirements embedded in lengthy PBM provider manuals that include overly broad confidentiality requirements and non-disparagement clauses, as well as requirements that pharmacies charge insured patients what the PBM says at point of sale. Some PBMs have even included provisions that can be interpreted as prohibiting communication with news media, policy makers, and elected officials. The following is an example of one such provision:

<u>contacting Sponsors or Media</u>. Provider hereby agrees (and shall cause its affiliates, employees, independent contractors, shareholders, members, officers, directors and agents to agree) that it shall not engage in any conduct or communications, including, but not limited to, contacting any media or any Sponsor and/or Sponsor's Members or other party without the prior consent of [PBM]. Further, Provider acknowledges and agrees that any breach of this Section by Provider (or any affiliate, employee, independent contractor, shareholder, member, officer, director or agent) would cause [PBM] immediate and irreparable injury or loss that cannot be fully remedied by monetary damages. Accordingly, in the event of a breach of this Section by Provider (or any affiliate, employee, independent contractor, shareholder, member, officer, director or agent), [PBM] shall be entitled to specific performance, including immediate issuance of a

temporary restraining order or preliminary injunction enforcing the terms of this Agreement, and to judgment for damages (including reasonable attorneys' fees and costs) caused by the breach, and to all other legal and equitable remedies available to [PBM].

Ultimately, these provisions have the effect of chilling a range of pharmacist communications with patients for fear of retaliation by the PBM. For this reason, the gag clause issue goes well beyond drug pricing disclosures. Further, community pharmacies like mine have very little negotiating power to strip these provisions out of our contracts.

As a solution to this problem, community pharmacies need a place to point to in the law that will allow for the free flow of information between them and their patients. NCPA strongly supports the Discussion Draft that is the focus of this hearing. The Draft is legislation to prohibit "gag clauses" in Medicare and private insurance by banning health plans from restricting a pharmacy's ability to inform a customer about the lower cost, out-of-pocket price for their prescription.

Just this summer, I was pleased to hear that the Center for Medicare and Medicaid Services (CMS) sent letters to plan sponsors in Medicare explaining that any form of gag clauses in contracts is unacceptable. In addition, twenty-five states have passed legislation prohibiting gag clauses. These actions give pharmacists the ability to point to laws and rules that prevent PBMs from restricting the free flow of information.

Conclusion

In conclusion, as Congress demands increased transparency into the prescription drug marketplace, this Committee can provide a much-needed stake in the ground to allow pharmacists

to freely discuss drug costs with their patients. Providing for the free flow of this kind of information is a step in the right direction to meaningfully address drug costs for Americans. Thank you.

Mr. BURGESS. Thank you, Mr. Chancy. Thanks for sharing your testimony with us.

Mr. Cunningham, you are recognized for 5 minutes to summarize your opening statement, please.

STATEMENT OF CURTIS CUNNINGHAM

Mr. CUNNINGHAM. Thank you. Chairman Burgess, Ranking Member Green, and members of the subcommittee, thank you for the opportunity to discuss Money Follows the Person Program.

In addition to serving as Assistant Administrator for Long-Term Care Benefits and Programs in Wisconsin, I am also the Vice President of the National Association of States United for Aging and Disabilities, known as NASUAD, which is a nonpartisan association that represents administrators of aging, disability, and long-term supports and services in all 50 States, District of Columbia, and territories.

I am also designated as the Wisconsin disability director and serve on the National Policy Work Group for the National Association of State Directors of Developmental Disability Services.

I am honored to be here today to represent NASUAD and speak about Money Follows the Person and its impact on individuals that

require long-term supports and services.

The MFP program, as it is frequently called, was first created by the Deficit Reduction Act of 2005 as a way to provide States with increased resources and flexibilities that assist in the transition of individuals from institutional long-term care settings to home and community-based services.

The creation of MFP gave States crucial tools to increase choices or options for individuals who receive long-term services and supports in accordance with the landmark Olmstead decision that mandates that States ensure that participants receive services in the most integrated setting based on their needs and their preferences. States began operating MFP in 2007, and between 2007 and 2017, 43 States transitioned over 75,000 individuals into the community.

MFP also results in significant cost savings. According to the national MFP evaluation, the average annual person's spending during the first year following the transition into the community declined by over \$20,000 for older adults and people with disabilities and by over \$48,000 for individuals with intellectual and developmental disabilities. All told, this has resulted in \$1 billion in savings during the first year of transition alone for these individuals.

The evaluation also estimated that 17 States evaluated, roughly one-quarter of the older adults and one-half of the individuals with intellectual and developmental disabilities would not have transitioned without the gupport of MED.

transitioned without the support of MFP.

One of the reasons MFP provides an opportunity for deinstitutionalization for individuals who would not otherwise move into the community is due to the flexible services that this program provides.

MFP allows for supplemental services that are not covered through the standard Medicaid long-term services and supports, and provides opportunities for innovation to address some of the common barriers to community transitions. Some examples include, in Wisconsin, we funded community living specialists who review nursing home diagnostic data to identify people who indicate they would like to move into the community, and these community spe-

cialists assist them in that movement.

Nearly every State has identified lack of accessible affordable housing as a significant challenge that can prevent community placements. In Tennessee, MFP funded a housing counseling and a pilot program to support bridge subsidies for individuals leaving institutions. Many States also use MFP funding to support programs that help beneficiaries gain and maintain employment, provide behavioral supports, provide outreach consultation with nursing facilities, and then also provide grants to Tribal entities to develop their own community relocation initiatives.

Critically, in Wisconsin, many other States use MFP funds to address waiting lists through diversion initiatives and expand available slots for their community-based waivers. States also use MFP to support Aging and Disability Resource Centers, which provide comprehensive information and referral services to keep people in the community. Finally, MFP also serves several States in their

person-centered thinking and organizational thinking.

Finally, it is important to remember that, behind each of these statistics, there are real people. I would like to share one of those stories. In Delaware, MFP changed the life of a young mother of three who was a victim of a violent crime. She found herself in a nursing home due to her injuries, which left her paralyzed from the waist down. Prior to the crime, she was working, supporting her family; and while in the facility, she had no income. Being in the nursing facility was difficult for her and her children. While they could visit her in the facility, she was not at home to be part of their daily lives or put them to bed at night.

MFP was able to transition her home with her children and her mother as their caretaker after spending 8 months in the facility away from her children. After the transition, she continued to improve the quality of life. She is learning how to drive an adapted vehicle. Her intention is now to attend vocational rehab so that she

can return to work to support herself and her children.

As you can see, these unique programs provide benefits to a wide range of people. Not only is it valuable to States. It is fiscally responsible and results in savings for the Federal Medicaid program. Lastly and most importantly, it improves the lives for the individuals we serve.

Although significant progress and success has been made in rebalancing HCBS, there is still a lot of work that can be done. Almost 60 percent of all Medicaid expenditures for long-term services and supports are delivered to older adults and people with physical disabilities or for institutional care.

On behalf of NASUAD, I therefore encourage Congress to continue this important program. Our members across the country have seen great value in the program, and the interventions have become more effective as the States experimented with and learned from innovative ways to provide these supports.

We encourage Congress to continue to work with NASUAD, our membership, and the broader aging and disability community to demonstrate the financial and human benefits of a program in order to secure the extension of MFP. Thank you for the opportunity to comment, and I would be happy to answer any questions you may have.

[The prepared statement of Mr. Cunningham follows:]

STATEMENT OF:

Curtis Cunningham

Assistant Administrator for Long Term Care Benefits and Programs
Division of Medicaid Services
Wisconsin Department of Health Services
Vice President
National Association of States United for Aging and Disabilities

REGARDING:

The Money Follows the Person Program and the EMPOWER Care Act

TO:

Subcommittee on Health Energy and Commerce Committee United States House of Representatives

September 5, 2018

Chairman Burgess, Ranking Member Green, and members of the subcommittee, thank you for the opportunity to discuss the Money Follows the Person Program. In addition to serving as the Assistant Administrator of Long Term Care Benefits and Programs in the Wisconsin Division of Medicaid Services, I am also the Vice President of the National Association of States United for Aging and Disabilities, known as NASUAD, which is a nonpartisan association that represents administrators of aging, disability, and long-term services and supports programs in all 50 states, the District of Columbia, and the territories. I am also designated as the Wisconsin Disability Director and serve on the national policy workgroup of the National Association of State Directors of Developmental Disabilities Services. I am honored to be here today to represent NASUAD and to speak about the Money Follows the Person program and its impact on individuals who require long-term services and supports.

The MFP program, as it is frequently called, was first created by the Deficit Reduction Act of 2005 as a way to provide states with increased resources and flexibilities that assist with the transition of individuals from institutional long-term care settings to home and community-based services. The creation of MFP gave states crucial tools to increase choices and options for individuals who receive long-term services and supports in accordance with the landmark Olmstead decision that mandates states to ensure that participants receive services in the most integrated setting based on their needs and preferences. States began operating MFP in 2007, and between 2007 and 2017 forty-three states transitioned over 75,000 individuals into the community. MFP was a crucial part of state progress in deinstitutionalization, which led to Medicaid programs spending a greater proportion of expenditures on home and community-based services than in institutional settings for the first time in Federal Fiscal Year 2013. I have seen this type of success firsthand in Wisconsin. In our agency, we use a scorecard to track our progress at improving key measures around deinstitutionalization, participant choice, and quality of life. Among other measures, we have specifically seen great progress in reducing the percentage of individuals on waiting lists as well as increasing the balance of expenditures in the community and we believe that an extension of MFP will help us continue these efforts.

MFP also results in significant cost savings. According to the national MFP evaluation, average annual per person spending during the first year following transition declined by over \$20,000 for older adults and people with disabilities, and by over \$48,000 for individuals with intellectual/developmental disabilities. All told, this resulted in over \$1 billion in savings during the first year of transitions alone for

¹ Olmstead v. L. C., 527 U.S. 581 (1999)

² https://www.medicaid.gov/medicaid/ltss/money-follows-the-person/index.html

³ https://www.medicaid.gov/medicaid/ltss/downloads/ltss-expenditures-fy2013.pdf

these individuals.⁴ The evaluation also estimated that, within 17 states evaluated, roughly one quarter of older adults and one half of individuals with Intellectual and/or Developmental Disabilities would not have transitioned without support from MFP. This substantiates that MFP is not just good for participants, but it is also fiscally a prudent grant program that results in hundreds of millions of dollars in savings during the first year after participants' transitions, and substantial additional savings during subsequent years.

One of the reasons that MFP provides an opportunity for deinstitutionalization of individuals who would not otherwise move into the community is due to the flexible services that the program allows. MFP allows for supplemental services that are not covered through standard Medicaid long-term services and supports. This provides an opportunity for innovation to address some of the common barriers to community transitions. One example of how Wisconsin uses MFP funding is to fund community living specialist. These individuals review nursing diagnostic information to see which individuals currently residing in nursing homes indicate that they want to go home or move into a community placement. These specialists utilize a wide range of supports to assist individuals identify a residence, as well as link these participants with extensive supports that help them remain in their home.

Nearly every MFP state identified a lack of accessible, affordable housing as a significant challenge that could prevent a community placement. Tennessee addressed this issue through a multifaceted approach, including housing counseling, and a pilot program to support bridge subsidies for individuals as they leave the institution. States also used MFP funding to support programs that help beneficiaries gain and maintain employment; provide behavioral support expertise; provide outreach and consultation with nursing facilities; and provide grants to tribal entities wanting to pursue their own MFP initiatives. And critically, in Wisconsin and many other states, we also used MFP funds to address waiting lists through diversion initiatives and expansion of available slots in some of our community-based waivers.

States also used Money Follows the Person funding to support Aging and Disability Resource Centers, which provide comprehensive information, referral, and options counseling services to help individuals access the most appropriate long-term services and supports based on their needs and

 $^{^{4}\,\}underline{\text{https://www.medicaid.gov/medicaid/ltss/downloads/money-follows-the-person/mfp-rtc.pdf}}$

⁵ https://www.kff.org/medicaid/issue-brief/tennessees-money-follows-the-person-demonstration-supporting-rebalancing-in-a-managed-long-term-services-and-supports-model/

preferences. In Virginia, they were able to use MFP dollars to move from a 16/7 information and referral system to a 24/7. And MFP also supported several states efforts to improve their personcentered thinking, organizational training, and technical assistance.

It is also important to remember that behind each of these statistics are real people — individuals and families whose lives have been changed for the better due to the MFP program. I would like to take a moment to share a few stories from around the country of people who have been helped by MFP.

In 2009, a woman from Tennessee named Mrs. Carol found that her health had taken a serious and critical decline. She weighed 547 lbs. and her body was failing her. She had cardiac issues, diabetes, depression, and renal failure. The doctor in the hospital told her there was nothing else they could do for her and sent her to a nursing facility as she needed 24/7 care. She felt that she had no voice and no worth. She required 2-3 person assistance to be moved and was dependent on others for everything; she could not even roll over without extensive assistance.

Things began to improve in 2010, shortly after Tennessee engaged with health plans to implement managed long-term services and supports. Through a combination of health plan interventions and MFP, Carol was encouraged for several years to transition out of the nursing facility. And although she was very depressed the programs encouraged her and assisted her with obtaining services necessary to lose weight and gain strength both physically and emotionally. The Money Follows the Person program utilized a person-centered approach to allow her to take control of her life and future. She was listened to and provided with important education. She made the decisions for her life and the rate of speed in which they occurred. She successfully transitioned out of the nursing facility in August of 2016 and is now back home with her husband and son.

Tennessee and her health plan listened to her and she gradually reduced her services as she gained independence. She was now in charge of everything in her life, and the services were only there to support her. She worked with her health plan to initiate consumer directed services and eventually changed her services as her support needs decreased. In Mrs. Carols' words she "graduated" and voluntarily disenrolled from Tennessee's CHOICES program in April of 2018. She now spends time as an elder advocate, volunteer with Hospice and enjoying other hobbies.

Robert Bond was sent to a Virginia nursing home in 2010 at the age of 25 years old. Mr. Bond had been diagnosed with Autoimmune Necrotizing Myopathy. He was aspirating for over a year and

then had pneumonia which placed him in the hospital. His parents were not sure that he was going to make it and did not have the resources to care for him at home. At discharge, he was moved to Sentara Nursing Facility. Mr. Bond had been attending Liberty University in Lynchburg, Virginia prior to his illness which had now placed him in a wheelchair permanently. As a quadriplegic, he had complex medical needs.

Youthful, Mr. Bond did not want his illness to slow him down. He wanted his own apartment and realized that he would need one that was handicap accessible. His illness gave him a new appreciation for life. Later, he met Sharon Franklin from the Independence Center who told him that that there was a resource for transitioning that would supply the supports that he needed. Mr. Bond had heard so many stories previously and was unsure if this could be true. The provider gave Mr. Bond a chance to think about the option and returned a month later. Mr. Bond decided to take a chance and proceeded forward by enrolling in the Money Follows the Person Program. A month later, Mr. Bond moved into his father's house and then later was able to be moved into his own apartment. Services provided included a water dispenser and a portable cooktop stove because he didn't have great reach. These items were most important to him. They provided a sense of independence when the attendant was not around. Mr. Bond also received new clothing and later, the program allowed for an electric door opener and a sky bell to be installed.

Since the transition or second chance at life, Mr. Bond is now employed in an eye clinic in the tidewater area, assists others transitioning from the nursing facility, and has also provided inspiration and motivational counseling to others with severe disabilities. His long-term goal is to have a second chance at driving.

In Delaware, MFP helped change the life of a young mother of three who was the victim of a violent crime. She found herself in a nursing home due to the injuries which left her paralyzed from the waist down. Prior to the crime she was working and supporting her family, while in the facility she had no income. Being in the nursing facility was difficult on her and her children. While they could visit her at the facility, she was not at home to be a part of their daily lives or to put them to bed at night. MFP was able to transition her to a home with her children and her mother, as a caretaker, after having spent eight months in a facility, away from her children. After her transition, she has continued to improve her quality of life and she is learning how to drive an adaptive vehicle. Her intention now is to attend Vocational Rehabilitation so that she can return to work to support herself and her children.

As you can see, this is a unique program that provides benefits to a wide range of people. Not only is it valuable to the states, it is fiscally responsible and results in savings to the federal Medicaid program. Lastly, and most importantly, it improves the quality of lives for the individuals we serve.

Although significant progress and success has been made regarding rebalancing to HCBS, there is still much work to be done. Almost 60 percent of all Medicaid expenditures for long-term services and supports delivered to older adults and people with physical disabilities are for institutional care. The recently-released MFP evaluation found that 71 percent of the individuals transitioned through the program were older adults or people with physical disabilities. The evaluation also indicated that the aggregate number of transitions is growing.

On behalf of NASUAD, I therefore encourage Congress to continue this important program. Our members across the country have seen great value from the program, and the interventions have become more effective as states have experimented with and learned from innovative ways to provide these supports. We encourage Congress to continue to work with NASUAD, our membership, and the broader aging and disability community to demonstrate the financial and human benefits of the program in order to secure an extension of the MFP program.

Thank you for the opportunity to comment, and I would be happy to answer any questions you may have.

 $^{^6\,\}underline{https://www.medicaid.gov/medicaid/ltss/downloads/reports-and-evaluations/ltssexpendituresffy2015 final.pdf}$

 $^{^{7}\,\}underline{\text{https://www.medicaid.gov/medicaid/ltss/downloads/money-follows-the-person/mfp-rtc.pdf}}$

Mr. Burgess. Thank you, Mr. Cunningham.

The chair now recognizes Mr. Matt Salo for 5 minutes to summarize your opening statement, please.

STATEMENT OF MATT SALO

Mr. SALO. Thank you so much, Chairman Burgess, Ranking Member Green, members of the subcommittee. My name is Matt Salo, and I represent the National Association of Medicaid Directors. These are the folks in each of the 56 States and U.S. terri-

tories who run the Medicaid program.

I want to briefly just frame Medicaid and what my members do before touching briefly on three of the bills that you are currently considering. I think it is important to recognize just how big, complex, and important Medicaid is. Medicaid covers more than 70 million Americans. We spent more than \$550 billion last year, and it is roughly 30 percent of the average State budget and 3 percent of the Nation's GDP.

Medicaid is the backbone of the U.S. healthcare system, and in many ways and for many of the populations that we are talking about today, it is the backbone of America. And I think that it is important, despite the complexity of all the things we are talking about—we are talking about some very, very different components of Medicaid today—it is important to keep in mind the importance and the breadth of the things that we try to achieve. And arguably, I think Medicaid is clearly the largest and most important healthcare program, not only in this country but arguably in the world.

One way that I think it is important to also frame it is, similar to the parable of the six blind men trying to describe an elephant and sort of only looking at what they can see and touch, if you look at any of the pieces today, you might think, oh, well, Medicaid's a program for medically complex kids or Medicaid's a program for frail seniors or adults with disabilities. It is all of those things and many, many more.

My members, the State Medicaid directors, their job, no matter what State they are in, is to try to improve the healthcare system to deliver a better healthcare experience to the people that we serve while being responsible stewards of both State and Federal taxpayer dollars, and to do so in ways that are meaningful and relevant in the State and in the cultural community that they reside.

My members are driving significant complicated healthcare reforms to the delivery system of Medicaid and the broader U.S. healthcare system. We are driving sustainable payment reforms to try to bring Medicaid from a fee-for-service system into a value-based system. This is complicated. This is multisector. This is multiyear. This is difficult work, but it is critically important.

Three of the bills I want to touch on real briefly. We have talked a lot about the ACE Kids Act. This has been a very complex, a very fluid piece of legislation. As Chairman Barton has referenced, it has been around for at least 6 years now. I would hope that the message that we give is that if we want something like this to be successful, look to the example of CHIP.

CHIP was a program created in 1997 that sought to improve coverage and care for kids in this country. And the way that it evolved

and the way that it was created and the way that it ultimately has become one of the most bipartisan and most successful programs that this committee has worked on is that it embraced two concepts, one of which is that if we want States to make significant progress in areas like this, it has got to embody two principles: one, enhanced Federal support; and, two, increased State flexibility. Because no matter what we are looking at, the ways that States, from New York to Texas to California and everything in between, their healthcare cultures, their healthcare systems are different, and it has to be cognizant and respectful of those differences as we are trying to provide the best possible healthcare, not to just to those kids but to everybody else that we serve. So, if we want this to be successful, we have to ensure that it is flexible, ensure that there is strong sustained Federal support, and I believe that we can get there.

Second, very, very briefly, Money Follows the Person. I can be very brief on this, because there is no question that this works. There is no question this is highly successful. There is no question this is incredibly important to continue not just for the short-term but for the long-term. I think we should be talking about how long can we reauthorize this for. Can we make this permanent? And that is one of the things that we always talk about is, if we find something that works, let's make it permanent. And I think clearly this works, and clearly this is an important part of our conversation.

The final piece on the Medicaid Fraud Control Units. Very important conversation, especially in light of increased movement from institutional to noninstitutional. But I would urge you also to think more broadly about how we are approaching program integrity. Program integrity is not just fraud or abuse or safety. It is those things, but it is more.

The Fraud Control Units exist within the Attorney General's Office, not within Medicaid. We have to make sure that if we are going to invest in targeted areas like this, which we should, we have to make sure that we are coordinating the efforts across the system. And I have got a couple of other ideas, in terms of things that we could do to improve this.

And then, just finally, I will say I would be happy to also talk about some of the other possible reforms in Medicaid that my members would love to see to help them in their efforts to improve the Medicaid program for taxpayers, for beneficiaries, for providers, and for all of us. So I would be happy to answer questions at the end, and thank you for having me.

[The prepared statement of Mr. Salo follows:]



Testimony of

Matt Salo

Executive Director

National Association of Medicaid Directors

Before the

United States House of Representatives Committee on Energy and Commerce; Subcommittee on Health

"Opportunities to Improve Health Care"

September 5, 2018

Chairman Burgess, Ranking Member Green, and members of the Subcommittee, thank you for the opportunity to testify today on legislative proposals to enhance the oversight of the Medicaid program and tools for states to improve health outcomes for key covered populations.

About NAMD

My name is Matt Salo, and I am the Executive Director of the National Association of Medicaid Directors (NAMD). NAMD is a bipartisan, nonprofit, professional organization representing leaders of state Medicaid agencies across the country. Our members drive major innovations in health care while overseeing Medicaid, the nation's largest health insurer which provides unique benefits and supports to its beneficiaries. NAMD serves as the voice for state Medicaid Directors in national policy discussions, supports state-driven policies and practices that strengthen the efficiency and effectiveness of Medicaid and actively monitors emerging issues in Medicaid and health care policy. NAMD also supports the leadership development of Medicaid Directors and their senior staff as they manage both the strategic orientation and day-to-day operations of the nation's largest health insurer.

Medicaid, together with the Children's Health Insurance Program (CHIP), provides health coverage for more than 71 million Americans; approximately one in five Americans are covered by these programs. Medicaid is jointly funded by the federal government and the states, which together spent \$553 billion in FY 2016, and is administered by states under broad federal standards.

The Medicaid population is diverse, including eligible children, pregnant women, low-income families, elderly adults, people with chronic conditions and people with physical, developmental or behavioral needs. Medicaid funds close to 50 percent of all births and is the primary payer of long-term care in this country. Medicaid also provides most of the nation's funding for HIV/AIDS-related treatments and mental health services, among other forms of health care. More than 40 percent of Medicaid spending is aimed at addressing the shortfalls of the Medicare program for individuals dually eligible for both. Medicaid is also one of the nation's largest payers of behavioral health and substance use disorder services, making it a key tool in the toolbox for tackling the ongoing opioid crisis.

The unique characteristics of Medicaid, with its joint federal and state funding structure and significant latitude for states to customize their programs to best serve the needs of their local populations, are vital to its success. As the Subcommittee considers statutory modifications to Medicaid, the core characteristics of flexibility for states to most appropriately administer their programs and federal investment in Medicaid's tools will ensure the program continues to provide high quality care to Medicaid beneficiaries and be a responsible steward of state and federal taxpayer dollars.

ACE Kids and the Role of Medicaid in Covering Medically Complex Children

As previously noted, Medicaid and the Children's Health Insurance Program (CHIP) are core sources of coverage for the nation's children. This includes children with complex medical conditions who require specialized benefit designs and services, such as children with serious behavioral health needs, rare pediatric diseases, or those in the foster care system.

Many states have prioritized developing initiatives that take advantage of delivery system characteristics and existing provider infrastructure to improve care for this complex and vulnerable population. These initiatives can be innovative and cross-cutting, tackling both medical services and the broader context of a child's life to improve outcomes. For example, Florida's Medicaid managed care program uses a specialized plan focused on providing services to children in foster care, and New York is piloting a unique approach under which pediatricians in a specific area are held accountable for a child's readiness to enter the school system. Efforts like these are underway across the country, demonstrating Medicaid Directors' commitment to continuing to enhance care for children.

It is important to note that when we speak about the medically complex child population, we are discussing a population that is not monolithic. Their needs are diverse, as any number of conditions can be categorized as medically complex. For this reason, states will continue to need flexibility from our federal partners to design and implement solutions that reflect the unique needs of the children covered in the state. A program design that succeeds in urban areas in Minnesota may not be transferable to frontier counties in New Mexico. That said, Medicaid Directors are always eager to learn from one another to address common challenges. Identifying

effective models, the factors driving the model's success, and sharing that information widely across the states can raise the bar nationwide. NAMD works to foster this dialogue among our members, and our federal partners at the Centers for Medicare and Medicaid Services (CMS) do so as well.

What Medicaid Directors would prefer to avoid is being required to adopt a specific model or benefit design for the entirety of the medically complex child population. For the reasons noted above, a one-size-fits-all approach to this population is less likely to achieve the shared aims of improved health outcomes than an approach which emphasizes the need for flexibility and creativity and accounts for the facts on the ground.

Basing new federal options for states in this area on existing models with which states are already familiar, such as health homes, is a promising approach. Many states are already using the health home model to target specific and complex subpopulations, such as individuals living with multiple chronic conditions, individuals with HIV/AIDS, and individuals with serious mental illness. Expanding the health home option to incorporate medically complex children, providing strong federal investment in the model, and maintaining the flexibilities the model offers for states to customize a health home for a specific population of complex children would likely garner state interest and promote improved health outcomes.

As a final point, consider the creation of CHIP and the success of that program as illustrative of the most effective approach to enhance children's coverage. Prior to CHIP's creation in 1997, states had the option to expand their Medicaid programs to cover what would become the CHIP-eligible population. Some states chose to do so, though not all did. CHIP positively changed this environment by adopting two key policies: first, giving states new tools to create benefit designs and coverage not available under Medicaid; and second, providing strong federal investment via a higher matching rate for CHIP. This combination of flexibility for states and meaningful federal financial support produced a successful program which helped significantly reduce the uninsured rate among children and enjoys strong bipartisan support to this day. Applying these principles of flexibility and investment to a new option for medically complex children will produce similar success.

Money Follows the Person: A Valuable Tool Supporting Rebalancing Long-Term Care Towards the Community

Medicaid is the nation's primary insurer of long-term services and supports (LTSS). The populations receiving these services may have physical, intellectual, or developmental disabilities that require specialized supports or even around-the-clock care. Others may simply be individuals who, as they grow older, need help with their daily activities. Many of those receiving Medicaid LTSS are dually eligible for Medicare, receiving services from both programs. Although people who receive Medicaid-funded LTSS represent a small proportion of the total membership, they typically have complex needs and represent almost half of Medicaid spending.

As the Subcommittee knows, by statute Medicaid provides mandatory coverage of LTSS in institutional settings, such as nursing homes. Medicaid can also provide coverage for in home-and community-based services (HCBS), though this is at states' option and states must seek a waiver from CMS to do so. This is often referred to as the "institutional bias" in the Medicaid statute. All states have elected to use one or more waivers, which allow individuals to receive their supports at home and/or in a community setting of their choice.

A key objective of both states and CMS for the past several years has been to rebalance the provision of Medicaid LTSS from institutional settings towards the community. Rebalancing refers to reducing reliance on institutional care and expanding access to community-based LTSS. A rebalanced LTSS system gives Medicaid members greater choice in where they live and from whom they receive services. It also delivers LTSS that are integrated, effective, efficient, and person-centered. Finally, increasing the proportion of LTSS spend in the community has enabled states and the federal government to achieve significant cost savings.

This work is challenging, resource-intensive, and requires sustained effort. Fortunately, states have received valuable support for their rebalancing efforts in the form of the Money Follows the Person (MFP) Demonstration grant program. First passed in 2005, MFP has provided states with significant financial resources to develop the infrastructure necessary to support individuals' transitions from institutions back into the community. States have leveraged MFP dollars creatively, drawing on these funds to educate consumers about LTSS, support development of

the HCBS workforce, expand the reach of existing HCBS programs, test new service options such as substance use disorder interventions, and provided a valuable source of longitudinal data spanning over a decade on the barriers to rebalancing and the solutions needed to address them. In rural states where institutions may be particularly isolating, MFP dollars have helped return individuals to their local communities. Thanks in part to MFP, for the first time in FY 2013, more than 50 percent of Medicaid LTSS spending took place in HCBS settings, and the trend appears to be continuing.

Unfortunately, the success of MFP is currently in jeopardy. The program sunset in 2016, though grant dollars are available to states through FY 2018 and may be spent into FY 2019. That means states are currently tasked with winding down MFP-supported programs, in case a reauthorization does not occur. States are actively working with CMS to identify which elements of MFP programs can continue to be supported via other authorities, but it is clear that without reauthorization and associated funding many MFP-funded programs will need to be ended. This would negatively impact the ongoing rebalancing work states are undertaking and has the potential to greatly increase Medicaid LTSS spending. The process of planning for program wind-down, even if such measures prove to be unnecessary, strains limited state resources and creates uncertainty for providers and beneficiaries.

In order to avoid these problems, Medicaid Directors strongly support a prompt reauthorization of MFP. This reauthorization should occur quickly enough to provide states with continuity for existing programs. We are pleased to see the Subcommittee considering reauthorization, and we support the policy modifications in the current legislative package – especially the alteration of the institutional stay requirement for MFP dollars from 90 days to 60 days. Shortening the required stay in an institutional setting would better support individuals who enter facilities for rehabilitation, and unfortunately tend to become long-term residents, absent supports to enable them to move back to the community.

Enhancing Investment in State Program Integrity Efforts

Medicaid Directors understand the critical importance of safeguarding the integrity of the Medicaid program, and take seriously their obligation to ensure scarce state and federal resources

are being well utilized and beneficiaries are safely and appropriately cared for. States are strongly committed to identifying and eliminating waste, fraud, abuse, inefficiencies, and neglect in their programs. Federal tools and resources for states to conduct program integrity activities are greatly appreciated.

Medicaid agencies are not alone in the effort to improve Medicaid program integrity. There are many entities with responsibilities and authority in this area, including federal auditors within CMS, the Health and Human Services Office of the Inspector General, and the Government Accountability Office. There are also separate entities at the state level, such as Medicaid Fraud Control Units (MFCUs).

The Subcommittee is considering legislation to provide federal funding for MFCU investigations in non-residential settings. As we noted in the discussion on MFP, states are looking to increase the amount of LTSS provided in these settings, and agree that ensuring these settings are safe is a critical aspect in continuing this work. However, as MFCUs are separate from the Medicaid agency and primarily oriented towards law enforcement, it is important to recognize the need for coordination among the Medicaid agency, law enforcement, and other entities playing roles in this area. Careful consideration must be given to minimizing duplication across program integrity authorities and activities.

We wish to call the Subcommittee's attention to other statutory changes, beyond the MFCU funding change considered here, which can make Medicaid program integrity activities more robust and effective.

First, the federal investment in state Medicaid program integrity work can be enhanced. Currently, state program integrity activities are counted as administrative spending for purposes of federal match. The administrative match is 50 percent, the lowest level of federal match available. We encourage the Subcommittee to consider a higher match – such as 75 percent, which is what MFCUs receive – to maximize state resources invested in program integrity. Significant federal match for other key priorities, such as the 90 percent match for upgrading Medicaid data systems, has been highly successful. Similar consideration should be given for Medicaid program integrity.

The second potential change concerns how Medicaid overpayments identified by states are handled. Under current law, any time the state identifies an overpayment, it is obligated to return the federal share of that payment. The federal repayment must take place even if, for circumstances beyond the state's control, the state is unable to recoup the overpayment amount. While Congress has made changes to extend the window under which this repayment occurs, it must still occur regardless. This policy imposes a financial burden for states in circumstances where overpayments cannot be recouped, thereby creating a barrier to effective program integrity efforts. In essence, the policy punishes the state for conducting good program integrity practice in identifying overpayments. We encourage the Subcommittee to consider altering how identified overpayments are treated in instances where the states are unable to recoup the overpayments.

Conclusion

Thank you again for the opportunity to testify before the Subcommittee on these important topics. We look forward to continuing to work with you and providing the perspectives of Medicaid Directors on further improvements to the program and the individuals we serve.

Mr. Burgess. Thank you, Mr. Salo. Thanks. Just a historical note since two of you now have brought up the Deficit Reduction Act of 2005. It was late in December of 2005 when this committee passed the Deficit Reduction Act. Mr. Barton was chairman at the time. And now all these many years later to hear about an enduring part of that that actually did perform as indicated, it is gratifying. It was a big bill with a lot of moving parts, but I am grateful that that one did deliver.

Mr. Merrill, we are grateful to have your presence on the subcommittee dais today. You are recognized for $5\ \mathrm{minutes}\ \mathrm{to}\ \mathrm{summa}$

rize your opening statement.

STATEMENT OF RICK MERRILL

Mr. MERRILL. Thank you very much. I thank Congressman Barton, Chairman Barton, Chairman Burgess, and Ranking Member Green. You guys did such a great job describing ACE Kids and the importance of it and the benefits of it. I am not sure I could top

that, but I will do my best to equal this today.

Chairman Burgess, Ranking Member Green, and members of the subcommittee, I am Rick Merrill, the President and CEO of Cook Children's Health Care System in Fort Worth, Texas, and I am Chair of the Children's Hospital Association Board of Trustees. On behalf of my hospital system, our CHA member institutions and the patients and families we serve, thank you for the opportunity to speak in strong support of H.R. 3325, the Advancing Care for Exceptional Kids Act of 2017, or ACE Kids, as we refer to it.

We are extremely grateful to Representatives Barton and Castor for their leadership on behalf of children, as the original cosponsors of this bipartisan legislation, and to the nearly 100 additional House Members who have joined them as cosponsors. We also wish to thank the leadership of the Energy and Commerce Committee and the Health Subcommittee for devoting considerable time and resources to working toward solutions in this important area.

In addition, we want to recognize Chairman Burgess and Ranking Member Green for their longstanding leadership and support of the Children's Health Insurance Program and the recent reauthorization of the Children's Hospital Graduate Medical Education Program, which was passed by the Senate last evening. Thank you for that.

Last year, Cook Children's treated children from more than 35 States, recorded nearly half a million child visits in our 60 pediatric specialty clinics, 240 visits in our Mercy Department and Urgent Care Center, and registered over 11,000 inpatient admissions. With over 1.5 million patient encounters a year, Cook Children's provides comprehensive and coordinated care across our fully integrated system, including home health services and a health plan which enrolls over 100,000 Medicaid children, many of whom have serious disabilities.

For many years now, we have taken care of some very sick kids, and I think we have done a good job in our part of Texas, but I am here today to tell you that we could and should do better. Medicaid covers over 37 million children. A small percentage of these kids have complex medical conditions requiring ongoing and specialized care. These children have diagnoses that are multiple and

varied, from cerebral palsy to cystic fibrosis to congenital heart disease and even childhood cancers. They typically are under the continuous care of multiple pediatric specialists and require access to specialized care and additional services, often from outside their home State. Additionally, their care accounts for a drastically disproportionate percentage of Medicaid spending on children.

Behind each of these data points is a real child and family, families like the Beckwiths. Alex and Maddy Beckwith of Keller, Texas, are some of the most remarkable, kindest 14- and 4-year-olds that you could hope to meet, but they both also suffer from mitochondrial disease, along with other health issues. Mitochondrial disease is a serious condition without a cure. It re-

quires lifelong medication and therapy.

Due to their conditions, Alex and Maddy, their care is complex and ongoing. And so they actually have become like family members to the staff at Cook Children's. They see 15 specialists between them and require major interventions to remain medically stable. The ACE Kids Act is about improving care for children like Alex and Maddy by expanding access to patient-centered pediatric-focused coordinated care tailored to their unique needs. The ACE Kids Act would modify Medicaid's existing health home option to give States the ability to implement health home specifically targeting children with complex medical conditions.

These new pediatric health homes would follow national guidelines in implementing a care plan for the medically complex child, coordinating care from providers, such as physicians, children's hospitals, specialized hospitals, nonphysician professionals, and home health and behavioral health providers. These homes will help families manage the challenges associated with their child's care while improving quality of care for the children enrolled.

care while improving quality of care for the children enrolled.

Participation will be completely voluntary for these children.
Families, healthcare providers, and the pediatric health homes will work within the existing State's Medicaid program, including those States with Medicaid managed care. The focus of ACE Kids is creating opportunities for providers, plans, and States to collaborate

to provide the best quality of care for these children.

The ACE Kids Act is also about using existing Medicaid resources more efficiently. A large and growing body of research shows that coordinating care for people with chronic conditions can, indeed, reduce spending. The potential cost savings the ACE Kids model could produce have been demonstrated through projects supported by the Center for Medicare and Medicaid Innovation. The CMMI Coordinating All Resources Effectively Award, that is the CARE Award, implemented care coordination programs serving 8,000 children with medical complexity. Collectively, the 10 hospitals participating in the CARE Award, including Cook Children's, reduced emergency department visits by 26 percent, reduced inpatient stays by 32 percent, and in just the full year of operation coordinating care for these children, care ultimately reduced overall Medicaid costs for these children 2.6 percent. Additionally, prior independent analysis of the ACE Kids Act conducted shows substantial potential long-term savings in the Medicaid program.

The ACE Kids Act will create a data and quality framework to drive improvement in care and further reduce cost. The bill out-

lines a definition of children with medically complex conditions who will be eligible to participate in the program and includes standardized data reporting requirements related to their care. This information and sharing does not exist in Medicaid today. There is currently no national data available to inform our policies for children with medical complexity.

Since its original introduction in the 113th Congress, the ACE Kids concept has continued to evolve, based on extensive stakeholder feedback. This bill reflects the results of this collaborative process and has received support from many organizations dedicated to children's health.

In closing, the ACE Kids Act will have an opportunity to help children and their families who face some of the most significant health challenges. On behalf of children's hospitals nationwide and the thousands of children and families that we care for at Cook Children's, we look forward to working with Congress to pass ACE Kids this year and advance solutions that improve care for all kids. Thank you.

[The prepared statement of Mr. Merrill follows:]





Executive Summary

- Mr. Merrill is speaking in support of H.R. 3325, "The Advancing Care for Exceptional Kids Act (ACE Kids
 Act) of 2017" as President and CEO of Cook Children's Health Care System in Fort Worth, Texas and Chair of
 the Children's Hospital Association (CHA) Board of Trustees.
- The goals of the ACE Kid Act are improving care for children with medical complexity in Medicaid, driving
 improvements in quality, and reducing program spending.
- The ACE Kids Act will give states the option to implement health homes specifically serving children with complex medical conditions.
- The pediatric health homes established under the ACE Kids Act will implement a specific care plan for the
 medically complex child, coordinating care from multiple highly specialized providers such as physicians,
 children's hospitals, specialized hospitals, non-physician professionals, home health and behavioral health all
 with a goal of creating easier access to needed services.
- The bill creates incentives for states to establish these models by providing a higher Medicaid federal match for
 care coordination services provided by the new pediatric health homes.
- Participation will be completely voluntary for children, families and health care providers, and the pediatric
 health homes will work within the existing structure of a state's Medicaid program including those states with
 Medicaid managed care.
- A growing body of research shows that the coordination of care for people with chronic conditions can save
 money through reductions in inpatient hospital stays and emergency room visits, improved medication
 management, better compliance on preventive care, and a guarantee that care is provided as close to a child's
 home and community as possible. Potential cost savings from the ACE Kids Act have been demonstrated
 through projects supported by the Center for Medicare and Medicaid Innovation (CMMI).
- The ACE Kids Act will also create a data and quality framework to drive improvement in quality of care and
 further reduce costs. There is currently no consistent national data available to inform our policies for children
 with medical complexity.
- Finally, the ACE Kids Act lays the groundwork for additional future advances in care by sharing best practices
 across state Medicaid programs.



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Statement for the Record

Rick W. Merrill, Chair, Children's Hospital Association Board of Trustees and President and CEO, Cook Children's Health Care System

In support of H.R. 3325, "The Advancing Care for Exceptional Kids Act (ACE Kids Act)"

Submitted to the Subcommittee on Health, House Committee on Energy and Commerce September 5, 2018 Chairman Burgess, Ranking Member Green, and members of the Subcommittee, thank you for the opportunity to speak in support of H.R. 3325, "The Advancing Care for Exceptional Kids Act (ACE Kids Act)." I am Rick Merrill, president and CEO of Cook Children's Health Care System in Fort Worth, Texas and Chair of the Children's Hospital Association (CHA) Board of Trustees.

Last year, Cook Children's treated children from more than 35 states, recorded nearly a half million child visits to our 60 pediatric specialty clinics, 230,000 visits to our Emergency Department and Urgent Care Centers, and registered over 11,200 inpatient admissions. With over 1.5 million patient encounters a year, Cook Children's provides comprehensive and coordinated care across our fully integrated system, including Home Health services and a Health Plan, which enrolls over 138,000 children who rely on Medicaid, many of whom have serious disabilities.

CHA represents 220 hospitals nationwide dedicated to the health and well-being of our nation's children. These hospitals vary widely in size and specialty, but they all exist to put our children's health first. On behalf of my own hospital system, our CHA member institutions and the patients and families we serve, I wish to offer our strong support for H.R. 3325, the Advancing Care for Exceptional Kids (ACE Kids) Act.

We are extremely grateful to Reps. Barton and Castor for their leadership on behalf of children as the original cosponsors of this legislation, and to the more than 90 additional House members who have joined as co-sponsors. We also wish to thank the leadership of the Energy and Commerce Committee and the Health Subcommittee for devoting considerable time and resources to working towards solutions in this important area. In addition, we want to recognize the leadership of Chairman Burgess and Ranking Member Green on important issues affecting





children's health, including extending funding for the Children's Health Insurance Program (CHIP) and the recent reauthorization of the Children's Hospitals Graduate Medical Education program (CHGME).

Medicaid covers over 37 million children. A small percentage of these kids have complex medical conditions requiring ongoing and specialized care. These children have diagnoses that are multiple and varied, from cerebral palsy to cystic fibrosis, and that impact multiple body systems at once. They typically are under the continuous care of multiple pediatric specialists — often seeing a dozen or more physicians — and require access to specialized care and additional services from within and outside of their state. Additionally, their care accounts for a drastically disproportionate percentage of Medicaid spending on children.

The ACE Kids Act is about fundamentally improving care for children with medical complexity in Medicaid, driving improvements in quality, and reducing program spending — all further strengthening the Medicaid program. The bill will do this by expanding access to patient-centered, pediatric-focused coordinated care models tailored to the unique needs of these children.

To date, a number of children's hospitals, working with physicians and local communities, have supported pilot programs that coordinate care among and between the large numbers of providers necessary to care for a child with medical complexity. These programs have a track record of improving the quality of care for the children enrolled, increasing family satisfaction and reducing costs. However, the acceleration and spread of innovative care coordination cannot be achieved on a piecemeal basis. Creating the greatest benefit for the greatest number of children requires a national approach.



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The ACE Kids Act will fill this need by advancing elements of a national framework to drive the creation of systems of care coordination informed by shared data and quality standards. It will also provide state and local flexibility in tailoring care for this very complex population. To achieve this, the ACE Kids Act will modify Medicaid's existing health home option. Currently, states may choose to establish a health home to coordinate care for Medicaid beneficiaries who have chronic conditions, but this option was not designed for this unique population of children. The ACE Kids Act will give states the option to implement health homes specifically serving children with complex medical conditions to improve their care.

The data supporting the ACE Kids Act is convincing, yet it is crucial to remember that behind the statistics are real children and families. The ACE Kids Act was developed in response to the experiences of these families and the clinicians serving them — families like the Beckwiths. Alex and Maddy Beckwith of Keller, Texas are the kindest 14 and 4-year-old you could hope to meet, but they also both suffer from mitochondrial disease along with other health issues. This disease is a serious, complex condition without a cure, which requires lifelong medication and therapy. Due to their conditions, Alex and Maddy's care is very complex and ongoing — so much so that they have become like family members to the staff at Cook Children's. They see 15 specialists between them and require major interventions to remain stable.

Such families are an inspiration every day, teaching us about hope, resilience and unconditional love. We urge you to watch this short video about Alex Beckwith, which captures why the ACE Kids Act and your support is enormously important to children and families who are enduring complex medical conditions:

https://youtu.be/jXeHXeGqZ-4





The new pediatric health homes created by this legislation will be required to follow national guidelines in providing and better organizing pediatric-specific care and care coordination services appropriate for the needs of this population, kids like Alex and Maddy. This will help families manage the heavy responsibility and logistical challenges associated with their children's care. The pediatric health homes established under the ACE Kids Act will implement a specific care plan for the medically complex child, coordinating care from multiple highly specialized providers such as physicians, children's hospitals, specialized hospitals, non-physician professionals, home health and behavioral health — all with a goal of creating easier access to needed services.

Enabling children to access more of their care in their own communities is critical to improving patient experience as well as realizing program savings. But the nearby health homes will also play an important role when required care is only available out-of-state. Helping to better facilitate out-of-state care is critically important, as pediatric medicine — particularly for children with medical complexity — is more regional in nature than adult care. In fact, even Alex and Maddy have needed to travel to Ohio and Maryland for treatments despite living so close to Cook Children's.

The bill creates incentives for states to establish these models by providing a higher Medicaid federal match for care coordination services provided by the new pediatric health homes. Participation will be completely voluntary for children, families and health care providers, and the pediatric health homes will work within the existing structure of a state's Medicaid program, including those states with Medicaid managed care. The legislation envisions payment models that will align reimbursement with the best outcomes for these children to reduce costs and support the highest quality of care. States will determine which alternative payment methodologies could be used for the health



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homes. Moving to these performance-based systems will further encourage improvements in utilization and costs, similar to what has been supported under the Medicare program for adults.

The ACE Kids Act is also about using existing Medicaid resources more efficiently. As noted, children with medical complexity account for a disproportionately large share of the Medicaid costs for children. A large and growing body of research shows that the coordination of care for people with chronic conditions can save money through reductions in inpatient hospital stays and emergency room visits, improved medication management, better compliance on preventive care, and a guarantee that care is provided as close to a child's home and community as possible.

Potential cost savings have been demonstrated through projects supported by the Center for Medicare and Medicaid Innovation (CMMI). CMMI's Coordinating All Resources Effectively (CARE) Award — involving 10 children's hospitals, including my own Cook Children's, with eight different state Medicaid programs, including DC — implemented care coordination programs serving 8,000 children with medical complexity. Collectively, these programs reduced emergency department visits by 26 percent and reduced inpatient days by 32 percent. In the first full year of operations coordinating care for these children, CARE ultimately reduced overall Medicaid costs by 2.6 percent while improving patient experience for 8,000 children. The CARE award results were made possible by effective collaboration between different providers, including children's hospitals and more than 40 separate pediatric practices. The ACE Kids Act will enable these innovations to spread nationally. An analysis of the ACE Kids Act introduced in the 114th Congress conducted by the American Action Forum showed billions in potential savings to the Medicaid program over 10 years.

¹ https://www.americanactionforum.org/research/14241/





Very importantly, the ACE Kids Act will also create a data and quality framework to drive improvement in quality of care and further reduce costs. The creation and collection of consistent data supporting development and sharing of best practices while informing clinical standards, including quality measures specifically designed for children, are key to achieving these improvements. Unfortunately, this information and sharing does not exist under Medicaid today; there is currently no consistent national data available to inform our policies for children with medical complexity.

The ACE Kids Act outlines a definition of children with medically complex conditions who will be eligible to participate in the program and includes standardized data-reporting requirements related to the care of children in the enhanced pediatric health homes. By supporting the development of consistent national definitions and standards, the ACE Kids Act will represent an important step forward to improving the knowledge base necessary to truly advance care for this most vulnerable population. Finally, the ACE Kids Act lays the groundwork for additional future advances in care by sharing best practices across state Medicaid programs to ensure this population receives prompt care from out-of-state providers when medically necessary, and by requiring the Medicaid and CHIP Payment and Access Commission to submit a report to Congress and the Secretary of Health and Human Services on the characteristics of children eligible for health homes and the effectiveness of the program overall.

Since its original introduction in the 113th Congress, the ACE Kids Act concept has continued to evolve based on extensive stakeholder feedback. The current language reflects the results of this collaborative process and we thank the bill's champions and Committee staff for their continued efforts. The current focus of the bill is on how providers can best collaborate with the family to provide the highest quality of care to these kids. This will look different depending on the state, community and needs of the child and family. The current version of the bill





is about organizing and coordinating services that the child needs, not about guaranteeing one provider or another a special place in that delivery system.

The evolved legislation has received support from many additional organizations dedicated to children's health. The ACE Kids Act is envisioned as a way for states, families and providers to work in partnership to ensure that the unique health care needs of this population are met and was designed with state flexibility in mind. We are thankful that so many members of Congress have joined together in embracing the goal of improving care for this population of vulnerable children.

The ACE Kids Act will enable the national improvement necessary to provide better care for children with medical complexity and reduce Medicaid spending. We ask lawmakers to prioritize kids' health by passing the ACE Kids Act this year.



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Mr. BURGESS. Thank you, Mr. Merrill.

Mr. Schmidt, you are recognized for 5 minutes to summarize your opening statement, please.

STATEMENT OF DEREK SCHMIDT, J.D.

Mr. Schmidt. Thank you, Mr. Chairman, Ranking Member Green, thank you all very much for conducting this hearing today. I want to particularly thank Representative Walberg and Representative Welch for their leadership in bringing forward H.R. 3891.

It is a bipartisan bill not only on your side but on ours, and I testify today wearing two hats: first, as the immediate past president of the National Association of Attorneys General, the nationwide organization of all 56 State, territory, and District of Columbia attorneys general, a nonpartisan organization. To the extent my testimony conveys information that is in the two National Association letters submitted with my testimony, it is testimony on behalf of the organization. To the extent I may testify on other matters, for example, illustrate points with experiences from Kansas, it is my testimony as the State of Kansas attorney general.

I would slip into the jargon, Mr. Chairman, the MFCUs, the Fraud Control Units, but we tend to call them MFCUs. Title 19 of the Social Security Act, of course, requires every State to have one or obtain a waiver. Forty-nine States, North Dakota being the exception, have a MFCU, as does the District of Columbia. None of

the territories does.

So there are 50 of them nationwide. Of those 50, 44 are housed within the Office of the Attorney General. The other six are housed at another location in State government, but, of course, none can be housed, by law, within the Medicaid program itself. The whole point in Congress' enactment is to have an outside entity watching, the fraud fighters, the abuse fighters outside connected with, coordinated with, communicating with, but separate from the program itself.

Kansas is one of those States where the MFCU is housed in the Attorney General's Office. These are valuable programs from a State perspective because, like the Medicaid program itself, the cost is shared. The ratios are slightly different. It is a 75-percent Federal/25-percent State mix on the cost. That is a tremendous value-added proposition from the standpoint of being able to detect, investigate, and prosecute Medicaid fraud or the abuse of Medicaid beneficiaries. And so they are very attractive and, therefore, robustly used among the States, including in Kansas.

HHS OIG data shows that in fiscal 2017, the total recoveries nationwide from the MFCUs were about \$1.8 billion, a little under \$2 billion, and the total number of criminal convictions were about 1,500, give or take. Of that number, about 370 of those 1,500 criminal convictions were patient abuse convictions as opposed to fraud against the program convictions. And it is that distinction between fraud and abuse investigations, prosecutions, and efforts to detect

that is the subject of H.R. 3891.

The distinction is important. I don't know the historical reasons for it. I suspect staff does. But for whatever reason, when Congress enacted the provisions in title 19, it drew a jurisdictional distinction between the ability of a Medicaid fraud control unit to address fraud, an effort to steal public money from the Medicaid program, and the authority of a MFCU to address the abuse of patients, whether it is physical or financial or sexual or whatever sort of abuse it might be.

And to boil it all down, the net is cast wider statutorily in terms of our ability to go after fraud than it is in terms of our ability to go after patient abuse. In a phrase, we can essentially go after fraud wherever we find it, but with respect to patient abuse, we can only go after it when we find it in what the statute calls a healthcare facility or in some States, at a statutory option, a board and care facility, in other words, in an institutional setting.

We cannot use those MFCU assets to detect, investigate, prosecute patient abuse cases in a noninstitutional setting. And obviously, when you lay that alongside the tremendous growth in HCBS services, home healthcare delivery services outside of an institution, that disconnect, the problem with that becomes obvious.

So consider, for example, our folks, for example, in Kansas investigating a home healthcare fraud, a PCA fraud sort of circumstance, and we are at a nonresidential or noninstitutional, in a residential setting for the purpose of figuring out where the money went, and we discover evidence of abuse or neglect of the patient. We can no longer use those MFCU assets to pursue the investigation and prosecution of the patient abuse or neglect, even though we can continue to pursue the investigation and prosecution of the financial fraud. We don't think that makes any sense. And that is precisely what H.R. 3891 is designed to collapse, to allow us the broader scope with respect to both.

This is not just an academic point. In my written testimony, I highlight some cases from Kansas, where we have prosecuted serious physical or other abuse against patients in an institutional setting. We have cases where we have not been able to proceed because we are in a noninstitutional setting. We functionally, in Kansas at least, we go beg, borrow, and plead for a local police department to please take up the cause, or a local prosecutor. And we just don't think that makes any sense from a policy standpoint in today's healthcare delivery method.

So we would encourage the enactment of H.R. 3891, both as our association and as myself. I would be delighted to answer any questions. And I would just end where I started. From our vantage point, like you, most of our members, not all of our members but most of our members are elected officials. We are Republicans, Democrats, and sometimes other, and there is no daylight on this issue among our members.

The first of the two letters that reflect NAAG policy had 38 signers. It was led by Attorney General Jepsen from Connecticut and myself, a Democrat and a Republican. The second had 49 of our 56 members. And remember, there are only 50 MFCUs. Forty-nine signed on, and it was led by Attorney General Jepsen and myself, Attorney General Donovan from Vermont, a Democrat from Vermont, and Attorney General Hunter, a Republican from Oklahoma. So we are all behind this, and we are grateful for your time.

[The prepared statement of Mr. Schmidt follows:]

Summary of Testimony in Support of H.R. 3891 Presented to House Committee on Energy and Commerce Subcommittee on Health By Kansas Attorney General Derek Schmidt September 5, 2018

H.R. 3891 would eliminate an outdated limitation in federal law, thereby expanding (at the option of individual states) the authority of Medicaid Fraud Control Units (MFCUs) to detect, investigate and prosecute Medicaid patient abuse in non-institutional settings. The National Association of Attorneys General, the nonpartisan association representing all 56 state, territory and District of Columbia attorneys general, supports H.R. 3891. I also support the legislation in my capacity as Attorney General for the State of Kansas.

The Social Security Act requires every state either to maintain a MFCU or to obtain a waiver. Most MFCUs are housed in the state attorney general's office. The MFCU has authority to detect, investigate and prosecute fraud in the Medicaid program and patient abuse or neglect. MFCUs have both civil and criminal authority.

MFCUs are funded 75 percent federal funds and 25 percent state matching funds. To maintain federal funding, states must comply with conditions on that funding. One of those conditions provides that MFCU assets may be used to address Medicaid fraud anywhere it is found but may be used to address Medicaid beneficiary-patient abuse only when it arises in either a health care facility or, at the option of individual states, in a board and care facility. This different scope results in undesirable outcomes: For example, a MFCU that discovers evidence of patient abuse while investigating fraud in a home health care setting may pursue the fraud but not the patient abuse.

H.R. 3891 eliminates this undesirable outcome by allowing states to use MFCU assets to address beneficiary-patient abuse wherever it may be found, including in non-institutional settings. But today, unlike when the federal statute establishing MFCUs was enacted, far more care is delivered to patients, including Medicaid beneficiaries, through home and community-based services outside of health care facilities. And when we discover that a patient-beneficiary is being abused in that non-institutional setting, I can see no logical policy reason to be prohibited from using MFCU assets to appropriately pursue that abuse.

H.R. 3891, if enacted, would take the blinders off the MFCUs and let them detect, investigate and prosecute Medicaid beneficiary-patient abuse where it may occur. I hope this important legislation can reach the President's desk before this calendar year is through.



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Testimony in Support of H.R. 3891

Presented to House Committee on Energy and Commerce

Subcommittee on Health

By Kansas Attorney General Derek Schmidt

September 5, 2018

Chairman Burgess, Ranking Member Green, and Members of the Subcommittee:

Thank you for this opportunity to testify in support of H.R. 3891, legislation that would eliminate an outdated limitation in federal law, thereby expanding the authority of Medicaid Fraud Control Units (MFCUs) to detect, investigate and prosecute Medicaid patient abuse in non-institutional settings. I appreciate and commend the work by Representatives Walberg and Welch to bring this important legislation forward.

I am the Attorney General for the State of Kansas, a statewide, elected constitutional officer of our state. I have served in this capacity since January 2011. As Kansas attorney general, I have made a priority of building capacity and focusing resources on fraud and abuse investigations and prosecutions, including but not limited to fraud and abuse in the Medicaid program.

Policy of the National Association of Attorneys General

I also am the immediate past president of the National Association of Attorneys General (NAAG), the nonpartisan association that represents all 56 state, territory and District of Columbia attorneys general in the United States. During my year as NAAG president in 2017-2018, I led our Presidential Initiative

titled: "Protecting America's Seniors: Attorneys General United Against Elder Abuse." As part of that initiative, our organization worked in a bipartisan, or nonpartisan, manner to gather information, hear from experts and practitioners, and help build capacity to prevent and combat elder abuse throughout the country and in our respective jurisdictions.

One specific action that came from our NAAG initiative was the endorsement from our organization for H.R. 3891 and its proposed expansion of authority to allow MFCUs to detect, investigate and prosecute Medicaid patient abuse in non-institutional settings. To that end, our organization authored two letters: A May 9, 2017, letter to then-Health and Human Services Secretary Tom Price expressing support for the policy of expanded MFCU authority and a March 28, 2018, letter to Representatives Walberg and Welch specifically supporting H.R. 3891. The first letter was signed by 38 attorneys general and the second by 49. Both were bipartisan. Under our NAAG procedures, both letters reflect the official policy statements of NAAG. Both are attached as exhibits to this testimony, and I incorporate them by reference as part of my testimony so that NAAG policy on this subject may be fully presented to the Committee. Also attached are the July 17, 2017, response from Secretary Price and the August 7, 2017, response from Health and Human Services Inspector General Daniel R. Levinson.

Thus, to the extent my testimony today reflects the content of those NAAG letters, it constitutes the views of the National Association of Attorneys General; to the extent I testify to matters outside those two letters, my testimony constitutes only my views as Attorney General for the State of Kansas.

The Value of MFCUs

The Social Security Act requires that every state, as a condition of participation in the Medicaid program, either maintain a MFCU or obtain a waiver. All but one state maintains a MFCU. States choose to situate their MFCU in various positions within state government. Forty-four MFCUs are housed in the state attorney general's office; Kansas is one of those states. Five states – Connecticut, Illinois, Iowa, Tennessee, and West Virginia – and the District of Columbia house the MFCU in another state agency.

North Dakota has received a waiver from the federal government and does not have a MFCU. None of the five territories has established a MFCU.

Our MFCU has both civil and criminal jurisdiction. When appropriate, we seek both injunctive and monetary relief in instances of civil false claims to the Medicaid program or other unlawfully made payments. We also investigate and prosecute criminal Medicaid fraud and patient abuse. While our MFCU attorneys occasionally work in federal court enforcing federal law as cross-designated Special Assistant United States Attorneys, most of our work is in state court enforcing state laws against Medicaid fraud and patient abuse. Because of the joint federal-state nature of the Medicaid program, we work closely with the United States Attorney and with appropriate federal law enforcement agencies. Our federal-state working relationship is excellent.

The size of MFCUs varies substantially by state, with the overall size continually overseen and subject to approval by the Department of Health and Human Services-Office of Inspector General (HHS-OIG). In Kansas, our MFCU employs four attorneys, four fiscal analysts, one nurse investigator, one legal assistant, a special agent-in-charge, and six special agents. The special agent-in-charge and the special agents all are sworn law enforcement officers. The total annual budget for the Kansas MFCU is approximately \$1.8 million. Of that amount, 75 percent is paid with federal funds and the other 25 percent with state matching funds. In a small state like Kansas, this federal financial support is critically important to enable us to maintain the important capacity to detect, investigate and prosecute instances of Medicaid fraud and of the criminal abuse – physical, sexual or financial – of Medicaid beneficiaries.

The federal funding that supports MFCUs is known as Federal Financial Participation, or FFP. It comes with conditions. Those conditions limit the uses of our MFCU assets. One of those conditions governs the type of cases our MFCU may handle. In general, cases within a MFCU's jurisdiction fall into one of two categories: Fraud committed against the Medicaid program itself, and abuse of patients who are Medicaid beneficiaries. Under federal rules, our MFCU may investigate and prosecute cases of financial *fraud*

against the Medicaid program wherever it may be discovered. Consequently, we have handled cases of Medicaid fraud in billing services, in nursing homes, in medical offices, in home health care settings, and in other situations. However, our MFCU may only investigate and prosecute cases of patient abuse when it occurs in a health care facility or board and care facility.

In a small state like Kansas, our MFCU provides important services in detecting, investigating and prosecuting the abuse of Medicaid patient-beneficiaries. Sadly, we have had occasion to investigate and prosecute almost every type of patient abuse imaginable – financial abuse, physical abuse and sexual abuse. Consider several recent examples of criminal abuse cases we have handled:

- Prosecuted a nursing home employee for physical or sexual abuse of five residents. The
 defendant was convicted of one count of attempted criminal sodomy and four counts of
 mistreatment of a dependent adult and sentenced to 91 months in state prison.
- Prosecuted a nursing home employee for sexual abuse of a resident. The defendant was convicted
 of one count of aggravated sexual battery and sentenced to 130 months in state prison.
- Prosecuted a couple who illegally used the assets of one of the defendants' mother, while acting as her power of attorney and trustee, to make purchases for themselves, including a house, farm and truck, while the mother was living in a nursing home and her expenses were going unpaid.

 Both defendants were convicted of mistreatment of a dependent adult and conspiring to mistreat a dependent adult and each defendant was sentenced to more than 90 months in state prison.

We are currently prosecuting a nurse for allegedly stealing narcotics intended for beneficiaries in nursing homes and diverting them for illicit use, thereby denying patients the pain treatment to which they were entitled. The defendant is charged with multiple counts in three different counties. This case remains pending, and of course the charges are merely accusations and the accused is presumed innocent unless and until proven guilty. Our office has more than a dozen similar cases of suspected or alleged patient abuse currently being investigated or prosecuted.

Clearly, the MFCU is an important instrument for justice and for protecting Medicaid beneficiaries from abuse. This is consistent with the intention of Congress in creating the MFCUs as evidenced by the statutory instruction that MFCUs were created, in part, to help ensure "that beneficiaries under the [State] plan [for medical assistance] will be protected from abuse and neglect in connection with the provision of medical assistance under the plan." See 42 U.S.C. SEC 1396a(a)(61)(emphasis added). But under current federal law, we are constrained from using these same important law enforcement tools in the MFCUs to protect Medicaid beneficiaries from abuse and neglect when the crime occurs someplace other than in a health care facility or, at the discretion of individual states, in a board and care facility – someplace such as in a home-health setting.

For emphasis, I would note that the expanded MFCU authority proposed in H.R. 3891 is a particularly important tool for combating elder abuse. As we noted in our NAAG letter:

Today, more than 74 million Americans are enrolled in Medicaid. Of those, more than 6.4 million are age 65 or older. Statistics cited by the Centers for Disease Control and Prevention (CDC) suggest that 1 in 10 persons age 65 and older who live at home will become a victim of abuse. Not surprisingly, CDC figures also suggest that most elder abuse is never detected, with one study concluding that for every case of elder abuse that is detected or reported, 23 more remain hidden.

See NAAG Letter to HHS Secretary Tom Price, May 9, 2017 (internal citations omitted). While the expanded authority would not be limited to addressing abuse against elder Medicaid beneficiary-patients, the importance of this tool in addressing elder abuse is what led NAAG to lend our support to this legislation as an outgrowth of our presidential initiative on combating elder abuse.

Importance of H.R. 3891

The difference in scope between a MFCU's anti-fraud authority and its narrower anti-abuse authority is the subject of H.R. 3891. This bill proposes to allow states the option of expanding their MFCU's scope to combat Medicaid beneficiary-patient abuse wherever it may occur, including in non-institutional settings. That state-by-state option, which mirrors the flexibility in current law that allows states to opt-in to using MFCUs to combat patient abuse in board-and-care facilities, is an important component of the bill. That is optional authority that, if H.R. 3891 is enacted, Kansas intends to exercise. From my vantage point, it makes little sense to allow broad MFCU authority to combat fraud when the public treasury is the victim but to insist on narrower MFCU authority to combat abuse when the Medicaid beneficiaries themselves are the victim. Whatever its original rationale, this distinction seems, at best, outdated.

Nevertheless, states must abide by that distinction and limit the scope of the efforts to combat patient abuse or risk losing their FFP.

In practice, the limitation on using MFCU assets to detect, investigate and prosecute patient abuse outside of an institutional setting has real consequences. In Kansas, we have seen at least two real-world, detrimental effects of this limitation:

• We have seen cases in which our MFCU agents, in the course of conducting a lawful investigation in connection with suspected fraud in home health care services being funded by Medicaid and provided in the beneficiary's home, have uncovered evidence of abuse of the Medicaid beneficiary-patient. Under current law, our MFCU could proceed to investigate and prosecute the fraud committed against the government program but could not proceed to investigate and prosecute the abuse committed against the beneficiary-patient. That is because of the current statutory restriction that limits a MFCU's authority over patient abuse only to institutional settings such as in a health care facility.

• We also have seen cases involving so-called "pill mills" involving the illegal diversion of narcotics from the lawful supply chain to the illicit market. In some cases, that diversion results in the misuse of these drugs causing death or great bodily harm. But if the diversion occurs entirely in a setting outside a health care facility or a board and care facility – for example, at a doctor's office – our MFCU is permitted to pursue the relatively small fraud (the stealing of pills from the Medicaid program) but not the much greater harm done to patients as a result of the diversion (the death or great bodily harm from misuse of the drugs).

That difference in scope between our MFCU's anti-fraud authority and its anti-abuse authority is poor public policy and, at least in my view, logically unjustifiable. It has roots in an era long ago when the delivery of most health services was in an institutional setting and, therefore, the opportunity for Medicaid beneficiary-patient abuse in a non-institutional setting, such as a home health care setting, was remote.

But today, far more care is delivered to patients, including Medicaid beneficiaries, through home and community-based services outside of health care facilities. And when we discover that a patient-beneficiary is being abused in that non-institutional setting, I can see no logical policy reason to be prohibited from using MFCU assets to appropriately pursue that abuse.

H.R. 3891 is designed to eliminate that barrier in federal law to using existing MFCU assets to protect Medicaid beneficiaries from patient abuse, regardless of where the abuse may occur. It proposes a small change in statute that has a large likelihood of providing better protection, and better justice, for Medicaid beneficiary-patients who are the victims of abuse.

For that reason, I strongly support passage of H.R. 3891 both as Kansas Attorney General and on behalf of the National Association of Attorneys General. This legislation, if enacted, would take the blinders off the MFCUs and let them detect, investigate and prosecute Medicaid beneficiary-patient abuse wherever it may occur. I commend Representatives Walberg and Welch for their leadership in bringing this

legislation forward, and I offer to work with the Committee in whatever manner may be helpful to advance this legislation and, I hope, find a way for it to reach the President's desk before this calendar year is through.

Thank you for your consideration of this important matter.



PRESIDENT George Jepsen Connecticut Attorney General

PRESIDENT-ELECT Derek Schmidt

VICE PRESIDENT Jeff Landry Louisiana Attorney Genera

MMEDIATE PAST PRESIDENT Marty Jackley South Dakota Attorney General

> EXECUTIVE DIRECTOR James McPherson

May 10, 2017

The Honorable Tom Price Secretary, U.S. Department of Health & Human Services 200 Independence Avenue, S.W. Washington, D.C. 20201

Dear Mr. Secretary:

As the Attorneys General of our respective states, we write to request a change in federal policy to allow use of the federal funds provided to our Medicaid Fraud Control Units (MFCUs)1 for the detection, investigation and prosecution of a wider range of abuse and neglect committed against Medicaid beneficiaries or in connection with Medicaid-funded services. Under the pertinent provisions of the Social Security Act, most state attorneys general have an important working relationship with their state's MFCU; in many states, the MFCU is housed within the state attorney general's office.2

As implied by its commonly used name, the MFCU has as its principal focus the detection and elimination of fraud within the Medicaid program. But Congress also created the MFCUs to help ensure "that beneficiaries under the [State] plan [for medical assistance] will be protected from abuse and neglect in connection with the provision of medical assistance under the plan." Indeed, at one place in the Social Security Act, Congress expressly refers to MFCUs as "medicaid fraud and abuse control unit[s]".4

Today, more than 74 million Americans are enrolled in Medicaid. 5 Of those, more than 6.4 million are age 65 or older. 6 Statistics cited by the Centers for Disease Control and Prevention (CDC) suggest that 1 in 10 persons age 65 and older who live at home will become a victim of abuse. Not surprisingly, CDC figures also suggest that most elder abuse is never detected, with one study concluding that for every case of elder abuse that is detected or reported, 23 more remain hidden.

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¹ These federal funds are referenced in regulation as "federal financial participation," or "FFP." See 42 C.F.R. § 1007.19.

 ² See 42 U.S.C. § 1396b(q).
 ³ See 42 U.S.C. § 1396a(a)(61) (emphasis added).

⁴ Id. (emphasis added).

⁵ January-March 2016 Medicaid MBES Enrollment report (Updated December 2016), available at https://www.medicaid.gov/medicaid/program-information/downloads/cms-64enrollment-report-jan-mar-2016.pdf (last accessed March 28, 2017).

See http://kff.org/medicaid/state-indicator/medicaid-enrollment-byage/?dataView=1¤tTimeframe=0&selectedDistributions=65plus&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D (last accessed March 28, 2017).

⁷ See https://www.cdc.gov/violenceprevention/elderabuse/consequences.html.

In light of those realities, the current strict federal limitations on states' ability to use MFCU assets to investigate and prosecute abuse and neglect are outdated, arbitrarily restrict our ability to protect Medicaid beneficiaries from abuse and neglect as Congress intended, and should be replaced or eliminated. We request authority to use federally funded MFCU assets to detect, investigate and prosecute abuse and neglect of Medicaid beneficiaries or in connection with Medicaid-funded services to the full extent the federal statute allows. Toward that objective, we offer two specific recommendations, both of which can be accomplished by changing current federal regulations:

First, we recommend allowing the use of federally funded MFCU assets to investigate and prosecute abuse and neglect of Medicaid beneficiaries in non-institutional settings. The Social Security Act expressly allows use of MFCUs to investigate and prosecute patient abuse/neglect in "health care facilities" or "board and care facilities," but the statute *does not prohibit* use of federal MFCU funds to investigate abuse/neglect in non-institutional settings—only the regulations impose that prohibition. ¹⁰ This regulatory restriction arbitrarily limits the scope of potential abuse or neglect cases our MFCUs can investigate or prosecute—for example, by excluding abuse or neglect of a beneficiary alleged to have occurred in a home health care or other non-institutional setting. This regulatory restriction appears to us in conflict with Congress's broad command that the MFCUs are to help ensure that Medicaid beneficiaries "will be protected from abuse and neglect in connection with the provision of medical assistance" under Medicaid. We recommend these regulations be broadened to allow use of federal MFCU funds to freely investigate and prosecute suspected abuse or neglect of Medicaid beneficiaries in whatever setting it may occur, including non-institutional settings.

Second, we recommend improving detection of abuse and neglect of Medicaid beneficiaries by broadening the permissible use of federal MFCU funds to screen complaints or reports alleging potential abuse or neglect. Under current regulations, federal MFCU funds may be used only for the "review of complaints of alleged abuse or neglect of patients in health care facilities." As with the first restriction discussed above, the regulatory limitation on the screening of only those complaints alleging patient abuse or neglect in health care facilities arbitrarily narrows the permissible use of MFCU assets and appears in conflict with the broad congressional command to help ensure that all Medicaid beneficiaries, not just those in institutions, "will be protected from abuse and neglect." This regulation effectively places blinders on the MFCUs in their ability to search for and identify cases of possible abuse and neglect of beneficiaries. The regulations should be broadened to allow use of federal MFCU funds to freely screen or review any and all complaints or reports of whatever type, in whatever setting, that may reasonably be expected to identify cases of abuse of neglect of any Medicaid beneficiary. The MFCUs should have the widest possible latitude to detect and identify potential abuse and neglect of Medicaid

^{8 42} U.S.C. § 1396b(q)(4)(A)(i).

^{9 42} U.S.C. § 1396b(q)(4)(A)(ii).

¹⁰ See, e.g., ⁴² C.F.R. § 1007.19(d)(1) ("Reimbursement will be limited to costs attributable to the specific responsibilities and functions set forth in this part in connection with the investigation and prosecution of suspected fraudulent activities and the review of complaints of alleged abuse or neglect of patients in health care facilities." (emphasis added)).

¹¹ See 42 C.F.R. § 1007.19(d)(1) (emphasis added); see also 42 C.F.R. § 1007.11(b)(1) ("The unit will also review

¹¹ See 42 C.F.R. § 1007.19(d)(1) (emphasis added); see also 42 C.F.R. § 1007.11(b)(1) ("The unit will also review complaints alleging abuse or neglect of patients in health care facilities...").

beneficiaries. We favor permitting the MFCUs to cast a wide net at the screening stage: Better to err on the side of reviewing complaints or reports that ultimately are determined to involve conduct outside the scope the MFCU may investigate or prosecute than to err through narrow screening criteria that can leave abuse or neglect of Medicaid beneficiaries undetected by the MFCU.

Mr. Secretary, we know you share our strongly held view that all persons should live free from abuse and neglect. The MFCUs are valuable assets to help make that freedom a reality for Medicaid beneficiaries. We respectfully request you take swift action to eliminate federal regulations that needlessly narrow our use of these valuable assets. Instead, we request to be freed to use federal MFCU funds to detect, investigate and prosecute abuse and neglect committed against Medicaid beneficiaries or in connection with Medicaid-funded services to the fullest extent permitted by federal statute.

Thank you for considering our recommendations. We stand ready to work with you to achieve this important objective.

Sincerely,

George Jepsen

Connecticut Attorney General

ahna Lindemuth Alaska Attorney General

Leslie Rutledge

Arkansas Attorney General

Karl A. Racine

District of Columbia Attorney General

Derek Schmidt

Kansas Attorney General

Mark Brnovich

Arizona Attorney General

Cynthia H. Coffman

Colorado Attorney General

Hawaii Attorney General

Curtis T. Hill, Jr. Indiana Attorney General

Andy Bestlear Kentucky Attorney General

Brian Frosh Maryland Attorney General

Bill Schuette

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Tom Miller Iowa Attorney General

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Maura Healey Massachusetts Attorney General

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PATRICK Momse

Patrick Morrisey West Virginia Attorney General

Wyoming Attorney General



THE SECRETARY OF HEALTH AND HUMAN SERVICES WASHINGTON, D.C. 20201

JUL 1 7 2017

The Honorable George Jepsen President National Association of Attorneys General Washington, DC 20036

Dear Attorney General Jepsen:

Thank you for your letter requesting that the U.S. Department of Health and Human Services change its current regulations to allow Medicaid Fraud Control Units (MFCUs) to receive federal financial participation to detect, investigate, and prosecute abuse and neglect of Medicaid beneficiaries in non-institutional settings. We share your concerns regarding the safety and wellbeing of Medicaid beneficiaries in all settings, and we are diligently working on responding to your inquiry.

This matter has been referred to Inspector General Daniel R. Levinson, from whom you can expect a direct response. As the agency responsible for overseeing MFCUs and administering the MFCU grant award, the Office of Inspector General would be in a position to respond to the issue you have raised.

Thank you again for your letter and your focus on protecting the safety and well-being of Medicaid beneficiaries.

Yours truly,

Whomas E. G

Thomas E. Price, M.D.



DEPARTMENT OF HEALTH AND HUMAN SERVICES

OFFICE OF INSPECTOR GENERAL



WASHINGTON, DG 20201

AUG 07 2017

The Honorable George Jepsen President National Association of Attorneys General Washington, DC 20036

Dear Attorney General Jepsen:

Thank you for your letter to Secretary Thomas E. Price, M.D., requesting that the U.S. Department of Health and Human Services (HHS) change its current regulations to allow Medicaid Fraud Control Units (MFCUs) to receive Federal financial participation (FFP) to detect, investigate, and prosecute abuse and neglect of Medicaid beneficiaries in non-institutional settings. As indicated by Secretary Price's letter of July 17, 2017, your letter has been referred to the Office of Inspector General (OIG) for response.

We share your concerns regarding abuse and neglect of Medicaid beneficiaries. We recognize that the laws governing Federal matching were established almost 40 years ago and do not reflect the shift in delivery and payment for health care services to home- and community-based settings. OIG believes that the law should be changed to expand MFCUs' use of FFP to include the detection, investigation, and prosecution of abuse and neglect of Medicaid beneficiaries in non-institutional settings. However, we do not believe that the change can be made by regulation.

The Social Security Act (the Act) currently allows for payment of FFP for MFCU activities in abuse and neglect cases involving Medicaid beneficiaries. Section 1903(q)(4)(A) of the Act specifically sets forth only two settings in which MFCUs may review complaints of abuse or neglect of patients: (1) health care facilities that receive Medicaid payments and (2) board and care facilities. Other non-institutional settings, such as home-based care and transportation, are not listed. Because the statute specifically enumerates some settings in which MFCUs can investigate abuse and neglect cases and receive FFP, the failure to include the others, according to statutory construction principles, is read as excluding them.

In cases in which a beneficiary is receiving services in his or her own home, the requirements of the statute are not met. Homes and most other non-institutional settings are neither health care facilities that receive Medicaid payments nor board and care facilities. Thus, the statute does not

¹ Section 1903(a)(6) of the Act requires HHS to pay a portion of the sums expended by a State "which are attributable to the establishment and operation of (including the training of personnel employed by) a State medicaid fraud control unit (described in subsection (q))." Section 1903(q) of the Act defines MFCU requirements, including MFCU duties regarding patient abuse and neglect.

Page 2 - The Honorable George Jepsen

permit FFP for the detection, investigation, and prosecution of abuse or neglect of patients in non-institutional settings.

HHS is bound by the statute and cannot expand the regulatory definition of "health care facilities receiving payments under the State Medicaid plan" to include non-institutional settings that do not receive Medicaid payments. While we cannot make the requested regulatory change, we have been and continue to be supportive of efforts to effect a statutory change that would allow MFCUs to receive FFP for the detection, investigation, and prosecution of abuse and neglect in non-institutional settings. OIG representatives have also identified the need for a statutory change in testimony before congressional committees, including, most recently, in May 2017 testimony.²

Thank you for raising this important issue. We continue to support the concept that MFCUs should receive FFP to conduct these investigations of abuse and neglect. If you have questions or seek additional information, please contact me, or someone from your staff may contact Ann Maxwell, Assistant Inspector General for Evaluation and Inspections, at (202) 619-2482.

Sincerely,

Daniel R. Levinson Inspector General

² Testimony of Christi A. Grimm, Chief of Staff, before House Committee on Energy and Commerce: Subcommittee on Oversight and Investigations: "Combatting Waste, Fraud, and Abuse in Medicaid's Personal Care Services Program," May 2, 2017, available at https://oig.hhs.gov/testimony/docs/2017/grimm-testimony-05022017.pdf



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March 28, 2018

Honorable Tim Walberg 2436 Rayburn House Office Building Washington, D.C. 20515

Honorable Peter Welch 2303 Rayburn House Office Building Washington, D.C. 20515

Dear Representatives Walberg and Welch:

As the Attorneys General of our respective states, we write in support of your legislation, H.R. 3891, that would expand the authority of Medicaid Fraud Control Units (MFCUs) to detect, investigate and prosecute Medicaid patient abuse in non-institutional settings.

On May 10, 2017, thirty-eight attorneys general wrote to then-Secretary Tom Price at the U.S. Department of Health and Human Services urging expanded authority for MFCUs to address patient abuse and neglect ("the NAAG letter"). Specifically, the NAAG letter requested HHS alter its regulations implementing the pertinent statutory provisions to broaden the permissible authority for MFCUs, and the associated use of federal financial participation (FFP), in two regards. First, it recommended "allowing the use of federally funded MFCU assets to investigate and prosecute abuse and neglect of Medicaid beneficiaries in non-institutional settings." Second, it recommended "improving detection of abuse and neglect of Medicaid beneficiaries by broadening the permissible use of federal MFCU funds to screen complaints or reports alleging potential abuse or neglect."

On August 7, 2017, HHS Inspector General Daniel R. Levinson responded to the NAAG letter stating "OIG believes that the law should be changed to expand MFCUs' use of FFP to include the detection, investigation, and prosecution of abuse and neglect of Medicaid beneficiaries in non-institutional settings." However, HHS concluded that such a change requires statutory amendment and could not be accomplished solely by regulation.

On September 28, 2017, you introduced H.R. 3891. We are informed that, in the drafting of your legislation, you were mindful of the NAAG letter and that you intended to implement the letter's recommendations. We have reviewed H.R. 3891 and understand that, if adopted, it would enable HHS-OIG to implement all changes requested in the NAAG letter. Your legislation permits, but does not require, each MFCU to exercise the expanded authority the bill proposes, just as current law does with board and care facilities. It is our understanding that States electing to operate under the expanded authority of H.R. 3891 would be able to use their MFCUs to detect, investigate and

prosecute cases of abuse or neglect of Medicaid patients in whatever setting abuse or neglect may occur and to do so without losing federal financial participation. ¹

This change is vitally important because it eliminates the blinders current law places on MFCUs' ability to detect, investigate and prosecute cases of abuse or neglect of Medicaid patients. Since the current statute was enacted decades ago, substantial growth has occurred in home and community-based services, office-based services, transportation services, and other settings that are neither "health care facilities" nor "board and care facilities" but where services are provided and thus patient abuse or neglect may occur. H.R. 3891 proposes a common-sense change that will better protect an often-vulnerable population and will maximize the benefits and efficient use of MFCU assets.

We also note that your bill is particularly timely and important in light of the national opioid epidemic. Consider, for example, a situation in which a Medicaid beneficiary in a home or community-based setting is provided prescription opioid painkillers in an unlawful manner, resulting in death or great bodily harm to the patient. Under current law, although the patient harm caused by distribution of those opioids may have been criminal, our MFCUs would be hampered or prevented from investigating or prosecuting the case of patient abuse because it occurred in a setting other than a health care facility or a board and care facility. Under H.R. 3891, however, MFCUs could exercise clear authority to pursue that sort of investigation and, if appropriate, prosecute that patient abuse, thus bringing more criminal and civil investigation and prosecution assets to bear in the fight against the opioid epidemic.

Thank you for your leadership in proposing H.R. 3891. We hope it can become law soon so our states may have the option to use the important new tools it would make available in the fight

¹ The NAAG letter requested expanded authority for MFCUs to "detect, investigate and prosecute" a wider range of abuse and neglect cases, and Mr. Levinson's response confirms that OIG favors "use of FFP to include the detection, investigation, and prosecution" of such cases. By "detect," the NAAG letter specifically sought broader authority for MFCUs to use FFP to "screen" complaints or reports alleging potential abuse or neglect." Current HHS regulations constrain states' ability to use MFCU assets to review complaints in order to detect which may allege patient abuse or neglect that would warrant investigation or prosecution using MFCU assets. See, e.g., 42 C.F.R. Sec. 1007.19(d)(1)(limiting FFP to "review of complaints of alleged abuse or neglect of patients in health care facilities")(emphasis added); see also 42 C.F.R. Sec. 1007.11(b)(1)(restricting authority of MFCU to "review[ing] complaints alleging abuse or neglect of patients in health care facilities" and to "review[ing] complaints of the misappropriation of patient's private funds in such facilities.")(emphasis added). For states that would choose to exercise the expanded authority in H.R. 3891, we read the bill to require elimination of these and similar regulatory barriers that restrict MFCUs authority to review complaints. Obviously, a review will necessarily precede a determination whether a complaint or report alleges Medicaid patient abuse or neglect that would fall within H.R. 3891's expanded authority to investigate or prosecute, and it would make no sense to arbitrarily limit review to complaints from patients in health care facilities if the authority to investigate and prosecute abuse and neglect is expanded to other settings.

against the abuse and neglect of all Medicaid patients -- wherever that may occur. If we may be of assistance in advancing this legislation, please let us know.

Sincerely, enk Schmidt Derek Schmidt George Jepsen Connecticut Attorney General Kansas Attorney General Mike Hunter T.J. Donovan Vermont Attorney General Oklahoma Attorney General Steve Marshall Lindemuth Alabama Attorney General Alaska Attorney General Mark Brnovich Leslie Rutledge Arizona Attorney General Arkansas Attorney General Cynthia H. Coffman Xavier Becerl California Attorney General Colorado Attorney General Matthew P. Denn Delaware Attorney General District of Columbia Attorney General Clapetre Christopher M. Carr Florida Attorney General Georgia Attorney General Runella. Sugali:

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Claude Earl Walker Virgin Islands Attorney General

Robert W. Ferguson Washington Attorney General

Brad Schimel

Wisconsin Attorney General

Mr. BURGESS. Great. Thank you, Mr. Schmidt.

Dr. Yoder, you are recognized for 5 minutes to summarize your opening statement, please.

STATEMENT OF DAVID YODER, PHARM.D.

Dr. Yoder. All right. Thank you, Mr. Chairman. First, I would like to thank both Chairman Burgess and the Ranking Member Green for their leadership in holding today's hearing and providing

an opportunity to discuss key ways to improve healthcare.

My name is David Yoder. I am the Executive Director, Member Care and Benefits at the Blue Cross Blue Shield's Federal Employee Program. BCBSA is a national federation of 36 independent community-based and locally operated Blue Cross and Blue Shield companies that collectively provide healthcare coverage for one in three Americans.

Blue Cross and Blue Shield companies offer quality healthcare coverage in all markets across America and participate in all Federal insurance programs. BCBSA, through the FEP, administers health insurance to approximately 5.4 million Federal employees, retirees, and their families. We are committed to high-quality affordable coverage for all, regardless of preexisting conditions.

Today I am going to address a couple areas. One is how BCBSA and its member companies are working to reduce fraud and abuse and the need to eliminate gag clauses related to prescription drugs. Fraud and abuse is an essential step to ensure the affordability of healthcare and addressing, reducing, and, to the extent possible,

preventing the opportunity for fraud and abuse.

BCBS companies are diligent in working to stay ahead of fraud and abuse. The BCBSA National Antifraud Department is dedicated to the support and promotion of BCBSA's antifraud efforts nationwide, including for the FEHBP program. This effort includes direct investigative support of local Blue Cross Blue Shield special investigative units, coordination of multiplan investigations, working with Federal and State law enforcement, and providing subjectmatter experts to BCBSA's Office of Policy and Representation, the media, and the government entities.

Among various governmental efforts, the Federal Government established the Healthcare Fraud Prevention Partnership, HFPP, to improve the detection and prevention of healthcare fraud. BCBSA and several of our member companies are active participants in the HFPP. We support the HFPP and Congress' desire to establish explicit authority for HFPP and its activities. As Congress takes steps to codify the HFPP charter, we recommend improvements to help the partnership fulfill its objectives, which were in my submitted written testimony.

Turning to gag clauses, BCBSA does not support the use of gag clauses and is unaware of any Blue Cross and Blue Shield company or contracted pharmacy benefit managers to have gag clauses in place with pharmacies. We commend CMS for taking a tougher position on gag clauses and support legislation to ban gag clauses and any prohibitions on allowing pharmacists to make information and cost savings known to the member at the point of sale.

To the extent that some of the industry includes such clauses in their contracts, consumers may be deprived of information that will help them make prudent decisions when paying for prescription drugs. With this in mind, we would also encourage pharmacists to advise patients on generic substitution and alternative medications, so long as this is done in direct communication with the dis-

pensing physician.

Full transparency is critical for consumers to have the necessary information to make choices that work best for them. It is also important that pharmacists advise consumers to consider the impact of not using insurance coverage to pay for their prescriptions. While certain beneficiaries might pay lower out-of-pocket costs on a given prescription, drugs purchased outside the insurance benefit in most cases will not count toward the beneficiary's deductible or maximum out-of-pocket limits, which may reduce the value of their insurance coverage.

That is why we support elimination of gag clauses. We believe that pharmacists should also inform consumers about the potential risks of not using their drug coverage so they can make more informed decisions.

In closing, BCBSA applauds the committee for taking on these important issues as it is critical that all stakeholders work together to ensure the affordability of healthcare for all Americans. We support these efforts to drive the healthcare system to higher quality, lower costs, and improve access to care for everyone.

In line with these goals, we urge Congress to continue its efforts to ensure that people have timely access to safe, effective, and affordable cutting-edge prescription medications when they need them. Achieving this important goal will require the public and private sectors to collaborate to develop solutions that benefit patients and the entire healthcare system. Thank you for the opportunity to testify today and your leadership in seeking opportunities to improve healthcare. And I look forward to taking any questions. Thank you.

[The prepared statement of Dr. Yoder follows:]

Testimony on

Opportunities to Improve Health Care

Ву

David Yoder, Pharm.D., M.B.A.

Executive Director, Member Care and Benefits

Government Programs and Federal Employee Program

Blue Cross and Blue Shield Association

Before the

House Energy and Commerce Committee

Subcommittee on Health

September 5, 2018

Introduction

My name is David Yoder and I am Executive Director, Member Care and Benefits at the Blue Cross Blue Shield Association's Federal Employee Program (BCBSA FEP).

BCBSA is a national federation of 36 independent, community-based, and locally operated Blue Cross and Blue Shield companies that collectively provide healthcare coverage for one in three Americans. Blue Cross and Blue Shield companies offer quality healthcare coverage in all markets across America and participate in all federal insurance programs, including the Federal Employee Health Benefits Program (FEHBP), Medicare Advantage, Part D, CHIP and Medicaid managed care programs. BCBS companies also serve individuals and employers in the small and large group markets. We are committed to high quality, affordable coverage for all regardless of pre-existing conditions.

For nearly a century, BCBS companies have provided secure and stable healthcare coverage to people in communities across the country, allowing them to live free of worry, free of fear. Serving one-in-three Americans nationwide (over 106 million), BCBS companies, their foundations, and their employees stand committed to their local communities – where they live and work. They do this by creating and supporting programs that drive positive health outcomes addressing some of the most pressing issues affecting the country today: community health disparities, the opioid epidemic and most recently providing aid to those in need after a catastrophic hurricane season.

BCBSA, through the FEHBP, administers health insurance under contract with the U.S. Office of Personnel Management (OPM) to approximately 5.4 million federal employees, retirees and their families. The FEP Director's Office of BCBSA, located in Washington, D.C., manages this contract, acting as the Blue Cross and Blue Shield Plans' agent with the OPM. I would like to thank Chairman Burgess (R-TX) and Ranking Member Green (D-TX) for their leadership in holding today's hearing and providing the opportunity to discuss key ways to improve health care. In my remarks today, I will address:

- I. How BCBSA and its member companies are working to reduce fraud and abuse;
- II. The need to eliminate "gag" clauses in prescription drug spaces; and
- III. Other key prescription drug policy opportunities to ensure people have access to safe, effective prescription medicines at the most affordable price.

Fraud and Abuse

An essential step to ensure the affordability of healthcare is addressing, reducing, and to the extent possible preventing, the opportunity for fraud and abuse. According to the National Health Care Anti-Fraud Association (NHCAA), health care fraud costs taxpayers \$68 billion every year and accounts for between three and 10 percent of all healthcare spending in the United States. BCBS companies are diligent in working to stay ahead of fraud (e.g., falsified claims; misrepresenting the provider of service; billing a non-covered service as a covered service) and abuse (e.g., over-prescribing medications; ordering unnecessary tests; keeping patients at the hospital for longer than necessary). The BCBSA's National Anti-Fraud

Department is dedicated to the support and promotion of BCBSA's anti-fraud efforts nationwide, including for the FEHBP program. This effort includes direct investigative support to Blue Plan Special Investigative Units (SIUs), coordination of multi-Plan investigations, working with federal and state law enforcement, and providing subject matter expertise to BCBSA's Office of Policy and Representation, the media, and governmental entities.

BCBS companies' fraud investigation units coordinate investigations with the FBI, the Offices of Inspector General for the U.S. Department of Health and Human Services and the Office of Personnel Management, state police and local police departments. They also assist with state and federal prosecutions. The management team within several BCBS companies' SIUs are in leadership roles with major health care anti-fraud organizations and associations, including the NHCAA. NHCAA membership consists of approximately 90 private health insurers, regulatory agencies, and federal, state, and local law enforcement agencies that have jurisdiction over health care fraud. Plan managers from the following BCBS companies currently serve on the Board of Directors: Florida Blue, BCBS North Carolina, BCBS Massachusetts, Anthem, Health Care Service Corporation, and Blue Shield of California. This representation allows us to strengthen our partnerships, provides development opportunities, allows for information sharing and strengthens our ability to identify, investigate, prevent, and report fraud, waste, and abuse affecting the FEHBP.

Among various governmental efforts, the Federal government established the Healthcare Fraud Prevention Partnership (HFPP) to improve the detection and prevention of healthcare fraud. BCBSA and several of our member companies are active participants in the HFPP. We support

the HFPP for bringing together a diverse population of fraud management, control, and enforcement parties to identify areas of potential risk posed by healthcare fraud and abuse.

We support Congress' desire to establish explicit authority for HFPP and its activities, better equipping them to define the rules and responsibilities of its members and expand the scope of allowable activities to address more in the spectrum of fraud and abuse in our healthcare system. As Congress takes steps to codify the HFPP Charter, we recommend the following improvements to help the Partnership fulfill its objectives:

- While completed studies of existing abuses have demonstrated some success in
 returning dollars to plans participating in a particular study, the benefits of these studies
 have not been leveraged nationally. We recommend establishing improved mechanisms
 to share learnings so all participants are aware of the lessons from the studies and can
 take action to address similar issues.
- In addition, the Medicare and Medicaid programs have significant clout and can set a national direction among the provider community for fraud and abuse. However, the HFPP appears to be prohibited by its Charter from advising these programs of the schemes it identifies, limiting its overall impact. If, instead, the HFPP were mandated to share such information with Medicare and Medicaid, fraud detection and prevention lessons learned from the HFPP could spread more widely in both the public and private sectors. If such a Charter change is made and produced positive financial results, additional funding for the HFPP may make financial sense, both for the public and private sectors.

Finally, clarifying the exceptions to sharing PHI/PII in fraud-related matters under HIPAA
would improve collaboration and cooperation of those who may be afraid to share
important data due to a lack of understanding of allowed exceptions. This action along
with some kind of good faith provision to protect employees engaged in fraud-related
work when sharing protected information may remove such roadblocks.

"Gag" Clauses

Another key step to improve healthcare is ensuring that consumers have the necessary information to make informed decisions about their care. While not a practice of the FEHBP, some contracts between pharmacies and purchasers (i.e., insurance companies, pharmacy benefit managers, and/or employers) include restrictions or "gag clauses" that prohibit pharmacists from informing consumers that the drugs they want could be purchased at a lower cost if the consumers paid out-of-pocket rather than purchasing through their insurance plan.

For example, if a customer's health plan has a \$20 copayment for a medication, but the plan's negotiated cost of the drug at the pharmacy is \$10, because of a gag clause the pharmacist could not advise the customer that he or she would save \$10 by paying for the drug out-of-pocket.

BCBSA does not support the use of gag clauses and is unaware of any Blue Cross and Blue Shield company or contracted pharmacy benefit managers (PBMs) that have gag clauses in place with pharmacies. Furthermore, BCBS companies using major PBMs like Prime Therapeutics, CVS Caremark and Express Scripts do not report use of these gag clauses. The use of these gag clauses is, in fact, not very prevalent.

We commend CMS for taking a tougher position on gag clauses, as noted recently in a letter to health plan sponsors in May clarifying that any form of gag clauses are unacceptable and contrary to their efforts to promote drug price transparency and lower drug prices. We also support current Medicare Part D rules that call for a beneficiary to receive a covered medication for the established copayment or cost-sharing, unless the negotiated cost of the medication is lower

BCBSA supports legislation to ban gag clauses and any prohibitions on allowing pharmacists to make information about cost savings known to the beneficiary at the point-of-sale. To the extent that some in the industry include such clauses in their contract, consumers may be deprived of information that will help them make prudent decisions when paying for prescription drugs. With this is mind, we would also encourage pharmacists to advise patients on generic substitution and alternative medications so long as this is done in direct communication with the dispensing physician.

Full transparency is critical for consumers to have the necessary information to make choices that work best for them. It also is important that pharmacists advise consumers to consider the impact of not using insurance coverage to pay for prescriptions. While certain beneficiaries

might pay lower out-of-pocket costs on a given prescription, drugs purchased outside of their insurance benefit will not count toward the beneficiary's deductible or maximum out-of-pocket (OOP) limits which may reduce the value of their insurance coverage.

While BCBSA is fully committed to ensuring individuals receive their medications at an affordable price, another trade-off with out-of-pocket payments is the potential health risk to the member. BCBS companies and PBMs have systems in place that check for potentially harmful drug interactions, but prescriptions purchased without insurance will not be in the system. Similarly, a company cannot help a member with medication adherence if it does not know that a member is on a particular drug.

For example, FEHBP operates a Medication Therapy Management program, working with 15 pharmacists to review prescriptions against a member's medical records and interact directly with members to make sure they are getting the best medical care. This program has proven to be effective in improving quality for members through meaningful and timely interactions and generating savings for the FEHB program and the Federal government. For example, in 2017 the program contributed to a 21 percent increase in preventing the dispensing of antibiotics for adults with acute bronchitis, consistent with established standards of care.

Thus, while we support elimination of gag clauses, we believe that pharmacists should also inform consumers of the potential risks of not using their drug coverage so that they can make more informed decisions.

Other Key Prescription Drug Policy Issues

BCBSA applauds the committee for holding this hearing and seeking this opportunity to improve the delivery of healthcare. We support these efforts to drive the healthcare system to higher quality, lower costs and improved access to care for everyone. In line with these goals, more is needed to ensure that people have timely access to safe, effective and affordable cutting-edge prescription medicines when they need them. BCBS companies across the United States have been working to move to value-based and outcomes-based arrangements for prescription medicines to achieve improved quality at lower cost. Based on these experiences as well as BCBS companies' generations of healthcare experience and commitment to ensuring their customers' health needs are met, BCBSA has identified four key strategies to address escalating prescription drug costs and ensure that people have timely access to safe, effective, cutting-edge prescription medicines and their generic equivalents at the most affordable price, and in the right setting. These include:

- 1) Reducing barriers that limit competition and consumer choice. Currently, significant barriers hinder patients' timely access to affordable, safe, effective and cutting-edge prescription medicines and their generic equivalents. Promoting competition and consumer choice will make prescription medicines more affordable.
- 2) Promoting greater transparency and sharing of information regarding the pricing of prescription medicines. Understanding how drug prices are currently established is a necessary step in discussing any policy options that are meant to address the unsustainable rate of rising prices. There should be transparency regarding the pricing of

prescription medicines. Specifically, information about a drug's price and its effectiveness should be widely available to the public. It is also important that health insurers know which new drugs are coming into the pipeline. This allows health insurers to work with doctors and pharmacists in planning and in working to ensure there are ways to get prescription medicines to patients at the most affordable cost.

- 3) Providing medical and healthcare professionals with the tools they need to support patient education and adherence. BCBS companies support policies that give medical professionals the tools they need to educate and support patients in taking their prescription medications as directed. Unfortunately, nearly three out of four people report that they do not always take their prescription medicine as directed. Addressing this problem would improve patients' health and safety, prevent adverse side effects and unnecessary hospitalizations, and, as a result, help to rein in costs.
- 4) Promoting additional regulatory changes that help patients get the right medicines for them, at the most affordable prices. BCBS companies believe that a number of regulatory adjustments can be made to increase competition and improve patient access to affordable prescription medicines, such as the off-label use of prescription drugs is regulated by the FDA, modifying drug marketing guidelines to improve transparency around pricing and effectiveness, and increasing patient access to more affordable medicines by allowing generic drug manufacturers access to brandname products.

More information on these recommendations can be found in our recently published BCBSA white paper, "Ensuring Patient Access to Safe, Effective and Affordable Prescription

Medicines."

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Again, we commend the committee for taking on these important issues as it is critical that all stakeholders work together to ensure the affordability of healthcare for all Americans. Achieving this important goal will require the public and private sectors to collaborate to develop solutions that benefit patients and the entire health system.

Again, thank you for the opportunity to testify today and your leadership in seeking opportunities to improve healthcare.

¹ "Ensuring Patient Access to Safe, Effective and Affordable Prescription Medicines," https://www.bcbs.com/sites/default/files/file-attachments/page/DrugPricing WhitePaper 110317.pdf

Mr. Burgess. Thank you.

Thank you, Dr. Yoder, and thanks to all of our witnesses for your testimony. So we will move into the question-and-answer portion of the hearing. And I would actually like to defer my questions until later in the hearing and recognize the vice chair of the full committee, Mr. Barton of Texas, 5 minutes for questions, please.

Mr. Barton. Thank you, Mr. Chairman, I am very honored and flattered to take your question time at this time. I sincerely mean

First, I want to ask unanimous consent, Mr. Chairman, to place into the record statements of support for the ACE Kids Act. We have almost two dozen national groups that are supporting the draft bill in its current form, and I would like to put that in the official record.

Mr. Burgess. Without objection, so ordered.

[The information appears at the conclusion of the hearing.]

Mr. Barton. Thank you, Mr. Chairman.

Mr. Merrill, I want to thank you for coming up from Fort Worth for your testimony. I want to thank you for all the years you and your national group that you are the president of this year have supported us and helped us to refine the bill. Can you tell the subcommittee—and I don't think you said this in your opening statement—what percent of Medicaid-eligible children meet the eligibility requirements of the ACE Kids Act?

Mr. Merrill. I would have to probably get that specific number

for you or percentage for you. It is definitely a small percent.

Mr. BARTON. I am told it is around 1 or 2 percent.

Mr. MERRILL. That is close to the number. I just wanted to make sure I stated an accurate number.

Mr. Barton. All right. This is a friendly hearing. We don't re-

quire total specificity. Mr. MERRILL. Just want to answer it as best I can and correctly.

Mr. Barton. All right. Now, to the best of your knowledge, this small percentage of Medicaid-eligible children that would qualify for ACE Kids, what is a seat-of-the-pants estimate about the cost to Medicaid by that 1 or 2 percent?

Mr. MERRILL. Yes, again, I would have to get the number for you. I don't have the number off——

Mr. Barton. If I were to throw out 30 percent, would you strongly disagree with that?

Mr. Merrill. Percentagewise, I think it is up close to 40 percent.

Mr. BARTON. Forty percent.

Mr. MERRILL. In terms of an actual dollar amount, I would have

to get that number.

Mr. Barton. So here we have a situation where, thankfully, of the 37 million eligible Medicaid children, there are not very many that have these complex medical conditions. But for those that do, they take a hugely disproportionate share of the cost.

Mr. Merrill. That is correct.
Mr. Barton. So, if we can do something that provides better care, more comprehensive care, and actually saves money, that is a win-win. Would you agree with that?

Mr. Merrill. I would absolutely agree with that. I think everyone does win. I would say all in, all win, frankly, on ACE Kids. I think that will matter greatly for these families, these children. It will matter to the State programs in saving Medicaid dollars and improving care and outcomes for these kids, and, as I said, all in, all win.

Mr. BARTON. Are you aware of any provider organization that actually provides services, whether it be doctors, therapists, hospitals, anybody in this country, that opposes the ACE Kids Act?

Mr. MERRILL. I am sorry?

Mr. BARTON. Are you aware of anyone that is actually providing

services to these eligible children that opposes this bill?

Mr. MERRILL. I think that any time a new bill or approach to care is introduced, organizations will have concern: What does it mean for me?

And based upon the original draft of 3 years ago and all of the work that has gone to try and address some of those concerns, the current bill, as it is reflected, I do believe, addresses most, if not all, of those concerns from those who might not originally have

been fully in support of.

Mr. BARTON. You can tell that you have been president of a national organization. I am throwing you softballs, and you are being very ecumenical. The answer is no, there is no national organization that provides care—now, there are some opponents but not of the people that are providing the care. To my knowledge, there are none.

Mr. MERRILL. Fair enough.

Mr. BARTON. Now, I want to ask Mr. Salo, you have mentioned two principles that legislation that actually works should have. You mentioned flexibility. Does ACE Kids have flexibility?

Mr. Merrill. It absolutely does.

Mr. Barton. I am asking the Medicaid director.

Mr. SALO. I got this one. I want to be careful about not spending too much time speaking to the actual structure of the current version because, as we have said, this legislation has evolved significantly over time. But our reading of the current version does seem to allow for greater flexibility. I think previous versions seem to say that States that were heavily invested in managed care as a delivery mechanism would actually get carved out, wouldn't be able to take advantage of this.

Mr. Barton. It is voluntary on a State basis—

Mr. SALO. If it is driven by the State, if it allows a State either that is heavy managed care or managed fee-for-service, like in a Connecticut, or something in the middle like Massachusetts with ACOs, as long as it allows the State to be able to design that in a way that meets not only the delivery system in their State but also meets the needs of the patients in that State.

And I think one of the other key issues is trying to get a handle on exactly how you define the population that is affected. As Mr. Merrill said, there is no Federal definition of this, and so the question is, are you talking about 2 million kids? Are you talking about 50,000 kids? You had research that talked about 8,000 kids and how that was effective. It is going to be important to allow this to be flexible enough for the State to figure out, how can we make this work? Because if it creates silos within what a State is trying to do, that is going to create conflict, and that is not sustainable.

Mr. BARTON. Mr. Chairman, my time has expired. Next time I would ask unanimous consent if I could ask the question and then answer it myself so that I could make sure I get the right answer I want.

Mr. Burgess. You usually do.

Mr. BARTON. With that, I yield back, Mr. Chairman.

Mr. Burgess. Thank you. Thanks to the vice chairman. The chair now recognizes the ranking member of the subcommittee, Mr. Green. I would ask just 5 minutes for your questions, please

Mr. GREEN. Thank you, Mr. Chairman.

And I am following my friend Joe Barton that we would all like to be able to answer our own questions.

So, thank you, thank the whole panel for being here today.

Mr. Chairman, I would like to ask unanimous consent request on behalf of Ranking Member Pallone entered into the record letters from the Medicare Payment Advisory Commission, MedPAC, and Medicaid and CHIP Payment Access Commission, MACPAC, concerning their request for legislation to ensure both commissions can access drug rebate data for their respective analysis. Ask unanimous consent.

Mr. Latta [presiding]. Without objection, so ordered.

[The information appears at the conclusion of the hearing.]

Mr. GREEN. Thank you, Mr. Chairman.

Mr. Merrill, thank you for being here today and sharing your expertise as a leading children's hospital, and, of course, you know where I am from. I have been involved with Texas Children's Hospital since I was a young State legislator in the seventies, but Cook Children's Hospital, I am glad my family hadn't had to take advantage of the Cook Hospital to treat out-of-State patients. In fact, in your testimony, you know that Cook Children's treated children from more than 35 States last year.

As you know the State-by-State nature of Medicaid program has made it difficult to coordinate care across State lines. The same State innovation and flexibility that makes Medicare/Medicaid able to respond to unique needs of the State's population can be the characteristics. I am hopeful that ACE Kids Act will help provide Cook Children's overcome this issue and ease some of the burden families are facing today when they are trying to coordinate your child's care. Would you please discuss difficulties that may arise when you are providing care for a medically complex child from out of State?

Mr. Merrill. Yes, there are, as most of you know, some States that do not have children's hospitals or some of the high-level care that is offered in some of the other States. And so, as a result, we do get referrals, as I mentioned, from a number of States. That is true for Texas Children's. That is true for a number of children's hospitals.

I would give you probably two examples. We had one particular patient that was referred to us from a neighboring State that did not have the high-level children services for bone marrow transplant services, and it becomes a negotiation and a long drawn-out discussion with the Medicaid program in those States. Those discussions can last anywhere from 2 weeks to 3 months. And in this

particular case, it took well over 2 months for us to get this patient

approved for the bone marrow transplant that they needed.

There is another example of a patient from up in the Midwest area who was referred to Cook Children's for some services that we offer that only a couple of other children's hospitals offer. It is a medically complex child, and it took us 3 months to negotiate a single case agreement. And in the end, we were never able to reach an agreement, and we do not know what happened to that patient.

So it puts at risk the health of these patients. The frustration, the anger from these parents, who really want to care for their kid, and certainly us on the receiving end, who want to deliver that care, all of us become very frustrated. And it is very difficult; it is time-consuming. And I believe that ACE Kids will allow us to streamline a lot of that effort so that we can get these kids quicker, sooner, to the right kind of care that they need.

Mr. Green. Thank you.

Mr. Salo, how can we disseminate, encourage more widespread adoption of best practices and care for children with medical com-

plexity more effectively across State lines?

Mr. SALO. So I think that is a key function that our organization can provide, working in close tandem with CMCS, with Center for Medicaid and CHIP Services. I think we have acknowledged that in the case of, when you are talking about patients who are crossing State lines and dealing with jurisdictional issues like that, there is clearly a need for additional best practices, additional guidance, additional tools to make that work well. And I think we have been open in conversations with my colleagues here, as well as our friends at HHS, about how can we do that, how can we figure out what works, both in terms of-well, it is mostly, I think, finding that balance between, how do you make the process as easy as possible for the family while also making sure that the cross-jurisdictional issues are respected and that we are not obligating an individual State to another State's decision or to individual providers who are setting up a silo that perhaps is not in the best interest of the population as a whole?

I think we can get there. I think there is a lot of potential for

best practices in this, absolutely.

Mr. Green. Mr. Chairman, I know I am out of time, but I want to thank our witnesses. And this is a piece of legislation—I think it is important that we move on this. Thank you.

Mr. LATTA. Well, thank you very much. The gentleman's time has expired and yields back.

And the chair now recognizes himself for 5 minutes. Mr. Cunningham, if I could start with you. While preparing for

today's hearing, I heard from a local, independent-living organization in northwest Ohio asking for my support of the EMPOWER Care Act. The center connects people with disabilities to programs and services that are necessary to achieve and maintain independence in the community

Without the Money Follows the Person, the MFP, Program, this center would not be able to hire staff to serve as transition coordinators and help individuals maintain independence outside of nursing facilities. Since 2008, this local program has achieved 524 total transitions, and 77 percent of those transitions have reached 365 days of independence.

Furthermore, in the State of Ohio in 2017, the average annual Medicaid savings for individuals utilizing MFP was over \$39,000 per person. How have the cost savings associated with the program been utilized for the benefit of your State Medicare population?

Mr. CUNNINGHAM. Sure. So, Wisconsin is fortunate to have a very robust home and community-based services program, and the way we have gotten there is through utilizing MFP and other resources to create some innovative practices. And we look at that and some of the practices, like housing counseling and other things that we developed through MFP, we have now included in our HCBS package of benefits because they have been shown to be proven effective in making sure people relocate.

And we see a reduction in cost. The average nursing home cost in fee-for-service is about \$5,256 per month. Our family care and HCBS programs have a PMPM of \$3,200. So it is in our interest.

MFP has also allowed us to, as we have expanded our HCBS services, to move people off the waitlist, and we are on the cusp of eliminating the waitlist for all of the people that need HCBS services.

Mr. Latta. Let me follow up. Are there any challenges the States face during the transitions that could be better addressed in reauthorization?

Mr. Cunningham. I think the flexibility, again, is very important. I think housing continues to be a challenge. The housing counseling that is done, we developed a database of available 811 housing vouchers through MFP. So I think just continuing the funding, I think the certainty of having MFP is also important because some of these programs that we have going, take 2, 3 years to test out, to see if they are cost-effective in moving forward. So I think that is what I would ask for now is to make sure this there is certainty there so we can keep some of these innovative practices going.

Mr. LATTA. Well, thank you.

Mr. Salo—am I pronouncing that right, is it Salo?

Mr. SALO. Salo. Mr. LATTA. Salo?

Mr. SALO. Yes, rhymes with "halo."

Mr. Latta. Let me follow up, because in addition to the letter of support I received for the MFP Program, I also heard from an Ohio mother who has great concerns with the program. She cited that MFP forces individuals with severe and profound intellectual and developmental disabilities into a one-size-fits-all care model rather than allowing the patients and families to choose a care setting that best fits their own medical needs.

Do you believe there are gaps in the program that should better account for individuals with complex medical and behavioral needs?

Mr. SALO. I know that there are differences in philosophy about the nature of the spectrum of institutional versus non-institutional care and some who come down along the lines of the least restrictive, as Olmstead is always better, but I think that, from the State perspective, it is really critical to be mindful and respectful of the individual or the family decision to figure out what is the setting that is best for them.

In most cases, that will be in their home or in their community. But we certainly know there have been lots of conversations over the years with—so, for example, parents of adult children with severe developmental or intellectual disabilities, whose kids have been in settings for a long time and are very fearful about having that changed. I think we need to be very, very mindful about not abruptly changing settings for people who are not ready for that.

But I think for most populations that we serve in the long-term care arena, the clear and undeniable trend is to move away from institutional and toward home and community-based settings.

Mr. LATTA. Thank you very much. My time is expired. And the gentle lady from California is recognized for 5 minutes.

Ms. Matsul. Thank you very much, Mr. Chairman.

And I want to thank all the witnesses today for being here. I am pleased that we are hosting this hearing to discuss important opportunities in Medicaid and potential ways to improve trans-

parency in our healthcare system. I want to follow up on the EMPOWER Act. It is really a strong

example of the importance of supporting Medicaid. The Money Follows the Person, MFP, is particularly important to seniors in institutional settings, such as nursing homes, who may be seeking care or services while still being surrounded by familiar faces and places.

And I think we all understand how important it is to look at this somewhat individually too, that there is not a one size fits all here as we move forward. And I really believe that each of us understand the concept of how important it is. And I also believe there are challenges here too.

I am interested also to hear more about the changes being made to the institutional residency period requirement. I understand that it will be decreased from 90 days to 60 days. How do you think changing the requirement will impact beneficiaries of the MFP? Mr. Cunningham?

Mr. CUNNINGHAM. Changing from 90 days to 30 days for the-Ms. Matsul. Ninety days to 60 days. That period requirement.

Mr. CUNNINGHAM. I am sorry. Could you repeat that?

Ms. MATSUI. OK. There are changes being made to the institutional residency period requirement. It will be decreased from 90 days to 60 days. I understand that that will give a lot more flexibility and allow other patients to be able to be involved in this. Is that correct?

Mr. Cunningham. Yes. Yes, that is correct.

Ms. Matsul. OK. Now, there have been multiple studies showing the MFP program can result in significant cost savings to States. And I think it is really important that Mr. Salo noted that the program expired in 2016, which forced States to scale back the program. And I am really concerned that this may have had unfortunate consequences for States and patients. Can you give me some examples here, with the challenges that might have occurred here?

Mr. Cunningham. Yes, so, as I mentioned, as many of the programs that are ongoing, like our nursing home community specialists, as many States are running out of grant funding, they are having to wind down those programs. And that is impacting their

ability to have those innovative processes to relocate people.

So I think a number of States have actually already expended their full grant amount, and I think in 2020 is when the full expenditures have to be completed. So, without an extension, even at the State level, you start to look at these programs and how do you maintain the staff to support these programs in the future once your grant funding goes away?

Ms. Matsui. Certainly, thank you.

And I want to talk a little bit about gag clauses. It is encouraging that this committee is taking steps to begin tackling the issue of transparency in our healthcare system. My understanding is that gag clauses impact the pharmacies, as well as the patients.

Mr. Chancy, would you like to comment on the impact gag clauses have on both patients and pharmacies, especially in rela-

tion to pharmacy benefit managers?

Mr. Chancy. Yes, I would love to. The gag clauses, actually, they do have an impact on both. The patient, our relationship is based on trust, and they depend on us to bring and help them maneuver through the intricacies of their healthcare, specifically with their prescription benefits. When we are not able to give them options, then it kind of puts us in a situation where we aren't able to give them information that we feel like they need.

If we do, then we are running the risk of being in violation of contracts that sometimes we didn't even know that we were in vio-

lation of.

Ms. Matsui. Right.

Well, Dr. Yoder and Mr. Chancy, how well informed do you think the public is about gag clauses? Do you think the patients know to ask about prices at the counter?

Mr. Chancy. They are not very informed, and I think that because of the way the contracts have been written, not many people have talked about them. I think they are seeing more in the news now, and there is a little bit more interest, but it is nowhere near where it needs to be.

Ms. Matsul. OK. If this legislation, Mr. Chancy, in front of us is passed, will pharmacists start telling patients about their alternatives? Or do you think there will be a need to have some sort of awareness or education campaign?

Mr. Chancy. I think pharmacies will, and I think a lot of pharmacists currently are doing that, but I think an awareness campaign would be fantastic.

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

Mr. Burgess [presiding]. The chair thanks the gentlelady. The gentlelady yields back.

The chair recognizes the gentleman from Kentucky, Mr. Guthrie, the vice chairman of the Health Subcommittee, 5 minutes for questions

Mr. GUTHRIE. Thank you, Mr. Chairman, and for the Ranking Member, for holding a hearing on the EMPOWER Act, H.R. 5306, which would reauthorize the Money Follows the Person Program. I was very pleased to introduce this bill with my colleague as bipartisan with Debbie Dingell.

First Mr. Salo and Mr. Cunningham, as you know, H.R. 5306, as currently drafted, would extend the Money Follows the Person for 5 years. While this is ideal, would a 1-year extension be helpful?

Mr. Salo. A 1-year extension, I would argue, is better than let-

ting it die. If those are the options?

Mr. GUTHRIE. Those are the options. Well, I don't know if those are the options, but if that is the option, then you would rather

have a 1-year—

Mr. Salo. A 1-year extension is better than letting it die. A 1-year extension is not ideal. That is not enough time. If you understand how State government works, you know that when programs are dependent on Federal funding, or any source of funding, if you don't have long-term certainty about where the money is coming from, how much is coming, and the direction and speed which it flows, you have uncertainty. When you have uncertainty, you clamp down, you tighten up, and you stop spending. You go really, really conservative.

And, if you get a year and you don't know what is going to happen that following year, you are probably not going to spend that money because you are going to be very, very cautious, and that is extremely disruptive to the people who need this. So the longer the extension, the better. I would argue making it permanent if you can, but 5 years is better than 1. One year is better than just letting it die.

Mr. GUTHRIE. Point well taken.

Mr. Cunningham?

Mr. CUNNINGHAM. Yes, I reiterate what he said. I think the other thing to consider is that, when States see only a 1-year extension, you start to look at one-time type of things that are not as effective as really driving the long-term change that we want to use this funding for, so, yes.

Mr. GUTHRIE. Thank you. I said for both. The point is well taken. Mr. Cunningham, through the Money Follows the Person Program, over 88,000 individuals have transitioned from nursing homes and other institutions back to their own homes? I know there seems like a lot of support in the room for this, and I am very supportive of that as well.

What have we learned through the MFP program and about how the quality of life improves for individuals when they transition

back to their homes and communities?

Mr. Cunningham. Sure, the MFP program does require a quality-of-life survey, and, at least in Wisconsin, when we ask if they are satisfied where they live, that satisfaction went from 68 percent to 72 percent. And then when we asked people that have transitioned to MFP if they like where they currently live, it went from 62 percent in the institution to 91 percent in the community.

Mr. GUTHRIE. People like to be home. And it is even more convenient and more helpful for the family members, too, to spend time with them and see them, more than in an institutional set-

ting.

Mr. Cunningham. It allows them to become a participating member of—

Mr. GUTHRIE. Well, there certainly is an appropriate role for institutions, but that is absolutely right.

OK. Again, Mr. Cunningham, of the 44 States that have recently participated in the Money Follows the Person, at least 10 States have exhausted their funds and stopped transitioning new participants to the community. By the end of the year, all remaining States will stop transitioning new participants through the program. Without an extension of this program, will we lose progress?

Mr. Cunningham. Yes.

Mr. GUTHRIE. It is a given, huh?

Will more seniors and people with disabilities be forced into costly institutional placements?

Mr. Cunningham. Yes.

Mr. GUTHRIE. And then has the recent uncertainty hurt transition efforts?

Mr. Cunningham. Yes.

Mr. GUTHRIE. You are going through that.

And then one extra one. You have spoken about the importance of supporting people with disabilities to transition from institutional settings to the community. What has Wisconsin done to promote these transitions, both using MFP dollars and making use of Medicaid as a whole, and how are individuals counseled in the transition?

Mr. Cunningham. So one of the big things we do is a community living specialist. And through the diagnostic service information on—through the MDS at nursing homes, there is a section Q that clearly asks the recipient, do you want to relocate into the community? And so we review and have set up a system where this information flows to our community living specialists in the ADRCs. And then they reach out to these people to discuss community options. So this is a cycling process. And so people that want to move out in the community are contacted and then worked to develop those community resources to move them in the community.

Mr. GUTHRIE. OK. Thank you so much.

Thank you for your effort, Mr. Chairman. I really appreciate your effort in bringing this today, and I will yield back my time. Thank you.

Mr. Burgess. The chair thanks the gentleman. The chair recognizes the gentlelady from Florida, Ms. Castor, 5 minutes for questions, please.

Ms. Castor. Well, good morning, and thank you, Mr. Chairman,

for calling this hearing.

Today I am thinking a lot about the children with complex medical conditions and their families. On behalf of the families across America who are faced with a complex condition that their child has, I want to thank everyone on this committee for moving the ACE Kids Act forward. It hasn't been easy. This has been a multiyear proposition. I have been working on this bill since the 113th Congress with Congressman Joe Barton, who has been the stalwart cosponsor and sponsor here, along with our partners: Jamie Herrera Beutler, Gene Green, Anna Eshoo, and Dave Reichert.

But the ACE Kids Act in this Congress has over 100 cosponsors, bipartisan, including a number of my Energy and Commerce colleagues, and I want to thank them, specifically Representatives Cárdenas, Clarke, DeGette, Engel, Kennedy, Peters, Rush, Bili-

rakis, Costello, Guthrie, Harper, Lance, Long, and Olson. And I encourage our other colleagues to sign on to the bill as well. And thank you for your steadfast commitment to care for these children.

We also have a number of patient and stakeholder groups supporting the ACE Kids Act that range from the Children's Hospital Association to the March of Dimes to the American Academy of Pediatrics, and many more. Thank you all for consistently standing up for children with complex medical conditions.

And I want to also take a moment to thank the committee professional staff for their dedication to families and the hours they have spent working on this bill in a bipartisan fashion, especially Rachel Pryor and Samantha Satchell on the Democratic side, and

Josh Trent and Caleb Graff on the Republican side.

Additionally, this bill would not be where it is today without the

stellar work of my legislative director, Elizabeth Brown, and Representative Barton's staffers: Krista Rosenthall, Gable Brady, and

Jeannie Bender.

But it is really the families who are the heroes here. It is the families of these kids that have explained to Members of Congress on both sides of the aisle how important it is to have coordinated care. I became an advocate for the children and families that this bill will help after spending significant time back home in Tampa at the St. Joseph's Children's Hospital Chronic Complex Clinic that was started 16 years ago by a wonderful pediatric critical care doctor named Dr. Daniel Plasencia.

The ACE Kids Act is somewhat modeled after the St. Joseph's Children's Hospital Chronic Complex Clinic and the 700 kids and families that they serve. But, Mr. Merrill, you know this is the idea of home health, a medical home for these kids, is not unique. It is

being done, and we need to take it to the national level.

The families I met with over the years have shared with me what they have gone through to get the proper care for their kids. The care that they were receiving was often fragmented and uncoordinated. But, most importantly, we have got to focus on making sure the kids have a better quality of life. And we think through this bill, we will be able to do that.

Mr. Merrill, you might remember Tish West testified a couple of years ago, and she said—I met her daughter Caroline, who has been treated at St. Joe's—she said: In the beginning of Caroline's life, I used to carry around these gigantic notebooks full of medical records and everything else so that we went from doctor to doctor, she would have to explain what was going on and what her illnesses were. But at this clinic, at this medical home now, they have the medical records; they are all electronic; everyone knows Caroline; they know what is going on with her.

Tish said: It is just a real collaborative effort, and she is much

healthier as a result of that.

Do you think we are going to be able to make progress for more

families if we pass the ACE Kids Act?

Mr. MERRILL. I absolutely do. And our own experience in Texas with our STAR Program, which is somewhat equivalent of ACE Kids, we actually have care coordination clinics and medically complex clinics that would mimic a lot of structure that we are contemplating in ACE Kids.

I would give you one example of, just recently—as we have 9,000 children that are signed up in our STAR kids; these are medically complex kids—and the Cook Children's Health Plan. And so we took the most complex children of those 9,000, and our care coordinators, for the first 2 weeks, spent numerous times on the phone with these families and made home visits to these families to look at not only what their healthcare needs were but their social needs.

There was one particular example where a child and family had been for months and months carrying their child up the steps because they had no wheelchair ramp for the child in the wheelchair.

We put a wheelchair ramp in for these families.

And so this care coordination and this care plan is, it is tailored for these specific families. And when it is tailored, we are able to anticipate needs, not just their medical needs but other social needs, and make it so much more easier for these families to navigate what can be a complicated system and help these children remain healthy.

I will just give you one quick example. This was actually a couple of weeks ago. We had a mother of one of these medically complex children call her case manager—and by the way, these case managers, as you well know, have these incredible close relationships with these families. There is respect. There is great communication

going on.

And this parent was distraught that she was getting close to the weekend and she wasn't able, through a series of events, to get a prescription filled for her child that was much needed for that weekend, called up our case manager. Our case manager calmed the mom down, because of that relationship, took care of the prescription order from the physician, went to the pharmacy, picked up the drug, and delivered it to the home for this family, avoiding, by the way, an ER visit, guaranteed, and probably an in-patient admission. So that is the kind of activity that we anticipate under ACE Kids, the kind of work that will make life easier but keep these kids healthier, keep them out of the hospital, keep them closer to home, and I think that is a very positive thing for these families and their children.

Ms. Castor. Thank you very much.

And, Mr. Chairman, I would like to ask unanimous consent to submit for the record a letter from St. Joseph's Children's Hospital's CEO in favor of the bill.

Mr. Burgess. Without objection, so ordered.

[The information appears at the conclusion of the hearing.]

The gentlelady's time has expired.

The chair now recognizes the gentleman from Virginia, Mr. Griffith, 5 minutes for questions, please.

Mr. Griffith. Thank you very much, Mr. Chairman.

Mr. Chancy, I am going to ask you a couple questions. You mentioned that community pharmacists have little negotiating power when it comes to contract provisions set by the pharmacy benefit manager, and we have seen that in PBMs; we have seen that before.

Can you explain how smaller and rural community pharmacies are disproportionately affected by this inability to effectively negotiate and how that can, in turn, negatively impact patients?

Mr. Chancy. Yes. And most of our pharmacies are in rural Georgia, and like, for example, one of our pharmacies, 25 percent of our business is through one PBM. And if they change their reimburse-

ment model or whatever, it impacts us in a great way.

And so the lack of getting on that contract or not getting on that contract depends on whether we, as a business, survive. One of the concerns in Georgia is we have four counties now that have no community pharmacies because of some of this, that they are deal-

ing with.

Mr. Griffith. And not just that, but can't it affect the patients as well? So I know the committee is tired of hearing about Clintwood and Haysi, but if you look at them on a map, they look like they are only about 5 or 10 miles, maybe 12 miles apart. But there is a big mountain in between them, and the mayor of Haysi told me one time it takes him an hour; he always plans on an hour to get to any of the meetings he has to have in the county seat of Clintwood.

So, if you are the community pharmacy in Haysi and the PBM takes you off, that patient is now going to have to drive to Clintwood to get their drugs and rely on somebody that—because most of us rely on our pharmacist, our community pharmacist. Is that not also a problem?

Mr. CHANCY. It is. And CVS Caremark, Caremark being the PBM, many times they require their patients to go to one of their pharmacies. And in rural Georgia, there is not a CVS in every community or county, and so it compromises them with access.

Mr. GRIFFITH. Yes, sir, I understand that.

Beyond drug-pricing disclosures, what are some of the other impacts that gag clauses have on the pharmacist-patient relationship? Can you think of any? Because I can think of one. A constituent came to me, and we were just talking about this whole gag issue, and she had stumbled across, and at first, she had questions about her pharmacist, because originally it wasn't considered a part of the formulary. So she had to pay cash for it. It cost her \$17.

And as Chairman Walden said in his opening statement, then they notified her it was in her formulary, and she called in her prescription, and they told her she would have to pay the copay of \$50. So she called her pharmacist all upset, thinking that he was doing something goofy. Doesn't that damage that relationship? And he explained to her that he wasn't allowed to tell her that, but since she had found out about it, she could pay with cash if she wanted to.

Mr. Chancy. Oh, definitely. And there are some times where the patient is required to get the brand instead of the generic, which is a cheaper copay, and I think it is just the rebates or some sort of agreements that they have worked out. And so that impacts them as well.

Mr. GRIFFITH. Attorney General Schmidt, I have some theories. I like listening to the testimony and listening to folks, and you did a great job, and you got some great people signed on to these letters. But one of the concerns that I might have if we have—and there is an answer to it, but it is going to take money and effort.

If you have got somebody who is skilled at determining financial fraud, they might go into the home—let's say the fictional char-

acters from "Seinfeld," George Costanza's parents, who were always fighting with one another—now, if one of them was the patient, somebody who is a financial investigator might automatically assume that there is some kind of abuse going on there, and they have been having that relationship that way, as the fictional characters, 50 years or so.

And so aren't you going to have to train folks to be able to distinguish between—financial fraud is different than physical or mental abuse, and there is a concern, and it gets complicated. Because I actually had a case one time where they thought the parents were doing something to an infant. I know this is a little bit different, but the infant was failing to thrive whenever it was in the parents home. We ultimately discovered the infant was allergic to dogs, and they had a dog in the house. So, every time they would put it in the aunt's house, the child would do better. They put it back in the parents' house, and the child would fail to thrive.

So there are a lot of complications with it, and I think that your financial investigators are going to have to be trained, if we give them this authority, and somebody is going to have to pay for that training, or else we will have people bringing cases that maybe

they ought not.

And one of my concerns there is that when you bring a case, particularly against a family member, you are yanking that family apart, and you are pulling that person out, and you really have to

walk with care. What do you say about that?

Mr. Schmidt. Right. Representative, certainly speaking for myself, I would be very sensitive to that concern. We see those types of dynamics, not just in the context of our Medicaid fraud work, but in the context of our broader criminal work for the State.

So we are accustomed to dealing with those sorts of distinctions. And we are human, and sometimes we get it right, and sometimes

we don't. But I believe we do in most cases.

I would say one thing: I can't speak for every State. Perhaps the larger States with larger Medicaid Fraud Control Units do have distinct, financial-crimes investigators versus patient-abuse investigators. For Kansas and I think for most of the small and midsize States, we do not. We do have dedicated fiscal analysts who are the number crunchers that don't go on and do field investigations. So they are purely financial.

But with respect to our investigators in our MFCU, we have six sworn law enforcement officers. They are all cross-trained. They handle physical abuse, sexual abuse, financial abuse, as well as fraud. And the reason for that, under current law, is that they are doing those abuse cases when they occur in a healthcare facility. So they already have the skills; they just can't apply them in the

non-institutional setting.

Mr. Griffith. All right, I appreciate that, and I yield back.

Mr. Burgess. The chair thanks the gentleman. The gentleman yields back.

The chair recognizes the gentlelady from Colorado, Ms. DeGette, 5 minutes for questions, please.

Ms. DEGETTE. Thank you so much, Mr. Chairman.

I note that we have a number of representatives of ADAPT here in the hearing room listening to this, and I want to welcome all of you. ADAPT was founded in Denver, my district, and I have worked with them and also the Atlantis community for many, many years. The Atlantis community is one of the oldest, independent-living centers in the country for individuals with disabilities, and they have really done courageous work over the years in educating all of us about why it is so important that we pass legislation that supports their independence and their ability to live in their homes and their ability to really lead the kind of productive American lives that everybody in this country should be able to do. So thank you all for coming out today.

There are a number of pieces of legislation that they support, but one of them specifically is H.R. 5306, the Ensuring Medicaid Provides Opportunities for Widespread Equity Resources and CARE Act. And then I want to thank Congresswoman Dingell and Con-

gressman Guthrie for sponsoring that.

In Colorado, funding for the Money Follows the Person Program is aimed at facilitating the transition of Medicaid beneficiaries from nursing and other long-term care facilities to community-based services. And since we implemented this in Colorado in 2013, we have already transitioned 214 folks with physical, intellectual, or developmental disabilities, mental illnesses, and other impediments to really being able to live in these community-based situations.

Mr. Cunningham, I wanted to ask you: Not only is this the right thing to do, but what I have heard is this actually saves money.

Can you talk about the cost savings of programs like this?

Mr. Cunningham. Sure. So, yes, it does. Community-based care is cheaper than institutional care. We see, mentioned in our nursing home fee-for-service, it is about \$5,256 per member, per month there. And in our home and community-based services programs, or community-based programs, the PMPM on average is about \$3,233. So that is a savings of about \$2,022 per member that you are moving out.

Given that they are numbers, there is always acuity and all this other stuff, but that is just a broad stroke of the estimate.

Ms. DEGETTE. And what are some of the other benefits to moving

folks out of nursing homes and into community-based?

Mr. CUNNINGHAM. Well, there is a lot. We operate from the view of person-centered planning and informed choice. So, once out in the community through person-centered planning, an individual can really think about how they want to self-actualize their own life and look at, employment, look at engagement with loved ones, with family and community, and, quite frankly, engage in a life and fulfill the hopes that we all have in our individual lives.

Ms. DEGETTE. Thank you.

I want to talk briefly about this other bill—what is the number—it is a draft, the PBM gag clause prohibition, what an important bill that is. And I just want to talk for a minute to you, Mr. Chancy, about this. I have been, for about the last year, Congressman Tom Reed from New York and I have been—we are the cochairs of the diabetes caucus, and we have been leading sort of an independent insulin inquiry.

And we sent letters of inquiry to the three brand name insulin makers about patient assistance programs and drug discount cards. And for a lot of these patients, these programs are a lifeline. Now, in your testimony, you stated that pharmacists can counsel patients about alternative purchasing options in some cases, such as when patients don't present a form of insurance.

If a patient asks about ways to lower their insulin cost at your pharmacies, do you counsel them about patient-assistant programs and drug discount cards?

Mr. Chancy. Yes, we do.

Ms. DEGETTE. OK. And as part of this consult, do you tell the patients and clients that these financial assistance programs may not count towards their out-of-pocket expenses such as deductibles and copayments?

Mr. CHANCY. Yes, we do.

Ms. Degette. Good, that is great.

Mr. Chairman, I am hoping, not just the PBMs, but the entire system of drug pricing is something we should be having hearings on, and we should be doing it before the end of this year. Because the PBMs, I mean, it is ridiculous that they tell pharmacies that they have these nondisclosure agreements. But really it is throughout the system. And I think we could still do it. I don't know about all the rest of my colleagues here, but I was home in Denver for most of the August recess; that is all people wanted to talk to me about, was the cost of healthcare and the ridiculous cost of prescription drugs. Thanks and I yield back.

Mr. Burgess. Thank you. The chair thanks the gentlelady.

The chair would remind members, we do have another hearing following this that is scheduled to begin at 1 p.m., and, generally, I am fairly generous with the time, but I am going to ask members to really confine themselves to the 5 minutes for questions.

With that, Mr. Bilirakis, you are recognized 5 minutes for ques-

Mr. BILIRAKIS. Thank you, Mr. Chairman, and I really—Mr. BURGESS. Oh, wait, would the gentleman suspend?

Mr. Bilirakis. Yes.

Mr. Burgess. I did not see Mr. Lance had ascended to the dais.

Mr. Lance, you are recognized for 5 minutes.

Mr. Lance. Thank you, Mr. Chairman.

I am not sure I have ascended to the dais, but I am certainly

pleased to be here.

Mr. Merrill, in your testimony, you talk at length about your involvement in the Center for Medicare and Medicaid's innovations demonstration: Coordinating All Resources Effectively Award Demo. You wrote, collectively, these programs reduced emergency department visits by 26 percent and reduced in-patient days by 32 percent.

The first full year of operations coordinating care for these children, CARE ultimately reduced overall Medicaid costs by 2.6 per-

cent while improving patient experience for 8,000 children.

Mr. Merrill, can you walk us through how CARE coordination works in practice? I certainly think it would be helpful for the committee to hear how this process works on a day-to-day basis in this demonstration and how the savings and patient satisfaction are being achieved.

Mr. MERRILL. Thank you for that question. I think CARE Coordination and Health Homes, as I mentioned earlier, tailor the care needs around that child, and by doing so, we are able to create efficiencies, improve care, and alleviate the burden that these families oftentimes experience in navigating what can be a very complex healthcare environment. I think that is where the patient experi-

ence improvement comes from.

If you look at the CARES grant, one of the things that we did through this, with the 10 hospitals, Cook being one of those that participated, is we did use a common definition. And I believe, again, a common definition is really important if we are going to make improvements in not just the care, but the outcomes and the patient experience. Peter Drucker said: If you can't measure it, you can't improve it.

And while we were able to take 10 hospitals across 8 States and use a common definition, that was just really the first year of savings. I think there is a whole lot more on the table, but if we can scale that to more than just 8 States, take it to 50 States, then I think we have a real opportunity to drive best practices and ultimately improve the kind of care we are looking for, for these chil-

dren.

But the CARE coordination from the health home is really where the rubber meets the road with these families, where you are working to tailor that very specific care model for that child.

Mr. LANCE. Thank you very much.

Attorney General Schmidt, thank you for your work on the important issue of expanding the authority of the Medicaid Fraud Control Units, to detect, investigate, and prosecute Medicaid patient abuse in noninstitutional settings. In your testimony, you detail some certainly very unfortunate stories that have been uncovered and stopped. I encourage all of my colleagues to read the testimony carefully.

What has me all the more concerned is that, even as noninstitutionalized care and Medicaid has expanded—and I support the expansion of Medicaid, and New Jersey has expanded it—the ability to protect these patients from the types of abuse has not. My question to you, Attorney General, without this important change to

law, what tools do States have to protect these patients?

Mr. SCHMIDT. Representative, the answer would vary State by State, but as a general matter, and certainly in Kansas, it would be the general tools we have for any criminal investigation on any criminal subject. And the reason that matters and is less optimal, in my view at least, than having the specified authority under the Fraud Control Units, is that these are specialized individuals in units focused on patient abuse, as well as financial matters, within the confines of the Medicaid program. They are focused.

We have 400-plus law enforcement agencies in Kansas. They are terrific people. They do a great job, and they are stretched far, far too thin and often are unable to be focused in a way that a specialized entity can. So I think you just go from the small pool to the big ocean if you don't have this sort of specialized capacity to deal

with abuse in the noninstitutionalized setting.

Mr. LANCE. Thank you very much, Attorney General, and my

thanks to the panel.

And I also want to thank those in the audience who are here advocating on behalf of this wonderful cause. And I have been hon-

ored to meet with some of those who are in the audience today, and we certainly welcome them for their advocacy here in Washington.

Mr. Chairman, I yield back 16 seconds.

Mr. Burgess. The chair thanks the gentleman.

The chair recognizes the gentlelady from Illinois, Miss Schakowsky, 5 minutes for questions, please.

Ms. Schakowsky. Thank you, Mr. Chairman.

Recently I met with a 9-year-old named Naomi Bytnar who has a complex medical condition and is being treated at Advocacy Children's Hospital in my district. And I am just so proud to cosponsor H.R. 3325, the bipartisan ACE Kids Act, which will help many children just like Naomi get the care they need. I thank all of you who

are supporting that.

I would also like to thank Representatives Dingell and Guthrie for introducing the bipartisan H.R. 5306, the EMPOWER Care Act. to reauthorize the Money Follows the Person, MFP, Program, which I am proud to cosponsor. The MFP Program has given over 88,000 individuals the opportunity to transition from institutional care, something I have been working on for decades now from my time in the legislature in Illinois.

Mr. Salo, without an extension of MFP, what will it mean for

seniors and people with disabilities?

Mr. Salo. Without extension of Money Follows the Person, what you are going to have is a definite subset of people who are in an institution, in a nursing home, who don't want to be there, who don't need to be there, and are going to have enormous difficulty making the transition out, so, yes.

Ms. Schakowsky. Mr. Cunningham, what challenges do States face in supporting transition from institutions to the community, and how does MFP address those challenges?

Mr. Cunningham. So I think obviously housing is a big issue of finding a resident, especially if you no longer have the housing since you have been in the institution. So, through housing counseling funded through MFP, through projects like developing databases of available section 811 housing vouchers, that also provides assistance.

I also think another area that has been funded is the Aging and Disability Resource Centers. And I would say that this entity is critical in a comprehensive, long-term care system, because they can not only advise about the resources that Medicaid has but also about Medicare, about other resources within the community, to create natural supports and lower the cost of care and the Medicaid program bears but also other systems bear. So we have used that MFP to fund those ADRCs also.

Ms. Schakowsky. Thank you for that.

Turning to the gag clause, I want to emphasize that this committee can be doing much more to lower prescription drug prices, for example, basic transparency and price spikes requiring that the price in direct-to-consumer prescription drug ads and Medicare prescription drug negotiations. So there are things that we could do, but we must get rid of gag clauses because providing patients with information about pricing is critical.

Dr. Yoder, though, I want to ask you—where are you? I am sorry. There you are. OK. You raise a really interesting point in your testimony that paying out of pocket impacts deductibles, maximum out-of-pocket costs and for seniors, the doughnut hole. Senior groups have told me that this information would be useful at the pharmacy.

So what is the effect on the beneficiary's deductible, maximum out-of-pocket limits when paying out of pocket? How does this af-

fect seniors in the doughnut hole?

Dr. Yoder. So, generally, when the medication is paid for out of pocket, those prescriptions don't get adjudicated to the PBM system. So there is no way for those accumulators to be added to that would reflect what the member's out-of-pocket is. So essentially that prescription is opaque to the health plan as well as the PBM. No one knows it was actually dispensed, other than the pharmacist who dispensed that. So it doesn't go toward any of those accumulators at all.

Ms. Schakowsky. So, when we talk about eliminating the gag rule, would it be useful, do you think, to share that information as well, so people really understand the consequences of paying out of pocket? In other words, someone might be told that if you pay the \$50, you now will climb out of the doughnut hole, rather than the

\$10 if you pay out of pocket?

Dr. Yoder. Absolutely. We support making sure that the members and the enrollees do know what the consequences would be for doing that. In addition to not just the accumulators, in most cases those prescriptions don't go against any of the checks for medication duplication, drug interactions, things like that, because they are not going into the PBM system to see what all the other medications that member may be taking. So we absolutely do support that transparency so members do understand what the consequences would be for paying out of pocket versus using their copay cards.

Ms. Schakowsky. What you just said is a safety issue that it

seems to me, why couldn't this be recorded?

Dr. Yoder. Because the way the prescription adjudication system works, the PBMs don't see those prescriptions. They never go into the systems at all because they are just at the local pharmacy. The local pharmacy can do checking on the prescriptions they have for that member, but if the member goes to different pharmacies, if the member uses mail order, things like that, those prescriptions never even enter into the system.

Ms. Schakowsky. That is a concern we ought to deal with. Let me just say, as somebody who has—I am over time. I am going to respect what you said, Mr. Chairman, and yield back.

Mr. BURGESS. Thank you. The chair recognizes Chairman Wal-

den, 5 minutes for questions, please.

Mr. WALDEN. Thank you very much, Mr. Chairman. Really good hearing, appreciate all your testimony.

Mr. Yoder, your testimony contemplates the possible downsides of cash purchases for medications which you were just talking about, such as mechanisms to catch potentially harmful drug interactions or medication nonadherence.

So I am kind of interested to hear how Mr. Chancy would respond to those concerns.

Mr. Chancy, in your experience, when discussing cash prices, do pharmacists have the necessary information before them to identify harmful drug interactions?

Mr. Chancy. Yes. Whether it is cash or whether it is insurance, our computer system will run the analysis on any drug inter-

actions.

Mr. WALDEN. All right. And are there ways that we can improve this legislation to avoid any unintended consequences concerning potentially harmful drug interactions or medication nonadherence, things we could do to improve this legislation to prevent the kind of problems that are being discussed right now?

Mr. Chancy. Yes.

Mr. WALDEN. What would those look like? Mr. CHANCY. Pertaining to adherence?

Mr. WALDEN. Yes. to medication nonadherence and to harmful

drug interactions.

Mr. Chancy. Well, I think if we are actually running it through the insurance, and I was not familiar with the insurance doing the drug-drug interactions on the back side, but I think if we were to know about those interactions, that would be helpful for us to help with the patients upfront, to make sure if there are any issues they are having, we can actually work with their physician to change medications or change drug regimens.

Mr. WALDEN. All right. Thank you.

Dr. Yoder, I am going to change gears here to the other bill. So I appreciate your providing ways we can improve the Healthcare Fraud and Prevention Partnership, and so I would like to focus on two of those. First, you mentioned that Blue Cross Blue Shield recommends creating improved mechanisms for the exchange of findings so that all participants are best informed of lessons gained from the experience.

What are some of the existing limitations on information sharing

that we should be aware of?

Dr. Yoder. A couple things come to mind. So one would be some of the HIPAA requirements that are out there. So right now the way the data sharing goes through a third party which deidentifies the data, which is great for analysis. But if there are actual particular instances of fraud, that information doesn't necessarily flow through because of HIPAA and because people are not real comfortable about having those conversations.

Mr. WALDEN. All right. Are there things Congress could do to im-

prove that information sharing?

Dr. Yoder. I think we would support any way that we could strengthen the committee charter or the charter for the organization to make it clear that you can share information within the confines that would not be HIPAA violations.

Mr. WALDEN. A violation of HIPAA, OK.

And, second, you note the partnership appears to be prohibited in its charter from advising Medicare and Medicaid of the schemes it identifies. I know that our staffs have asked HHS for a better explanation of why the charter is not allowed to provide advice to the Federal Government, a Federal official, or a Federal agency.

Are you familiar with the background of why the charter in-

cludes this firewall?

Dr. YODER. No, unfortunately, we are not familiar with why that would be in there.

Mr. WALDEN. OK. And the draft bill includes report language that Congress recommended by Ranking Member Pallone. Do you believe that having the partnership report to Congress would amplify opportunities to prevent fraud and abuse across all payers?

Dr. YODER. We actually don't have a position on that. It is hard

to tell whether that would be impactful or not.

Mr. WALDEN. All right. Frank and I think it probably would be, so you might want to have an opinion on that later that is good,

positive. Just kidding.

I think that is all I have for now. I appreciate your testimony on all these bills. We have got a lot of work to do, and we do it well on this subcommittee, and I appreciate the leadership of Dr. Burgess and yield back.

Mr. Burgess. The chair thanks the gentleman.

The chair recognizes the gentleman from Maryland, Mr. Sarbanes, 5 minutes for questions.

Mr. SARBANES. Thank you, Mr. Chairman.

I want to thank the panel for your testimony. Very important pieces of legislation that we are discussing today. All have earned bipartisan support for obvious reasons, given what you have been telling us and, I think, given the statements of our colleagues here on both sides of the aisle.

I wanted to focus on the EMPOWER Care Act again because a lot of people have spoken to it, but I think it is really critical. Obviously, we are at this stage where the authorization has expired. States have been sort of living on the reserves associated with it for some time, but that is going to be running out quickly. And the State of Maryland faces that challenge as well. So it is important for us to get this done, and that is what the purpose of the legislation is.

The reason this is called the EMPOWER Act is because it is about empowerment. It is about giving the opportunity for independence, to make sure that seniors, people with disabilities, others have the opportunity to live and thrive in a more independent setting and redesigning the Medicaid program so it can help to support that.

So, Mr. Salo, I am going to direct this to you. And you have addressed it to some degree already. But I am interested again in just the perspective on what this does to promote independence and the benefits of it. I was thinking earlier that we often or increasingly we have been talking about how social determinants are having an impact on the way we deliver healthcare. But in a sense, what is offered by the EMPOWER Act and the Money Follows the Person approach is kind of a reverse of that.

If you think of it, it is using our healthcare system and the way we reimburse and organize the delivery of care to, in a sense, create social dividends. And so maybe you could speak again to that idea of how this program is creating social dividends, independence, employment opportunities that might not have been possible under the old construct, empowering individuals to be contributing members of their own community in ways that previously they

might not have been able to be and, therefore, strengthening the broader community that benefits our country.

So talk about the social dividends. I have sort of just grabbed that phrasing for the purposes of this question, but I would be interested in, again, your perspective on what that independence op-

portunity offers to people.

Mr. SALO. Sure. I think I would be somewhat remiss—and acknowledging it is outside of the purview of this conversation today, but I would be somewhat remiss in not reminding everyone that this country doesn't have a long-term care system. We have Medicaid. Medicaid is it. Medicaid is by far the dominant player in long-term care, whether it is institutional or noninstitutional, for everyone in this country.

And because Medicaid is a means-tested program, that means that when Americans need long-term care services and supports, they have to go on Medicaid, and they have to impoverish themselves. Those are the rules. We didn't design it that way, but that is how we have fallen into it. That is how the system works. And I would argue, as a macro construct, that is not terribly empow-

ering to begin with.

So I would just encourage as we look to the future to say, are there other ways we can think about providing the necessary long-term services and supports to Americans through other means? But having said that, within the construct of Medicaid, clearly what we are seeing is if we can embrace—and we have, but as we embrace the trend for self-determination—whether that is where do I want to live, do I want to work, how can I work, who do I want to associate with—MFP and many other efforts that have been underway in Medicaid for the past three decades have all been about empowering people and about providing freedom.

That I think is an incredibly important dividend. And I think what you see as a result of MFP, specifically getting people out of an institution who don't want to be there or who shouldn't be there, or whether it is any of the other efforts to try to provide upfront alternatives to prevent people from going into that institution in the first place, it is all about, how can we empower the individual and give them the self-determination that they need to make those meaningful choices for themselves? And I would argue that that makes their lives better, their family lives better, and

their community lives better.

Mr. Sarbanes. I appreciate that. Just to close, I would say that, within that larger construct, it can be frustrating sometimes. I think what you are saying is the MFP approach is an innovation, and we should pursue more innovations like that that can be empowering to people because it is better for our entire community when we do that.

Thank you, and I yield back.

Mr. Burgess. The chair thanks the gentleman.

The gentleman from Florida is recognized for 5 minutes for questions, please.

Mr. BILIRAKIS. Thank, Mr. Chairman.

I appreciate it. And I appreciate you agenda-ing the ACE Kids Act today. It is great legislation. I have been a strong supporter, a longtime supporter of that legislation. Bipartisan bill.

In the Tampa area, St. Joseph Children's Hospital has been running a Chronic-Complex Clinic for children, and I have toured that particular hospital and that clinic, and I tell you it is a wonderful

thing. It is a great concept.

I have had the opportunity again to tour it over the past few years and see how integrated care model can benefit the children with complex medical issues. Again, the children, we have seen examples time and time again where the children come up here and show us how well they are doing and how it benefits them and their families.

Mr. Merrill, you mentioned that children with medically complex conditions account for a large share of the Medicaid costs for children. Can you talk about how a medical home, such as the one at St. Joseph's, can bring savings to Medicaid? Do you have research

showing these savings?

Mr. Merrill. Yes, thank you. Great question. There have been some studies, independent studies, done that have shown that the potential savings for ACE Kids for the Medicaid children could be anywhere from up to \$5 billion to \$13 billion over a 10-year period. And, as I said, under the CAREs grant, even though 2.6 percent sounds fairly small, I think that is just the beginning of some opportunity for us to really, if we can scale this across all 50 States instead of just one-offs at different organizations—and I know the hospital you mentioned, they do incredible work there, but they are by themselves. They are siloed. And if we can create a national database in which we are sharing data, working together, driving best practices, then, in the end, I think we truly can create the savings that everyone is looking for but also improve the patient experience through these coordinated care health homes.

Mr. BILIRAKIS. And that is the priority, to improve the patient's experience and the quality of care for the child. And, again, it is convenient for the parents. So I would like to see a hospital in

every region of the country that has the ACE Kids model.

Again, is quality measure data currently collected in Medicaid or Medicare?

Mr. Merrill. Yes, I think it is by State, and you will see different States starting to implement quality measures with a payfor-play component to it. We are unaware of any quality measures that are specific to this medically complex population. I think that this bill contemplates that, as it should.

One of the very most important first things that I believe we should look at as a quality indicator is patient and family satisfaction. That is really what this bill is all about, making life much more convenient for these families, allowing them to navigate the

healthcare system easier and have the better outcomes.

We could implement outcome measures, reduced readmissions, for example, for this population, because this population tends to bounce back into the hospital. But if we are successful at creating the medical home, then we believe that we can keep these children out of the hospital more often, closer to home, and deliver better care and better outcomes as a result of that.

Mr. BILIRAKIS. It is so very efficient too, because the doctors, they have multiple appointments during the day, they can see—

Mr. Merrill. That is correct.

Mr. BILIRAKIS [continuing]. The doctors. And, again, it is great for the child and the family. So I appreciate it. It is a no-brainer, as far as I am concerned, but sometimes no-brainers don't get passed up here. And I really appreciate the chairman agenda-ing this bill. It has got to get done.

Mr. Salo, you mentioned that it is important to avoid one size fits all and to allow for a flexible benefit design. And I agree. We have one Medicare program, but we have 50 Medicaid programs, each

designed to serve the unique needs of their States.

Mr. Salo and Mr. Merrill, do you think that the latest discussion draft for ACE Kids promotes a flexible benefit design for States? Maybe, Mr. Salo, you want to go first. I know we don't have a lot of time.

Mr. SALO. Sure. I think we made a lot of progress, and I think as long as it continues to allow Florida to acknowledge its current delivery system, Florida has a separate managed care organization

completely focused on kids in the foster care system.

New York has a system in place that holds pediatricians accountable for making sure that kids arrive at school at kindergarten ready to learn. There are efforts like this underway in lots of places. We want to make sure that this is a complement and improvement to those efforts as opposed to just running into them in a conflicting way.

Mr. BILIRAKIS. Mr. Merrill.

Mr. MERRILL. This bill actually allows each State to implement the program that works for them. In Texas, with our STAR Kids, we have Medicaid managed care, and it works pretty well. I think it can work equally well in a fee-for-service environment. And so I think that is the flexibility that is built into this, so that the States can, number one, opt in or out; and if they opt in, they can use their delivery system that they have in place today.

Mr. BILIRAKIS. It makes sense to me. And I want to thank the lead sponsors of this bill, of course, former Chairman Barton and also Representative Castor, and all the cosponsors. I am one of

them as well.

Thank you very much. And I yield back, Mr. Chairman.

Mr. Burgess. The gentleman yields back. The chair thanks the gentleman. The chair recognizes the gentleman from Oklahoma, Mr. Mullin, 5 minutes for questions.

Mr. MULLIN. Thank you, Mr. Chairman. And thank you to our

witnesses for being here. I am going to jump right into it.

Mr. Salo, first of all, can you talk about how, in addition to the obvious benefit to States of enhanced funding, the ability to incorporate medically complex children into a health home is a critical improvement compared to the current law?

Mr. SALO. Sure. I think if you look at any State in the country, what Medicaid directors are trying to accomplish is a move away from a historical healthcare system in this country, not just Medicaid but Medicare and commercial, that has been fee-for-service. And we are moving toward a world where care is coordinated. It is managed. It is holistic, and it is patient-centered.

That will look different in different States. It might be managed care. It might be ACOs. It might be patient-centered medical homes. It might be health homes. Each of those is going to work

in the political and geographic and cultural realms in which those States reside.

If we acknowledge those, then I will channel my good friend Dennis Smith, who once talked about the historical healthcare system for people with disabilities, for kids with medically complex needs, for frail seniors. The fee-for-service system, FFS, he said, it should stand for fend for self because that is what we require; that is what we are requiring of them.

And what Medicaid is trying to do is to create a system that is going to make it so that people don't have to spend their lives navigating multiple different silos and that the care itself is coordinated and managed in a better way. That is what Medicaid is trying to do.

Mr. MULLIN. Thank you.

Mr. Schmidt, what protections do patients currently have when Medicaid Fraud Control Units detect abuse in a noninstitutional setting?

Mr. Schmidt. With respect to protections from the Medicaid Fraud Control Unit, I think the historic answer is none, or realistically, if we detect it, we are going to call some other law enforcement agency and say: Please take a look, we can't.

Mr. Mullin. How often do they actually pick it up?

Mr. Schmidt. It depends on the jurisdiction. We have had cases in Kansas that, for example, in some of our more robustly staffed jurisdictions, that they will take it. We have had others where we haven't felt good about having to hand the case off.

Mr. MULLIN. They simply don't have the manpower or the knowledge to do it?

Mr. SCHMIDT. That is correct.

Mr. Mullin. Are there any other settings that Medicaid Fraud Control Units are prohibited from addressing patient abuse?

Mr. Schmidt. I believe the answer to that is no, but I would sure want to double-check that with the folks that—there is nothing else on my radar screen. Nothing else on my radar screen.

Mr. Mullin. Can Medicaid Fraud Control Units detect, investigate, and prosecute fraud inside the Indian Health Service facilities?

Mr. Schmidt. I don't know the answer to that. Sir, we don't have that issue having arisen in Kansas and I just don't know. I can certainly check with folks that would, if that would be helpful, and have them follow up.

Mr. Mullin. Can Medicaid Fraud Control Units pursue cases of patient abuse in his facilities?

Mr. Schmidt. I would have to do the same.

Mr. Mullin. Do the same?

Mr. SCHMIDT. Do the same.

Mr. MULLIN. My point that I am trying to get at, obviously, Medicaid is a tool which can be utilized for the benefit of those in need and those in most critical need. It can also be utilized to help strengthen systems like his. But if we are going to be in the business of trying to investigate fraud, then we also need to have the ability to go into where it is being used, not limited access.

And I am sure you can appreciate that. We want to make sure that, one, the dollars that was invested in Medicaid is being used

properly by those that are receiving the funds.

And what I am trying to get at is, if there is a way for us to be able to help, we do want to help because, as you mentioned, our attorney general, Mike Hunter, is associated in helping on an important bill. We are also in desperate need of wanting to find out how we can help strengthen our his system. We don't know if there is abuse going on, because it hasn't been investigated. We don't believe there is, because we believe our Tribes are extremely good stewards of what they are using their assets for. You can go and you can look at the his facilities and the health clinics and the Indian hospitals throughout my district, and it is amazing what is happening, but can it be utilized further?

So my whole point on asking those questions—and I didn't expect you to know, because currently I don't think there is—I am here wanting to say I want to help. If we believe there is a reason for us to do it, I want to help. I want to make sure that those dollars are being used properly so we are not going after everybody, but

we are only going to focus on the bad actors.

With that, Mr. Chairman, I yield back.

Mr. BURGESS. The chair thanks the gentleman. The gentleman yields back.

I think all members of the Health Subcommittee have been recognized, and we will now turn to members off the subcommittee.

And, Mr. Welch, you are recognized for 5 minutes for questions,

please.

Well, let me clarify that statement. All members of the subcommittee with the exception of your subcommittee chairman, who deferred his questions. So you may go ahead of me. Mr. Welch, you are recognized for 5 minutes.

Mr. Welch. Mr. Burgess, you are always doing a generous thing.

Thank you very much.

I want to speak to Mr. Chancy about the gag rule. That is astonishing. Mr. Carter and I have a bill in to get rid of it. But can you just give some description of what it feels like to be a pharmacist. And in my experience, the pharmacists have very close customerpharmacist connections, and they are guiding their customer in the use of that medication, and it is a place the customer can go to because they trust the pharmacist.

So what is it like for a pharmacist to have this gag order when if he or she didn't have it and was free to speak, they could save

that customer, who they value, an awful lot of money?

Mr. Chancy. It puts us in a very compromising situation because, like we had mentioned earlier, our relationship with our patients are based on trust. And they depend on us to maneuver—this stuff is complicated. We have to stay on our toes to keep up with it, and our patients really depend on us. And when we can't be fully forthright with them, then that just puts us in a compromising situation.

Mr. Welch. It kind of makes you feel dirty, right? It is awful, because they trust you. They are putting their medical situation in your hands. They are asking you intimate questions about, you know, this was my reaction, what do you think I should do? And

they are assuming, since they trust you, that among other things, if you could save them a hundred bucks, you would, because it is not money going in your pocket.

Mr. CHANCY. Oh, no, definitely not.

Mr. WELCH. Do you have any idea why it is legal to put handcuffs on your ability to act?

Mr. CHANCY. It has always been a bad rope for us.

Mr. Welch. Mr. Chairman, just bipartisan, I hope we can get rid of this. The idea that a pharmacist can't give relevant information on how to save money for their customer really is inexcusable. So

I appreciate the hearing that you are having.

Thank you. And I want to talk to the attorney general a bit about your work. Our Medicaid Fraud Unit in Vermont does a tremendous job, and it is both recovering money and, I think, also a deterrent against would-be malefactors. And, of course, when this legislation was initially passed, most of the Medicaid services were provided. They were provided in institutional settings.

So I would just ask you to elaborate about your reasons for supporting this legislation, and I have a bill in in order to accomplish

your goals. But thank you.

Mr. Schmidt. Thank you, Representative. And, again, thanks to you and Representative Walden for your leadership in making this real. And as I mentioned earlier, I worked very close with my friend, your attorney general, General Donovan, on this. And he and I have talked many times—I certainly don't purport to speak for him—but both coming from lightly populated States with substantial rural areas, how important this expansion is to allow us to have the capacity of skilled investigators and prosecutors who are expert in patient abuse matters to be available and deployable in areas that simply don't have them with respect to local resources.

So I think it is vitally important, and it doesn't make any sense to have this arbitrary restriction that I can see.

Mr. Welch. Right. And my understanding, in the Vermont Medicaid Fraud Unit, we return a lot more money than it costs to run it. I think it is like six to one. I don't know what it is in your State.

But is there any reason to be apprehensive that if we expanded your authority to recover and deter bad conduct outside of the cur-

rent law, that it would be a financial drain?

Mr. Schmidt. No, I don't think so. And I guess I would offer just a couple of thoughts on that point. Number one, obviously, the financial recoveries of a MFCU come principally from the fraud side, not the abuse side. And so I do understand at least those who articulate, well, it is different. But, having said that, most of the Medicaid Fraud Control Units, including ours in Kansas, are selffunding, and they are returning money to the taxpayers. And so I have no concern along those lines.

Mr. WELCH. In Kansas, sort of like Vermont, you are kind of

tight with a dollar, right?

Mr. SCHMIDT. I think that is true, and we wear that as a badge of honor

Mr. WELCH. Well, I think Mr. Walberg is too, so it has been great working with him. And I thank you for your work and your testimony on that.

Mr. SCHMIDT. Thank you, Representative. Mr. WELCH. Thank you. And I yield back.

Mr. BURGESS. The chair thanks the gentleman. The gentleman yields back.

The chair recognizes the gentleman from Michigan, Mr. Walberg, 5 minutes for your questions, please.

Mr. WALBERG. Well, my good friend and colleague from Vermont,

I am not tight; I am efficient.

Mr. Chairman, thank you for holding this hearing, and thank you for including our legislation as part of the bill packages here. I would like to ask, Mr. Chairman, unanimous consent to submit for the record letters from the National Association of Attorneys Generals, Families USA, and Partnership for Medicaid Home Based Care, and express support for H.R. 3891.

Mr. Burgess. The ranking member is concerned about the letter from Families USA, but I think I will go ahead and accept them.

We will.

[The information appears at the conclusion of the hearing.]

Mr. WALBERG. Thank you.

Attorney General Schmidt, thank you for being here today and for your efforts in highlighting the need for legislative reforms of-

fered by myself and my colleague, Representative Welch.

Medicaid Fraud Control Units play a vital role in bringing those who commit Medicaid provider fraud, patient abuse and neglect to justice. In my home State of Michigan, Medicaid Fraud Control Units, or MFCUs, recovered over \$7 million in taxpayer dollars in 2017 and contributed to 24 convictions. Nationally, MFCUs are responsible for about \$1.8 billion in recovered funds and 2,500 convictions.

I commend the work of these State Fraud Control Units and the attorneys general for protecting the most vulnerable of our population from harm as well as ensuring taxpayer resources are being

used appropriately. So thank you.

Attorney General Schmidt, as you know, currently MFCUs may only investigate cases of patient abuse that occur in institutional facilities, et cetera. Let me move to what this bill could possibly do. If our legislation were to become law and MFCUs were permitted to widen the scope of their investigations, do you have any sense of how many Medicaid beneficiaries could be protected from abuse or the amount of taxpayer funds that could be recovered?

Mr. Schmidt. Representative, I don't have hard data, and I am not aware that it exists. If it does, I don't have it. I can give you

anecdotal information from Kansas with numbers.

Mr. WALDEN. That would be helpful.

Mr. Schmidt. And you can draw from that what you will. In State fiscal year 2018—we are on a July through June fiscal year in Kansas. In State fiscal year 2018, our MFCU received 16 referrals of suspected patient abuse. Of that number, we found a way to investigate or cause to be investigated 11. That leaves a difference of five. Out of those five, I didn't go back and personally review the files before this hearing, but if normal patterns hold, I suspect probably half of those there simply wasn't evidence of a crime, and so there was no further action to be taken, which leaves one or two that, had we had the ability to proceed in the non-

institutional setting, we could have investigated and, assuming

there was evidence, prosecuted.

To put that in context for Kansas, we also prosecuted to conviction 16 criminal cases last year in our MFCU. It is coincidental that is the same number as the referrals. They aren't connected. So had we added one from a noninstitutional setting because of your bill, that would be a 6-percent increase in the number of convictions. If it were both, it would be a 12-percent increase.

Mr. Walberg. Could you give us an example of one of those

where you had to turn a blind eye because of the inability?
Mr. SCHMIDT. Absolutely. The one that comes to mind that troubles me the most, it was a case in a very small county, very rural county, lightly resourced, both on the police law enforcement side

and on the prosecutor side.

The matter came to our attention technically on a fraud claim, but it was obviously more than that. It was a case where an individual was being paid by the Medicaid program to provide personal care services in home for a beneficiary. The beneficiary was either nonambulatory or had substantial mobility restrictions, and so the PCA was supposed to be there all night long sitting with this person, providing the appropriate care. They didn't, and they billed for it, which is how it came to our attention as a fraud matter.

The reason it was particularly distressing is that, on one of those evenings before this was all uncovered, the beneficiary, who was a smoker, was home alone when the PCA was supposed to have been there. The person was smoking, it appears, in bed. The cigarette dropped. It caught the house on fire, and the individual died. Now, there was Medicaid fraud in a small amount of dollars, but obviously the much greater harm there was the question of whether there was a criminal homicide, whether there was a negligent manslaughter or reckless manslaughter or some other form of prosecutable homicide, and we did not have the ability to use our MFCU assets to investigate that.

So we had to go back to the local police and the county attorney who called us in the first place and say: We are sure glad to help out of other assets, but we can't take this. We can prosecute him for two or three thousand bucks' worth of fraud, but that is not

what this is really about.

Mr. WALBERG. Thank you. Thank you, and I yield back.

Mr. Burgess. The chair thanks the gentleman. The gentleman yields back.

The chair recognizes the gentlelady from Michigan, 5 minutes for questions, please.

Mrs. DINGELL. Thank you, Mr. Chairman and Ranking Member Green, for allowing me to participate today in holding this hearing.

There are several bills being considered today. I am going to mostly confine myself to the EMPOWER Care Act before my colleague Mr. Carter speaks. And when his bill gets introduced, I am going to tell you of a story last week of picking up a prescription that was \$1,300, and after you peeled me off the ceiling and I called the doctor and screamed and talked to the pharmacist, got an equivalent for \$40. I am much more aggressive than many in asking questions, but, Mr. Carter, I am on your bill when you get it in.

But now I will confine my remarks to—and that is a very true story—H.R. 5306, the EMPOWER Care Act, which I am proud to author with my friend and colleague, Congressman Brett Guthrie.

Improving long-term care has been one of my top priorities since coming to Congress. And as I have listened to all of you talk today, our long-term care system is broken. It doesn't work. Most people think Medicare covers it, as Mr. Salo previously noted, and are shocked to learn that if you are going to get sick, better do it only 90 days, 90 first, you are out, and that Medicaid is actually the single largest payer of long-term care in this country. And the private market is totally broken as well.

As we have heard in the testimony this morning, one program that is working well in terms of enhancing opportunities for independent living and supporting aging with dignity and has bipartisan support is the Money Follows the Person Program. We have discussed what it is this morning. It provides grants to States to cover transitional services for individuals who want to leave a nursing home or another institution and transition to the commu-

nity care setting.

I have been working with my colleague Brett Guthrie from Kentucky to reauthorize this successful program that is proven to save taxpayers money and has successfully transitioned thousands of people from institutions to a community setting where they can be with their loved ones. We need to expand the program before it expires. I agree with you that 1 year isn't enough, but I will take 1 year if that is all we can get, because time is running short.

So I am going to ask Mr. Cunningham these questions. Mr. Salo,

if you want to chime in.

Money Follows the Person was created through bipartisan efforts. The program has been operating for more than a decade, and the legislation we are considering would have reauthorized the program for another 5 years. We will take the 1. Why is this such a priority? How does this kind of long-term reauthorization support institutional transition efforts?

Mr. CUNNINGHAM. So I think one of the big things for MFP is that every State kind of has their own home and community-based waiver programs. And so depending on each State, MFP can be that flexible tool that can be used to move people out of institutions into the community. And so that flexibility is critical.

Mrs. DINGELL. What challenges do States face in supporting transition from institutions to the community? How does MFP help

address these challenges?

Mr. CUNNINGHAM. Šo, for many States, a lot of the services, such as housing counseling and other referrals, counseling, detection of people that want to relocate, these may or may not be covered as part of the Medicaid program.

So MFP can step in to provide those services. And then they can relocate into the community where some States may have available personal care assistants and other home and community-based

services that can support them. So it bridges that gap.

Mrs. DINGELL. Thank you. We know that hundreds of thousands of people with disabilities continue to wait on waiting lists for home and community-based services. How does MFP help address

the problem for the population of people in institutional settings, and what would happen if we don't renew this?

Mr. CUNNINGHAM. So, in Wisconsin, what we have done with the enhanced Federal match is that we have reinvested that into our long-term care program to reduce and eliminate waiting lists. And within 36 months, we are going to be an entitlement for all individuals that need Medicaid home and community-based services.

And so MFP has been a vital part, and that reinvestment of those dollars into the long-term care system continue to support

providing community-based services.

Mrs. DINGELL. I want to thank all of you for everything that you are doing. Five minutes isn't enough time. But before I yield back, I would ask the chairman for unanimous consent to include for the record letters of support for H.R. 5306 from the Area Agencies of Aging Association of Michigan, the National Association of State Directors of Developmental Disability Services, the National Association of States United for Aging and Disabilities, and a group letter signed by dozens of health and aging organizations.

Mr. Burgess. Without objection, so ordered.

[The information appears at the conclusion of the hearing.]

Mrs. DINGELL. Thank you. And I am over my time. Mr. Burgess. The chair thanks the gentlelady.

The chair now recognizes the gentleman from Georgia, 5 minutes for your questions, please.

Mr. CARTER. Thank you, Mr. Chairman. And thank all of you for

being here.

Mr. Chairman, I want to thank you for holding this hearing today and for including the discussion on the gag clause legislation. It is something that is very important and something that I have stressed since I have been in Congress and something that is important to patients. I think that is the point that I would like to get across most is that this is something that is really hurting patients more than it is hurting anyone.

Mr. Chancy, I want to thank you for being here. I appreciate it very much. I know you have traveled a long way, as a lot of you have, but I wanted to ask you, Mr. Chancy, examples of gag clauses. Now, I think everybody by this point understands what we are talking about when we are talking about gag clauses, but have you actually seen a contract that had the language in there that—and perhaps it wasn't written the way that you would understand it, but have you ever seen a contract like that?

Mr. Chancy. First of all, it is very difficult for us to even get our hands on these contracts, and they change frequently. So I have

not seen anything that even stated that it was a gag clause.

Mr. CARTER. Right. But just because it is not stated, there are other ways that the pharmacy benefit managers can get at this. You mentioned earlier about CVS/Caremark. CVS, of course, is a competitor, a national chain, I believe the largest drug chain in America. And yet Caremark, one of the top three PBMs in America, is the same company. You can make the argument that the Caremark owns CVS or CVS owns Caremark. It doesn't matter; they are the same thing. But there are other ways. Do you ever get audited by any of these groups?

Mr. CHANCY. Yes, we do. Actually, one of our stores is next door to a CVS, and they do audit us.

Mr. CARTER. So, actually, you have got a contract with a PBM that has a drugstore right next to you, and you are getting audited by that PBM that owns that drugstore right next to you. Do you find that somewhat intimidating, if you will?

Mr. Chancy. Yes, and it is challenging at times.

Mr. Carter. I can imagine. I wanted to ask you, in your written testimony, you gave some examples of where you had actually told some patients about this. And I believe there was one example with a mayor of one of the municipalities around. Can you share that very quickly?

Mr. Chancy. Yes, that is correct. He came in, and his prescription came to be \$26. And they had just changed insurance plans. And we told him that if you paid cash for this, it would be cheaper. And he said: I don't understand; I want to use my insurance.

And I said: Well, our cash price is \$8, but if we use your insurance we have to charge you \$26—because the PBM was actually taking \$24 back from us.

Anyway, the point was out of pocket was \$8 for him. Using his

insurance, he had to pay \$26.

Mr. CARTER. So this point was brought up. I believe, Dr. Yoder, you may have brought it up. And it is a valid point, that, if you don't use your insurance, it is not going to go toward your deductible

Mr. Chancy, do you have an opportunity to know how close a patient is to their deductible? Is that any kind of information that you are privy to as a pharmacist?

Mr. CHANCY. No, we don't. The only way we find that out is if we bill it through their insurance and we find out that they have met their deductible or they haven't. So we fill prescriptions or

process prescriptions until we get to that point.

Mr. Carter. But if we were realistic about this, the example that Representative Dingell just gave, now, that would have been \$1,300 going toward a deductible. She made the choice to pay the \$40, which obviously I think most of us would have. But the other example that you gave where it was \$7 as compared to \$26, that is not really going to impact the deductible that much, is it?

Mr. CHANCY. Oh, no, not at all.

Mr. Carter. I don't think it is going to help them get there. So, with all due respect, Dr. Yoder, that is the point we are trying to make here. Generally, that is an extreme case. And that is exactly what we are talking about. That is nothing short of ridiculous, and we all understand that.

One other point that was made by Dr. Yoder was the fact that if you don't get it filled through the insurance company, that you may not see a drug interaction. But is it true, Mr. Chancy, that most pharmacies now have programs where—drug interactions are—before you fill a prescription, you are going through the patient's profile and looking at all the drugs that are on there anyway?

Mr. Chancy. That is correct.

Mr. CARTER. OK. So it really should not be that much of a problem, unless they are getting it somewhere else, which could happen. But, for the most part, you find your patients to be getting their medications at one drugstore.

Mr. Chancy. That is correct.

Mr. Carter. OK. Boy, 5 minutes flies when you have been waiting around all day to ask questions. I do want to thank all of you for being here, and this is something that is very important. Again, Mr. Chairman, I want to thank you for this discussion and this hearing today. Very important. I could not agree with you more that this is the most important subcommittee in Congress. So thank you, and I yield back.

Mr. Burgess. And the most productive.

I recognize myself for 5 minutes.

Mr. Chancy, I just have to ask you, when you sign a contract, it is voluntary, so no one is forcing you to sign the contract. Do you have the option of not signing the contract and saying, "Hey, come back to me with a contract that doesn't have these nondisparagement riders in it"?

Mr. CHANCY. We do have the option of opting out, but we don't

always know what is in the contract.

Mr. Burgess. I guess that bothers me a little bit. But I can remember early in the days of managed care, as a physician, I had complained about a contract, and the lawyer advising the practice said, "Well, you signed a stupid contract."

I said, "Well, how do you tell it is a stupid contract?"

He said, "That is the first one they give you, and you signed it." The only reason I am bringing this up is because, as a profession, it may be incumbent on us as part of our profession to be ever-vigilant on behalf of our patients, especially as we get into more and more situations where ownership is not in the hands of the community pharmacist, not in the hands of the practicing physician, but in the hands of an insurance company, the government, or someone else. And, again, that is the only reason I bring that up is the charge for all of us has got to be not—transparency will only go so far. You have got to be vigilant on top of that.

Mr. Cunningham, let me just ask you, because you mentioned some of the supplemental services that are covered, and you men-

tioned housing specifically. Is transportation ever covered?

Mr. CUNNINGHAM. I know the ability to develop plans to assist with transportation, in Wisconsin that is a covered benefit in our community. So what the ADRC would do is assist in developing a plan to ensure the individual has proper transportation in the community to both medical and also for social events.

Mr. Burgess. Because Wisconsin is one thing, but Texas, the distances are large. But it seems with ride-sharing abilities now, that actually could be quite cost-effective. You are not sending a taxicab company out to pick someone up, but with the ride-sharing apps that people are so accustomed to using now, again, it seems like that could be an option for increasing participation or increasing compliance on the part of the patient. That is why I was wondering if that had been one of the things that you had studied in your efforts.

Mr. CUNNINGHAM. Yes, it is a covered benefit in our waiver program. But to the extent they don't have transportation, I think that would be either MFP would be able to—used to identify an afford-

able transportation. I am not totally sure of the exact reimburse-

ment to the transportation provider.

Mr. Burgess. I may follow up. I will do some followup on that myself. But you intrigued me with your comments, General Schmidt. We have spent a lot of time in this subcommittee and the full committee dealing with the problems from opiate abuse and the recovery therefrom. And so some of your comments about the prosecutorial side, it is one thing to find that there has been diversion, but if a patient is actually harmed in the process.

We study sober homes to some extent here, and we had a panel of family members that came and talked to us. And three of those five panel members, family members, all talked about the danger and the damages from sober homes in not providing the type of care that they were supposed to provide, and people actually suffered as a consequence. Has that been any part of your experience

as well?

Mr. Schmidt. I don't know about the sober homes in particular, Mr. Chairman. But yes, I think I mentioned in my written testimony, we have criminal charges currently pending against an individual, of course, not yet adjudicated, so she is innocent unless and until proven guilty, but who was delivering—she was a nurse in a variety of facilities, sort of rode a circuit and was supposed to be delivering medications to beneficiaries and instead was diverting those medications to illicit uses and obviously causing some fairly substantial harm to the beneficiaries, either in terms of pain management didn't happen or some of the medications' other purposes. So, yes, we have seen that.

And then the flip side of that, with respect to perhaps the intersection between H.R. 3891 and opioid enforcement, we are looking at cases currently. We haven't filed any of these yet, so they may or may not pan out, either under current law or under expanded authority. But potential diversion cases, I will call them pill mill-type cases in a colloquial, where the diversion occurs outside of a healthcare facility or outside of a board and care facility. So they

are outside the scope of the MFCU now.

And one of the things that we just sit around and sort of scratch our heads on is, well, what is our legal theory if we were able to prove this? And right now our legal theory if I want to use the MFCU assets is the fraud to the program for diverting those pills. I can prosecute for a few bucks a pill the financial loss.

But if that diversion results in serious bodily injury or death to somebody who is misusing those pills, which would be a separate crime under Kansas and Federal law, I can't use the MFCU assets to prosecute that much greater ill, and that just doesn't make sense to me.

Mr. Burgess. You are right. And this subcommittee, we are all about making sense.

Mr. Merrill and Mr. Salo, I apologize.

Mr. Merrill, I just have to ask you, because we talked about this a little bit offline when we visited about this. You mentioned the STAR programs in Texas, and, of course, some of the headlines recently from one of the big managed care companies was not providing quite the services or their ability to reduce cost was essen-

tially reducing benefits. And you had some thoughts about it is important to pay attention to the payer in some of these instances.

So could you kind of reprise those comments for this subcommittee?

Mr. MERRILL. Well, I guess in its basic level, care is really never and should never be coordinated at the payer side of the equation. It should be coordinated at the provider side of the equation.

All of these caregivers play a role in this, but I can speak specifically about our own experience at Cook Children's. Since we are a provider-based HMO, we don't have premium expense or dollars or profits that have to go to Wall Street. It is a model that has been out there for quite some time. But the dollars that would normally go to Wall Street we actually reinvest in our community, and that allows us to do more care for these kids.

So I think you have a difference in philosophy on these two different approaches. I do believe personally that provider-based health plans do better work, because their premium expense is all focused on taking better care of these kids. And I know there has been some controversy over that in the STAR Kids program. If you read those articles, you will see that the complaints or concerns that were expressed were on that side of the equation and not on the provider side of the equation. I am telling you as straightforward as I know how, but that is I think the reality of the situation.

Mr. Burgess. I thank you for sharing that, because when you told me that the other day, I thought that was an important concept that needs to be out there.

Mr. Green, do you have any concluding thoughts?

Mr. GREEN. Nothing further, Mr. Chairman. Can I ask for 3 minutes at some future hearing?

Mr. Burgess. I was just aggregating all of the extra time I gave members on your side and capitalizing upon it. It is like access to capital, right?

So seeing that there are no further members wishing to ask questions, I once again want to thank our witnesses for being here today.

Additionally, in addition to all the other documents that we have accepted for the record, I want to submit documents from PillPack, Incorporated; LeadingAge; Medicaid Health Plans of America; and the American Association of Medical Colleges.

[The information appears at the conclusion of the hearing.]

Mr. Burgess. Pursuant to committee rules, I remind members that they have 10 business days to submit additional questions for the record, and I ask that witnesses submit their responses to those questions within 10 business days upon receipt of the questions.

Without objection, the panel is again thanked and the subcommittee is adjourned.

[Whereupon, at 12:54 p.m., the subcommittee was adjourned.] [Material submitted for inclusion in the record follows:]



Association of American Medical Colleges 655 K Street, NW, Suite 100, Washington, DC 20001-2399 T 202 828 0400

September 5, 2018

The Honorable Charles Grassley 135 Hart Senate Office Building United States Senate Washington, DC 20515

The Honorable Joe Barton 2107 Rayburn House Office Building United States House of Representatives Washington, DC 20515 The Honorable Michael Bennet 548 Russell Senate Office Building United States Senate Washington, DC 20515

The Honorable Kathy Castor 2052 Rayburn House Office Building United States House of Representatives Washington, DC 20515

Dear Senators Grassley and Bennett and Representatives Barton and Castor:

On behalf of the Association of American Medical Colleges (AAMC), I am writing to express support for The Advancing Care for Exceptional Kids Act of 2017 (ACE Kids Act, S. 428, H.R. 3325). Thank you for your leadership in introducing this bipartisan legislation to improve health care for children with complex medical conditions on Medicaid.

The AAMC is a not-for-profit association dedicated to transforming health care through innovative medical education, cutting-edge patient care, and groundbreaking medical research. Its members are all 151 accredited U.S. medical schools; nearly 400 major teaching hospitals and health systems, including 51 Department of Veterans Affairs medical centers; and more than 80 academic societies. Through these institutions and organizations, the AAMC serves the leaders of America's medical schools and teaching hospitals and their more than 173,000 full-time faculty members, 89,000 medical students, 129,000 resident physicians, and more than 60,000 graduate students and postdoctoral researchers in the biomedical sciences.

The ACE Kids Act is an important piece of legislation that creates a patient-centered delivery system for a unique population of children to help ensure access to care across state lines and reduce the burden on these children's families. Under this legislation, specially-designed health homes created for children with complex medical conditions would employ national quality standards and coordinate care, which are both essential to improving quality of care and reducing costs.

The ACE Kids Act, which is voluntary for states, families, and providers, would create savings to Medicaid by reducing hospitalizations and emergency room visits while providing essential services and supports for these children. As such, the AAMC is happy to support this legislation.

Thank you for your leadership in introducing this critical legislation — we look forward to working with you to advance this bill this year. If you have any questions, please contact Len Marquez, AAMC Senior Director of Government Relations, at lmarquez@aamc.org.

Sincerely,

Karen Fisher, JD Chief Public Policy Officer

Ka Straker

Adult Congenital Heart ** Association







The Honorable Chuck Grassley 135 Hart Senate Office Building Washington, D.C. 20510

Representative Joe Barton 2107 Rayburn House Office Building Washington, DC 20515 The Honorable Michael Bennet 261 Russell Senate Office Building Washington, D.C. 20510

Representative Kathy Castor 2052 Rayburn House Office Building Washington, DC 201515

Dear Senators Grassley and Bennet and Representatives Barton and Castor:

On behalf of the millions of volunteers, families, and kids dedicated to improving the health and quality of care for patients with cardiovascular disease, including congenital heart defects, we are writing to offer our support for the Advancing Care for Exceptional Kids Act of 2017, or the ACE Kids Act (\$.428). We urge Congress to pass this bill into law and establish better coordination of care for our medically complex children.

Congenital heart defects are the most common birth defect in the United States. Nearly 40,000 infants are born with some type of congenital heart defect each year. Thanks to advances in research, treatments, and early detection and diagnosis, most infants born with a congenital heart defect now survive and live longer lives. It is estimated that there are at least 2.4 million individuals living in the United States with a congenital heart defect. However, survivors, particularly those with more complex forms of congenital heart defects, are more likely to develop additional heart problems later in life and have co-morbidities that need coordinated care throughout the life-span. Unfortunately, many of these survivors do not receive the care they need.

Therefore, we support the ACE Kids Act and efforts to improve care for children with complex medical conditions, such as congenital heart defects. Specifically, the creation of Enhanced Pediatric Health Homes (EPHH) and nationally designated children's hospital networks would improve coordination of care for children with serious congenital heart defects by linking pediatric resources across multiple providers. These networks would also help to remove barriers to highly specialized care by allowing kids covered by Medicaid and the Children's Health Insurance Program to access the full range of care they need, including providers across state lines.

As a part of the EPHH, care coordination and transition services are vital to the long-term outcomes for children with CHD. Providing children with the right care, from the right providers, at the right time is critical to the long-term success of these children. The fee-for-service health care system has resulted in fragmentation of care for children with a CHD. This legislation creates a state option in Medicald in

which the payment model would follow the structure of Medicaid Health Homes. States, working with CMS, will be encouraged to develop alternative payment methodologies involving risk sharing and performance-based models. We strongly advocate for patient/family engagement in the development of these models, as well.

The ACE Kids Act would also collect data and develop standards of care to help researchers and providers improve treatments for kids with congenital heart defects. Increased care coordination and data collection are not only critical to improving health outcomes for kids with congenital heart defects but to reducing health care costs, too.

We have made tremendous progress in our understanding and treatment of congenital heart defects, but we have a long way to go. People with congenital heart defects still face life-long health risks, and the ACE Kids Act is an important step towards helping these kids live longer, healthier lives.

We thank you for your support on this important issue and look forward to working together with you to move this legislation through Congress.

Sincerely,

Adult Congenital Heart Association

American Heart Association

Mended Little Hearts

Pediatric Congenital Heart Association

American Academy of Pediatrics

AAP Headquarters
345 Park Blvd
Itasca, It. 60143
Phone: 630/626-6000
Fax: 847/434-8000
E-mail: kidsdocs@aap.org
www.aap.org

Reply to AAP Washington Office 601 13th St NW, Suite 400N Washington, DC 20005 Phone: 202/347-8600 E-mail: kids1st@sap.org

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The Honorable Joe Barton 2107 Rayburn House Office Building Washington, DC 20515 The Honorable Kathy Castor 2052 Rayburn House Office Building Washington, DC 20515

Dear Congressman Barton and Congresswoman Castor:

On behalf of the American Academy of Pediatrics (AAP), a non-profit professional organization of 67,000 primary care pediatricians, pediatric medical subspecialists, and pediatric surgical specialists dedicated to the health, safety and well-being of infants, children, adolescents, and young adults, I write to share our support for H.R. 3325, the Advancing Care for Exceptional (ACE) Kids Act.

This legislation seeks to address existing challenges facing children with complex medical conditions by improving the coordination of care across multiple providers and services. Additionally, the legislation would incentivize states to expand access to patient-centered, pediatric-focused coordinated care models tailored for children with medical complexity, which can lead to improved quality of care for this population.

The ACE Kids Act directs the Secretary of the Department of Health and Human Services to evaluate and promulgate guidance on best practices for ensuring that children with complex medical conditions receive prompt care from out-of-state providers, a challenge that many pediatricians, pediatric sub-specialists and pediatric surgical specialists face when providing care to this population. The legislation also includes a focus on robust data collection, quality improvement and coordination between the child's medical home and the specialty care that is often outside the child's home community.

Children with medical complexity, as do all children, deserve access to the highest quality care in a medical home. We thank you for your leadership in introducing this critical legislation. If you have any questions, please contact Marielle Kress in our Washington, D.C. office at 202/347-8600 or mkress@aap.org.

Sincerely,

Collun a Kraft

Colleen A. Kraft, MD, MBA, FAAP

President



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July 25, 2018

The Honorable Chuck Grassley 135 Hart Senate Office Building Washington, D.C. 20510

The Honorable Joe Barton 2107 Rayburn House Office Building Washington, D.C. 20515

The Honorable Michael Bennet 261 Russell Senate Office Building Washington, D.C. 20510

The Honorable Kathy Castor 2052 Rayburn House Office Building Washington, D.C. 20515

Dear Sens. Grassley and Bennet and Reps. Barton and Castor:

On behalf of The American Board of Pediatrics, I wish to express our support for S. 428 and H.R. 3325, The Advancing Care for Exceptional Kids Act of 2017 (The ACE Kids Act). Thank you for your leadership in introducing this bipartisan legislation to improve care for children with complex medical conditions.

The American Board of Pediatrics certifies more than 80,000 pediatricians in the United States based on standards of excellence that lead to high quality health care for children. Board-certified pediatricians have demonstrated standards that exceed those required for licensure alone. Hence the ACE Kids Act is entirely consistent with our vision of improving the health of children.

We are well aware that children with complex medical conditions have chronic life-limiting illnesses and disabilities that often require the coordination of medical care by multiple medical specialists and subspecialists. The ACE Kids Act creates a patient-centered delivery system for this unique population of children. It will also greatly reduce the burden on many families by ensuring ready access to care across state lines, which is often required due to the highly specialized nature of the care.

Under the ACE Kids Act, specially-designed health homes for children with complex medical conditions would:

- employ national quality standards and coordinate care, both essential to improving quality of care and lowering costs.
- include a full range of acute, post-acute and primary care providers, as well as behavioral health professionals.
- focus on outpatient treatment to ensure children get the care that they need in the most appropriate settings closest to home, while reducing unnecessary hospitalizations and emergency room visits.

Providing the most appropriate care for these children is a national challenge. The ACE Kids Act will bring us closer to ensuring these vulnerable children receive the care they need. Thank you for your work on behalf of children and their families.

Sincerely,

David G. Nichols, MD, MBA

President & CEO

The American Board of Pediatrics

A MEMBER OF THE AMERICAN BOARD OF MEDICAL SPECIALTIES



Heart House 2400 N Street, NW Washington, DC 20037-1153 USA

202-375-6000 800-253-4636 Fax: 202-375-7000 www.ACC.org

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Interim Chief Executive Officer Cathleen C. Gates

The mission of the American College of Cardiology and the American College of Cardiology Foundation is to transform cardiopacular care and improve heart health. August 15, 2018

The Honorable Chuck Grassley 135 Hart Senate Office Building Washington, D.C. 20510

The Honorable Joe Barton 2107 Rayburn House Office Building Washington, D.C. 20515 The Honorable Michael Bennet 261 Russell Senate Office Building Washington, D.C. 20510

The Honorable Kathy Castor 2052 Rayburn House Office Building Washington, D.C. 20515

Dear Senator Grassley, Senator Bennet, Representative Barton and Representative Castor:

On behalf of the American College of Cardiology (ACC), we are writing to express our support for S. 428/H.R. 3325, the Advancing Care for Exceptional Kids Act of 2017 (ACE Kids Act). Thank you for introducing this legislation to improve care for children with complex medical conditions.

The ACC is a 52,000-member medical society that is the professional home for the entire cardiovascular care team. The College's mission is to transform cardiovascular care and improve heart health. The ACC leads in health policy formation, standards and guidelines. The College operates national registries to measure and improve care, provides professional medical education, promotes cardiovascular research and bestows credentials on cardiovascular specialists who meet stringent qualifications.

The ACE Kids Act would improve care coordination for children with medical complexities on Medicaid, especially in instances when they would need to visit multiple providers across state lines. Specially-designed health homes would employ national quality standards and coordinate care, and include the full range of acute, post-acute and primary care providers, as well as behavioral health professionals. This legislation clarifies that the program would be voluntary for states, providers, and families, and work within the existing structure of a state's Medicaid program, including those states with Medicaid managed care. It would also enable the gathering of national level data on rare, complex conditions to determine best practices. These are laudable goals that aim to help our most vulnerable patients, and are in complete alignment with ACC's mission.

Of the more than 30 million children covered by Medicaid, two million have complex medical conditions such as cancer or congenital heart defects. Congenital heart disease (CHD), a life-long consequence of a structural abnormality of the heart present at birth, is the number one birth defect in the nation. CHDs affect nearly 1% of—or about 40,000—births per year in the United States. While the diagnosis and treatment of CHD has greatly improved over the years, most patients with complex heart defects need special care throughout their lives. CHD patients would benefit from the array of outpatient and community services provided by the ACE Kids Act.

The ACC commends you for your leadership in addressing the needs of medically complex children. We look forward to working with you to advance this crucial legislation.

Sincerely.

C. Michael Valentine, MD, FACC

President, American College of Cardiology



Association of Medical School Pediatric Department Chairs

Executive Office: 6728 Old McLean Village Drive • McLean, VA 22101-3906 Phone (703) 556-9222 • Fax (703) 556-8729 • www.amspdc.org • info@amspdc.org

July 24, 2018

The Honorable Chuck Grassley 135 Hart Senate Office Building Washington, D.C. 20510

The Honorable Joe Barton 2107 Rayburn House Office Building Washington, D.C. 20515 The Honorable Michael Bennet 261 Russell Senate Office Building Washington, D.C. 20510

The Honorable Kathy Castor 2052 Rayburn House Office Building Washington, D.C. 20515

Dear Sens. Grassley and Bennet and Reps. Barton and Castor:

On behalf of the Association of Medical School Pediatric Department Chairs (AMSPDC), we are writing to express our support for S. 428 and H.R. 3325, The Advancing Care for Exceptional Kids Act of 2017 (The ACE Kids Act). We thank you for your leadership in introducing this bipartisan legislation to improve care for children with complex medical conditions on Medicaid.

Children with complex medical conditions have chronic life-limiting illnesses and disabilities, often see six or more specialists and a dozen or more physicians, and require care that takes them across state lines. Under the current Medicaid system, parents of children with multiple, life-threatening disabilities struggle to coordinate the complex care of their kids, which often requires care of providers in several states. Only federal legislation can fix the fragmented system for children with complex medical conditions that require regional care.

The ACE Kids Act creates a patient-centered, pediatric-focused delivery system for this unique population of children to ensure ready access to care across state lines and reduce the burden on these children's families. Specially-designed health homes created for children with complex medical conditions under the ACE Kids Act would employ national quality standards and coordinate care, both essential to improving quality of care and lowering costs. These health homes would include the full range of acute, post-acute and primary care providers, as well as behavioral health professionals. The health homes would focus on outpatient care to ensure children get the care that they need in the most appropriate settings closest to home, while reducing unnecessary hospitalizations and emergency room visits.

The ACE Kids Act, which is voluntary for states, families and providers, can deliver savings to Medicaid through increased efficiencies, including reducing hospitalizations and emergency room visits, while providing the array of outpatient and community services and support needed by these children. We are happy to support this important legislation.

Providing children with complex medical conditions enrolled in Medicaid the best possible care is a national challenge and the ACE Kids Act will bring us closer to ensuring these vulnerable children receive the care they need. We thank you for championing the ACE Kids Act and look forward to working with you to advance this critical legislation this year.

Sincerely,

Michael Artman, MD President, AMSPDC

Joyce C. Hall Eminent Scholar in Pediatrics Senior Vice President, Pediatrician-in-Chief

Children's Mercy Hospital

Chairman, Department of Pediatrics

University of Missouri-Kansas City School of Medicine

University of Kansas School of Medicine



4340 East West Highway, Suite 350 Bethesda, MD 20814 Phone: 301.657.0881 Fax: 301.657.0869 Email: info@autism-society.org Web site: www.autism-society.org

August 20, 2018

The Honorable Kathy Castor U.S. House of Representatives Washington, D.C. 20515

Dear Representative Castor,

The Autism Society of America writes to thank you for your leadership on introducing the bipartisan Advancing Care for Exceptional Kids Act of 2018 (ACE Kids Act, H.R. 3325). The ACE Kids Act creates the opportunity for states to provide coordinated care through enhanced pediatric health homes (EPHHs) to children with complex medical conditions.

For too long we have seen families of children born with disabilities struggle to find comprehensive care plans that follow their child through crucial transition periods. This bill creates organized care plans for children, supports for the family, a health information technology system to link services and access to a full range of both specialty and subspecialty medical services.

Most importantly, this bill removes some of the stress families deal with by providing adequate treatment and support for so many people who have a challenging situation.

Thank you again for introducing this important bill. The Autism Society is pleased to support this bill and work with you and the rest of the Congress to pass this bill into law.

Sincerely

Joe Joyce Chair, Autism Society



June 21, 2018

The Honorable Chuck Grassley 135 Hart Senate Office Building Washington, D.C. 20510

The Honorable Joe Barton 2107 Rayburn House Office Building Washington, D.C. 20515 The Honorable Michael Bennet 261 Russell Senate Office Building Washington, D.C. 20510

The Honorable Kathy Castor 2052 Rayburn House Office Building Washington, D.C. 20515

Dear Senators Grassley and Bennet and Representatives Barton and Castor:

On behalf of Autism Speaks, we are writing to express our support for S. 428 and H.R. 3325, The Advancing Care for Exceptional Kids Act of 2017 (The ACE Kids Act). We thank you for your leadership in introducing this bipartisan legislation to improve care for children with complex medical conditions on Medicaid.

Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of individuals with autism and their families. We do this through advocacy and support; increasing understanding and acceptance of autism spectrum disorder; and advancing research into causes and better interventions for autism spectrum disorder and related conditions.

The majority of children with autism aspectrum disorder have co-occurring developmental, psychiatric or neurological disorders. In addition, children with autism often have other co-occurring medical conditions such as gastrointenstinal disturbances, sleep problems, and seizure disorders. As a result, children with autism often may see many clinicians – including physicians and multiple specialists. Children with autism who have significant needs may require care that takes them across state lines. Under the current Medicaid system, parents of children with multiple, life-threatening disabilities struggle to coordinate the complex care of their kids, which often requires care of providers in several states. Only federal legislation can fix the fragmented system for children with complex medical conditions that require regional care.

The ACE Kids Act creates a patient-centered, pediatric-focused delivery system for this unique population of children to ensure ready access to care across state lines and reduce the burden on these children's families. Specially-designed health homes created for children with complex medical conditions under the ACE Kids Act would employ national quality standards and coordinate care, both essential to improving quality of care and lowering costs. These health homes would include the full range of acute, post-acute and primary care providers, as well as behavioral health professionals. The health homes would focus on outpatient care to ensure children get the care that they need in the most

appropriate settings closest to home, while reducing unnecessary hospitalizations and emergency room visits.

The ACE Kids Act, which is voluntary for states, families and providers, can deliver savings to Medicaid through increased efficiencies, including reducing hospitalizations and emergency room visits, while providing the array of outpatient and community services and support needed by these children. We are happy to support this important legislation.

Providing children with complex medical conditions enrolled in Medicaid the best possible care is a national challenge and the ACE Kids Act will bring us closer to ensuring these vulnerable children receive the care they need. We thank you for championing the ACE Kids Act and look forward to working with you to advance this critical legislation this year. If you have any questions please contact angela.lello@autismspeaks.org at (202) 955-3111 ext. 58677.

Sincerely,

Stuart Spielman

Stuart Spielman

Senior Policy Advisor and Counsel



1215 K STREET, SUITE 1930 SACRAMENTO, CA 95814 916.552.7131 www.ccha.org

September 6, 2018

The Honorable Joe Barton U.S. House of Representatives 2107 Rayburn House Office Building Washington, DC 20515

SUBJECT:

H.R. 3325 (BARTON) ADVANCING CARE FOR EXCEPTIONAL KIDS ACT

SUPPORT

Dear Representative Barton:

On behalf of the California Children's Hospital Association (CCHA), representing California's eight free-standing, not-for-profit children's hospitals, I write in SUPPORT of your H.R. 3325, the Advancing Care for Exceptional Kids Act (ACE Kids Act), which will expand access to patient-centered, pediatric-focused coordinated care models tailored for children with medical complexity, while simultaneously reducing program spending.

Medicaid covers over 37 million children, and a small percentage of these kids have complex medical conditions requiring ongoing and specialized care. In fact, their care accounts for significant percentage of all Medicaid spending on children. The ACE Kids Act addresses existing challenges — identified by families and physicians — facing these children, including the provision and coordination of care across multiple providers and services, and easing access to out-of-state care.

The ACE Kids Act adopts a proven approach for treating kids with medical complexity, as demonstrated through the CMS Innovation Center, formerly the Center-for Medicare and Medicaid Innovation (CMMI). The ACE Kids model reduced costs and improved quality based on the documented care of thousands of medically complex children. CMMI's Coordinating All Resources Effectively (CARE) award — involving 10 children's hospitals and eight different state Medicaid programs, including DC — reduced emergency department visits by 26 percent and reduced inpatient days by 32 percent. In the first full year of operations coordinating care for 8,000 children, CARE ultimately reduced overall costs by 2.6 percent while improving patient experience. The ACE Kids Act would enable these innovations to spread nationally, and create a national framework to improve data collection and quality of care. It will allow for better coordination for out-of-state care, and spur innovation and the sharing of best practices between states.

Importantly, the ACE Kids Act would be optional for states, providers and families. It would also work within the existing structure of a state's Medicaid program, including those states, like California, with Medicaid managed care. The bill would allow for the creation of enhanced pediatric health homes and provide incentives for states to participate.

For all of these reasons, CCHA is pleased to SUPPORT your H.R. 3325 (Barton), the ACE Kids Act, which will improve Medicaid for the sickest children and reduce program spending.

Sincerely,

Unix Unter

Mira Morton Director of Government Relations

Cc:

The Honorable Doris Matsui The Honorable Anna Eshoo The Honorable Tony Cárdenas

Believing in the spirit of a child.



July 3, 2018

The Honorable Chuck Grassley 135 Hart Senate Office Building Washington, D.C. 20510

The Honorable Joe Barton 2107 Rayburn House Office Building Washington, D.C. 20515

Re: S. 428 and H.R. 3325

The Flonorable Michael Bennet 261 Russell Senate Office Building Washington, D.C. 20510

The Honorable Kathy Castor 2052 Rayburn House Office Building Washington, D.C. 20515

Dear Sens. Grassley and Bennet and Reps. Barton and Castor:

ChildSerre provides care to nearly 5,000 children per year in Iowa with special healthcare needs, including some with the most medically complex conditions. Our mission is to partner with families to help children with special healthcare needs live a great life. On behalf of ChildSerre, I am writing to express our support for S. 428 and H.R. 3325, The Advancing Care for Exceptional Kids Act of 2017 (The ACE Kids Act). We thank you for your leadership in introducing this bipartisan legislation to improve care for children with complex medical conditions on Medicaid.

Children with complex medical conditions have chronic life-limiting illnesses and disabilities that often see several specialists and multiple physicians, and require care that can take them across state lines. Under the current Medicaid system, parents of children with complex conditions struggle to coordinate the care their children need, which includes providers in multiple locations and even out of state. Only federal legislation that creates regional systems of care can fix the fragmented system for children with complex medical conditions.

The ACE Kids Act, which is voluntary for states, families and providers, creates a patient-centered, pediatric-focused delivery system for this unique population of children to ensure ready access to care across state lines and reduce the burden on these children's families. Specially-designed health homes created for children with complex medical conditions under the ACE Kids Act would employ national quality standards and coordinate care, both essential to improving quality of care and lowering costs. These health homes would include the full range of acute, post-acute and primary care providers, as well as behavioral health professionals. The health homes would focus on outpatient care to ensure children get the care that they need in the most appropriate settings closest to home, while reducing unnecessary hospitalizations and emergency room visits.

Senators Grassley & Bennet / Representatives Barton & Castor July 3, 2018 Page 2

The ACE Kids Act can deliver savings to Medicaid through increased efficiencies, including reducing hospitalizations and emergency room visits, while coordinating the array of outpatient and community services and support needed by these children. We are happy to support this important legislation.

Providing children with complex medical conditions enrolled in Medicaid the best possible care is a national challenge and the ACE Kids Act will bring us closer to ensuring these vulnerable children receive the care they need. We thank you for championing the ACE Kids Act and look forward to working with you to advance this critical legislation this year.

Julaymo Teri Wahlig, MD, MBA

Chief Executive Officer



P.O. Box 2371, Alexandria, VA 22301 - Phone 703 683 7500 - Fax 703 683 4482 - www.duchennemd.org Joel Wood President

The Honorable Chuck Grassley 135 Hart Senate Office Building Washington, D.C. 20510

The Honorable Joe Barton 2107 Rayburn House Office Building Washington, D.C. 20515 The Honorable Michael Bennet 261 Russell Senate Office Building Washington, D.C. 20510

The Honorable Kathy Castor 2052 Rayburn House Office Building Washington, D.C. 20515

Dear Sens. Grassley and Bennet and Reps. Barton and Castor:

On behalf of the Foundation to Eradicate Duchenne, I am writing to express our support for S.428 /H.R.3325, The Advancing Care for Exceptional Kids Act of 2017 (The ACE Kids Act). We thank you for your leadership in introducing this bipartisan legislation to improve care for children with medical complexity on Medicaid.

Duchenne Muscular Dystrophy is the world's #1 lethal childhood genetic disorder and only effects boys and young men. Duchenne is a relentless disease that requires a complex set of treatments and constant vigilance on behalf of patients, their parents and the dedicated medical professionals who provide care. Due to the frequency and high cost of care, those battling Duchenne often rely on Medicaid for part or all of their medical care, and their parents act as de facto care coordinators.

Children with complex medical conditions, like Duchenne, often see six or more specialists and a dozen or more physicians, and require care that takes them across state lines. Under the current Medicaid system, parents of children with multiple, life threatening disabilities struggle to coordinate the complex, multi-state care of their kids.

The ACE Kids Act advances s an organized system of health care delivery for this unique population of children to ensure ready access across state lines and to reduce the burden on their families. Nationally designated children's hospitals networks created under the ACE Kids Act would employ national quality standards and coordinate care, both essential to improving quality and saving money. These networks would include the full range of acute, post-acute and primary care providers, with children's hospitals as anchors, and a focus on

outpatient care to ensure children get the care that they need in the most appropriate settings closest to home, while reducing hospitalizations and emergency room visits.

We believe ACE Kids Act can improve quality of care for the millions of children with medical complexity in Medicaid, while at the same time strengthening the program. The Foundation is happy to join the more than 20 national organization devoted to children's well-being that have already come out in support of The ACE Kids Act. Providing the best possible care for children with medical complexity enrolled in Medicaid is a national challenge that needs a national solution and requires Congress to act. We thank you again for introducing the ACE Kids Act and we look forward to working with you to advance this legislation in Congress.

Sincerely

Joel Wood

President & Founder

The Foundation to Eradicate Duchenne



www.iprc.info 914-573-IPRC 914-573-4772 email: info@iprc.info

July 10, 2018

The Honorable Chuck Grassley 135 Hart Senate Office Building Washington, D.C. 20510

The Honorable Joe Barton 2107 Rayburn House Office Building Washington, D.C. 20515 The Honorable Michael Bennet 261 Russell Senate Office Building Washington, D.C. 20510

The Honorable Kathy Castor 2052 Rayburn House Office Building Washington, D.C. 20515

Dear Sens. Grassley and Bennet and Reps. Barton and Castor:

On behalf of The International Pediatric Rehabilitation Collaborative (IPRC), representing over 50 pediatric rehabilitation provider organizations, we are writing to express our support for S. 428 and H.R. 3325, The Advancing Care for Exceptional Kids Act of 2017 (The ACE Kids Act). We thank you for your leadership in introducing this bipartisan législation to improve care for children with complex medical conditions on Medicaid.

Children with complex medical conditions have chronic life-limiting illnesses and disabilities and require care from many specialists and physicians. That care often takes them across state lines as they obtain specialty services from multiple service providers, hospitals, and organizations. Under the current Medicaid system, parents of children with multiple, life-threatening disabilities struggle to coordinate the complex care of their kids, which often requires care of providers in several states from multiple provider entities.

Only federal legislation can fix the fragmented system for children with complex medical conditions that require regional care. Many of our IPRC members provide services for these exceptional children and support their families as they experience this hardship. Improvements to the system are crucial. Addressing these barriers of excessive travel, payment restrictions, and limited communication among providers will reduce redundancy, improve ease of access, and streamline care.

The ACE Kids Act creates a patient-centered, pediatric-focused delivery system for this unique population of children to ensure ready access to care across state lines and reduce the burden on these children's families. Specially-designed health homes created for children with complex medical conditions under the ACE Kids Act would employ national quality standards and coordinate care, both essential to improving

quality of care and lowering costs. These health homes would include the full range of acute, post-acute and primary care providers, as well as behavioral health professionals. The health homes would focus on outpatient care to ensure children get the care that they need in the most appropriate settings closest to home, while reducing unnecessary hospitalizations and emergency room visits.

The ACE Kids Act, which is voluntary for states, families and providers, can deliver savings to Medicaid through increased efficiencies, including reducing hospitalizations and emergency room visits, while providing the array of outpatient and community services and support needed by these children. The International Pediatric Rehabilitation Collaborative is pleased to support this important legislation.

Providing children with complex medical conditions enrolled in Medicaid the best possible care is a national challenge and the ACE Kids Act will bring us closer to ensuring these vulnerable children receive the care they need. We thank you for championing the ACE Kids Act and look forward to working with you to advance this critical legislation this year.

Sincerely,

Cindi M. Hobbes

Cirle metrosh

Director, International Pediatric Rehabilitation Collaborative



OFFICE OF GOVERNMENT AFFAIRS

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July 24, 2018

The Honorable Chuck Grassley 135 Hart Senate Office Building Washington, DC 20510

The Honorable Joe Barton 2107 Rayburn House Office Building Washington, DC 20515 The Honorable Michael Bennet 261 Russell Senate Office Building Washington, DC 20510

The Honorable Kathy Castor 2052 Rayburn House Office Building Washington, DC 20515

Dear Sens. Grassley and Bennet and Reps. Barton and Castor:

On behalf of the March of Dimes, a unique collaboration of scientists, clinicians, parents, members of the business community, and other volunteers representing every state, the District of Columbia and Puerto Rico, I would like to express our support for S. 428/H.R. 3325, the Advancing Care for Exceptional Kids Act of 2017 (ACE Kids Act).

March of Dimes appreciates your leadership in introducing this bipartisan legislation to improve care for children with complex medical conditions on Medicaid. Infants and children

with complex medical conditions and their families often face daunting obstacles in obtaining the care they need to be healthy, grow and thrive. Many such children see multiple specialists and providers and require care that takes them across state lines. Parents frequently struggle to coordinate this complex web of fragmented care.

The ACE Kids Act creates a patient-centered, pediatric-focused delivery system for this unique population of children to ensure ready access to care across state lines and reduce the burden on these children's families. Specially-designed health homes created for children with complex medical conditions under the ACE Kids Act would employ national quality standards and coordinate care, both essential to improving quality of care and lowering costs. These health homes would include the full range of acute, post-acute and primary care providers, as well as behavioral health professionals. The health homes would focus on outpatient care to ensure children get the care that they need in the most appropriate settings closest to home, while reducing unnecessary hospitalizations and emergency room visits.

Providing children with complex medical conditions enrolled in Medicaid the best possible care is a collective responsibility, and the ACE Kids Act will bring us closer to ensuring these vulnerable children receive the care they need. We thank you for championing the ACE Kids Act and look forward to working with you to advance this critical legislation.

Sincerely,

Cynthia Pellegrini

Senior Vice President for Public Policy and Government Affairs

1



PRESIDENT David Napier Youth Home, Inc.

VICE PRESIDENT/PRESIDENT/ELECT Richard Wolleat Northwood Children's Services Duluth, Minnesota

SFCRETARY Tricia Delano Jackson-Feild Behavioral Health Services Jarratt, Virginia

TREASURIER Denis D. McCarville AK Child & Family Anchorage, Alaska

IMMEDIATE PAST PRESIDENT Steven A. Girelli Klingberg Family Centers New Britain, Connecticut

DIRECTORS L. Gail Atkinson Devereux Advanced Behavioral Health League City, Texas

John Damon Canopy Children's Solutions Jackson, Mississippi Michele Madley Gibault Children's Services

Terre Haute, Indiana John Regitano Family Centered Services of Alaska Fairbanks, Alaska

Fairbanks, Alaska
Randall J. Rider
Crossroad Child & Family Services, Inc.
Fort Wayne, Indiana

Mary Stone-Smith Catholic Community Services of Western Washington Tacoma, Washington

DIRECTORS AT-LARGE Charlene Hoobler The Barry Robinson Center Norfolk, Virginia

Kevin Keegan Catholic Charities Timonium, Maryland

EXECUTIVE DIRECTOR
Patricia Johnston

June 5, 2018

The Honorable Chuck Grassley 135 Hart Senate Office Building Washington, D.C. 20510

The Honorable Joe Barton 2107 Rayburn House Office Building Washington, D.C. 20515 The Honorable Michael Bennet 261 Russell Senate Office Building Washington, D.C. 20510

The Honorable Kathy Castor 2052 Rayburn House Office Building Washington, D.C. 20515

Dear Sens. Grassley and Bennet, and Reps. Barton and Castor:

On behalf of the National Association for Children's Behavioral Health, I writie to express our support for S. 428 and H.R. 3325, The Advancing Care for Exceptional Kids Act of 2017 (The ACE Kids Act). We thank you for your leadership in introducing this bipartisan legislation to improve care for children with complex medical conditions on Medicaid.

Children with complex medical conditions have chronic life-limiting illnesses and disabilities, often see six or more specialists and a dozen or more physicians, and require care that takes them across state lines. Under the current Medicaid system, parents of children with multiple, life-threatening disabilities struggle to coordinate the complex care of their kids, which often requires care of providers in several states. Only federal legislation can fix the fragmented system for children with complex medical conditions that require regional care.

The ACE Kids Act creates a patient-centered, pediatric-focused delivery system for this unique population of children to ensure ready access to care across state lines and reduce the burden on these children's families. Specially-designed health homes created for children with complex medical conditions under the ACE Kids Act would employ national quality standards and coordinate care, both essential to improving quality of care and lowering costs. These health homes would include the full range of acute, post-acute and primary care providers, as well as behavioral health professionals. The health homes would focus on outpatient care to ensure children get the care that they need in the most appropriate settings closest to home, while reducing unnecessary hospitalizations and emergency room visits.

The ACE Kids Act, which is voluntary for states, families and providers, can deliver savings to Medicaid through increased efficiencies, including reducing hospitalizations and emergency room visits, while providing the array of outpatient and community services and support needed by these children. We are happy to support this important legislation.

Providing children with complex medical conditions enrolled in Medicaid the best possible care is a national challenge and the ACE Kids Act will bring us closer to ensuring these vulnerable children receive the care they need. Thank you for championing the ACE Kids Act. We look forward to working with you to advance this critical legislation this year.

Sincerely,

Patricia Johnston

Executive Director



Headquarters 5 Hanover Square Suite 1401 New York, NY 10004 P.917-746-8300 www.napnap.org

June 28, 2018

The Honorable Chuck Grassley 135 Hart Senate Office Building Washington, D.C. 20510

The Honorable Joe Barton 2107 Rayburn House Office Building Washington, D.C. 20515 The Honorable Michael Bennet 261 Russell Senate Office Building Washington, D.C. 20510

The Honorable Kathy Castor 2052 Rayburn House Office Building Washington, D.C. 20515

Dear Sens. Grassley and Bennet and Reps. Barton and Castor:

On behalf of more than 9,000 pediatric nurse practitioners and fellow pediatric-focused advanced practice registered nurses committed to providing optimal health care to children, the National Association of Pediatric Nurse Practitioners (NAPNAP) appreciates your leadership in introducing the "Advancing Care for Exceptional Kids Act of 2017 (ACE Kids Act)" (S. 428/H.R. 3325). Your legislation would provide critically needed help to improve care for children with complex medical conditions on Medicaid. NAPNAP and its members strongly support your efforts.

As you know, advanced practice registered nurses (APRNs) who concentrate on children's care, including pediatric nurse practitioners (PNPs), are critically aware of the importance of stable, affordable health coverage in ensuring that families and their children receive the timely health care they need. Practicing in primary care, specialty, and acute care settings, APRNs dedicated to pediatric care have provided quality health care to children and families for more than 40 years in an extensive range of practice settings such as pediatric offices, schools, and children's hospitals — reaching millions of patients across the country every year. Our members diagnose, treat and refer for care the growing number of children facing the challenge of complex medical conditions.

Pediatric-focused APRNs know that children with complex medical conditions have chronic life-limiting illnesses and disabilities, often see six or more specialists and a dozen or more pediatric providers, and require care that takes them across state lines. Parents of children with multiple, life-threatening disabilities struggle to coordinate their youngsters' complex care under the current Medicaid system, which often requires care furnished by providers in several different states. Only federal legislation can fix the fragmented system for children with complex medical conditions that require regional care.

Thanks to your efforts, the ACE Kids Act would create a patient-centered, pediatric-focused delivery system for this unique population of children to ensure ready access to care across state lines and reduce the burden on these children's families. Specially-designed health homes created for children with complex medical conditions under the ACE Kids Act would employ national quality standards and coordinate care, both essential to improving quality of care and lowering costs. These health homes would include the full range of acute, post-acute and primary care providers, as well as behavioral health professionals. These health homes would focus on outpatient care to ensure children get the care that they need in the most appropriate settings closest to home, while reducing unnecessary hospitalizations and emergency room visits.

The ACE Kids Act, which is voluntary for states, families and providers, can deliver savings to Medicaid through increased efficiencies, including reducing hospitalizations and emergency room visits, while providing the array of outpatient and community services and support needed by these children. NAPNAP and its members are happy to support this important legislation.

Providing children with complex medical conditions enrolled in Medicaid the best possible care is a national challenge, and enactment of the ACE Kids Act will bring us closer to ensuring these vulnerable children receive the care they need. We are grateful to you for championing the ACE Kids Act, and we are eager to work with you to ensure that this critical legislation is enacted into law this year. Please feel free to contact NAPNAP for assistance on these or any issues or policies related to children's health care. We have a wide breath of experts ready and eager to assist you in framing a healthier future for our children.

Tresa E. Zielinski, DNP, RN, APN-NP, CPNP-PC President



September 4, 2018

The Honorable Joe Barton The Honorable Kathy Castor United States House of Representatives Washington, D.C. 20515

Dear Congressman Barton and Congresswoman Castor:

On behalf of the National Down Syndrome Society, the leading human rights organization for all individuals with Down syndrome, I am writing to express our support for H.R. 3325, the "Advancing Care for Exceptional (ACE) Kids Act of 2017." We commend you for your leadership in sponsoring this legislation.

NDSS is the largest nonprofit organization dedicated to advocating for people with Down syndrome and their families at the federal, state and local levels of government. We are at the forefront of public policy efforts to improve the quality of healthcare provided to people with Down syndrome. H.R. 3325 is one such effort because it will improve the process by which children with Down syndrome who participate in the Medicaid program, and who also have other complex medical conditions, are able to obtain quality care and coordinated treatments.

According to the National Institutes of Health (NIH), at least one-half of all children with Down syndrome also have co-occurring conditions that contribute to the medical complexity of Trisomy 21. Leukemia and congenital heart disease are examples of common afflictions early in life that necessitate extensive medical intervention. Other common co-occurring conditions include obstructive sleep apnea, seizure disorders, neurobehavioral problems, pulmonary hypertension, thyroid diseases, celiac disease, gastrointestinal defects, Type I diabetes, immune system dysfunction, and metabolic dysfunction.

Because their complex medical conditions can be costly, many children with Down syndrome depend on state-based Medicaid programs. But they also require specialized care in centers of excellence, often times outside of their state, and Medicaid rules can limit access to coordinated care.

H.R. 3325 creates a mechanism for states to participate in a national framework for children with Down syndrome who also have other complex medical conditions, as well as other children with medical complexities and their families, to receive cost-effective and coordinated health care and support. This framework could significantly reduce the necessity for more extensive medical interventions later in life, thus improving the long-term financial viability of the Medicaid program.

The Honorable Joe Barton The Honorable Kathy Castor September 4, 2018 – Page 2

Thank you for your leadership and support on this important issue. NDSS welcomes the opportunity to work with you to advance this legislation.

Sincerely,

Sara Hart Weir, MS President & CEO

National Down Syndrome Society



July 10, 2018

The Honorable Chuck Grassley 135 Hart Senate Office Building Washington, D.C. 20510

The Honorable Joe Barton 2107 Rayburn House Office Building Washington, D.C. 20515 The Honorable Michael Bennet 261 Russell Senate Office Building Washington, D.C. 20510

The Honorable Kathy Castor 2052 Rayburn House Office Building Washington, D.C. 20515

Dear Sens. Grassley and Bennet and Reps. Barton and Castor:

The Tricare for Kids Coalition is a stakeholder group of children's health care advocacy and professional organizations, disability advocacy groups, military and veterans' service organizations and military families committed to ensuring that Tricare meets the unique health needs of the more than two million children of military families covered by Tricare.

While all children have unique needs as compared to adults, military children face unique experiences due to the very nature of their parents' service.

The Coalition writes to express support for S. 428 and H.R. 3325, The Advancing Care for Exceptional Kids Act of 2017 (The ACE Kids Act). We thank you for your leadership in introducing this bipartisan legislation to improve care for children with complex medical conditions on Medicaid.

Children with complex medical conditions have chronic life-limiting illnesses and disabilities, often see many physicians and specialists, and require care that takes them across state lines. Under the current Medicaid system, parents of children with multiple, life-threatening disabilities struggle to coordinate the complex care of their kids. Only federal legislation can fix the fragmented system for children with complex medical conditions that require regional care.

While military families may not be the first population that comes to mind when considering the ACE Kids Act, it is imperative to note that more than 200,000 children of active duty and retiree military families covered by Tricare are also relying on Medicaid for coverage pertaining to their complex medical conditions.

The ACE Kids Act helps ensure a patient-centered, pediatric-focused delivery system for this unique population of children to ensure ready access to care and reduce the burden on these children's families, specifically, coordination and integration of care among families and providers, which is critical for highly mobile military families who move frequently.

Furthermore, the ACE Kids Act has promise as a model for care coordination and integration, that could help to transform complex pediatric care in Tricare and the military health system (MHS). One of the key findings of a recent Defense Health Board report on pediatric care is the continued and longstanding need for better care coordination for families of children with special and complex care needs, especially as these families PCS (move) across the country.

The Tricare for Kids Coalition supports the ACE Kids Act both in order to meet the needs of military families whose children rely on Medicaid, and as a potential model for care coordination within Tricare and the military health system.

Providing children of military families with complex medical conditions enrolled in Medicaid the best possible care is a national challenge; the ACE Kids Act will bring us closer to ensuring these vulnerable children receive the care they need, as well as build a foundation that may be able to serve as a model for improved care coordination for mobile military families.

We thank you for championing the ACE Kids Act and look forward to working with you to advance this critical legislation this year.

Sincerely,

Kara Tollett Oakley Kara Tollett Oakley Chair 799 9th Street NW Suite 210 Washington, DC 20001 T (202) 354-2600 vizientinc.com

vizient

July 26, 2017

The Honorable Joe Barton 2107 Rayburn House Office Building Washington, D.C. 20515

The Honorable Kathy Castor 2052 Rayburn House Office Building Washington, D.C. 20515

Dear Representative Barton and Representative Castor:

I am writing on behalf of Vizient, Inc. to offer our support for the "The Advancing Care for Exceptional Kids Act of 2017" (H.R. 3325 – ACE Kids Act). We believe that protecting and strengthening care for our most vulnerable populations are essential steps in the pursuit of a better, more patient-centered health care delivery system. The ACE Kids Act represents meaningful, bipartisan work to improve the Medicaid program for children with medical complexity, and Vizient applauds the legislation.

Vizient is the nation's largest health care performance improvement company. We serve a diverse membership that includes academic medical centers, pediatric facilities, community hospitals, integrated healthcare delivery networks and non-acute health care providers. Our headquarters are in Irving, Texas, with locations in Chicago, Washington, D.C., and other cities across the country.

Our members have been on the front lines of delivery and clinical reforms, investing in and committed to efforts to fundamentally improve how care is delivered. These organizations provide critical health care services for their communities. Vizient strongly encourages legislation that protects and advances delivery system reforms that improve the quality of care, reduce expenses to Medicaid, and save patient lives. The ACE Kids Act would help achieve this triple-aim strategy by expanding access to patient-centered, pediatric-focused coordinated care for children with medical complexity.

Vizient believes that empowering Americans through health coverage is critical to success in care. The ACE Kids Act makes sure that kids can access the coordinated care they need – across multiple providers and services. It reduces the burden on their families and addresses existing challenges in Medicaid coverage. On behalf of our members, we applaud this bipartisan legislation that takes a common sense approach to improving care for children who need it most.

We thank you for your commitment to improving patient care for children with complex medical issues and their families and are pleased to offer our endorsement of the ACE Kids Act.

Please do not hesitate to contact me at shoshana.krilow@vizientinc.com or 202-354-2607 if you have any questions about Vizient or if there is any way we can be of assistance in supporting this legislation.

Sincerely,

Shoshana Krilow

Shodhamakulan

Vice President, Public Policy & Government Relations



425 | Street, NW • Suite 70 | Washington, DC 2000 | 202-220-3700 • Fax: 202-220-3759 www.medpac.gov

Francis J. Crosson, M.D., Chairman Jon B. Christianson, Ph.D., Vice Chairman James E. Mathews, Ph.D., Executive Director

September 4, 2018

The Honorable Greg Walden Chairman Committee on Energy and Commerce U.S. House of Representatives 2185 Rayburn House Office Building Washington, DC 20515

The Honorable Michael Burgess, M.D. Chairman, Subcommittee on Health Committee on Energy and Commerce U.S. House of Representatives 2336 Rayburn House Office Building Washington, DC 20515

The Honorable Frank Pallone, Jr. Ranking Member
Committee on Energy and Commerce
U.S. House of Representatives
237 Cannon House Office Building
Washington, DC 20515

The Honorable Gene Green Ranking Member, Subcommittee on Health Committee on Energy and Commerce U.S. House of Representatives 2470 Rayburn House Office Building Washington, DC 20515

RE: Drug pricing and rebate data

Dear Chairmen and Ranking Members:

The Medicare Payment Advisory Commission (MedPAC) is an independent, legislative branch agency established by the Balanced Budget Act of 1997 (P.L. 105-33) to provide expert policy and technical advice to the Congress on issues affecting the Medicare program. Medicare spending has grown substantially over the last decade, particularly for prescription drugs, placing an increasing financial burden on the taxpayers and beneficiaries who finance it. Congress plays a vital role in overseeing Medicare and solving these fiscal challenges so that the program remains secure for current and future beneficiaries. MedPAC serves as an important source of information and advice to the Congress as it exercises that oversight. To enable MedPAC to best advise the Congress on how to address the problems stemming from the high and rising costs of prescription drugs, I am writing to request a narrow change in law that would grant MedPAC staff access to important drug pricing and rebate data that other congressional agencies are already able to use. The change in statute is necessary because MedPAC is unable to access the data under existing statutory authority.

MedPAC uses a wide variety of data in order to support the Congress' oversight of Medicare, and the Commission has a strong track record of protecting different types of proprietary and confidential information. For example, MedPAC uses and keeps secure the bids that private insurance plans submit under Medicare Parts C and D, data that Medicare Advantage plans

Drug pricing and rebate data September 4, 2018 Page 2

submit on encounters between beneficiaries and their health care providers, and data on beneficiaries' use of prescription drugs.

To ensure that the Congress has comprehensive and up-to-date information, MedPAC strives to use all available data pertinent to our analyses. The Commission uses these data to provide information to the Congress on spending by Medicare and its beneficiaries and to help the Congress develop policies to improve the value of taxpayer dollars used to finance the program. MedPAC delivers this information in mandated reports, congressional testimony, and frequent briefings to congressional staff.

The large growth in drug spending has been a key contributor to the financial strain on Medicare and its beneficiaries. Today, Medicare spends more than \$100 billion annually on prescription drugs under Parts B and D, and beneficiaries are exposed to more than \$20 billion in cost sharing liability. For the last several years, cost sharing liability for drugs has grown at nearly 7 percent annually. Of particular concern is the growing number of beneficiaries who are exposed to very large cost sharing amounts when they take extremely high-priced drugs.

Despite broad data access under its authorizing statute, MedPAC is unable to access important drug pricing and rebate information under Medicare Parts B and D, and under Medicaid, because of how specific places of the Social Security Act are constructed (for example, MedPAC is not specifically named in Section 1927(b)(3)(D) of the Social Security Act as one of the entities with access to certain data detailing how much the Medicare program and its beneficiaries pay for prescription drugs). Because we lack these important data, we have been limited in the analysis and information we can provide to the Congress as it grapples with how to bring down the prices of drugs for beneficiaries and taxpayers. A statutory change giving us access to these data would enhance our capabilities for assisting the Congress on issues related to prescription drug costs.

With these data, MedPAC staff could:

- Assist Congress in understanding the true costs (net of rebates) of prescription drugs to beneficiaries and taxpayers under the Medicare program.
- Evaluate different policy options that aim to bring down the prices of drugs and the cost sharing that beneficiaries face for their medicines at the point of sale.
- o Provide insight into how Part D plans manage the growth in drug prices.
- Analyze the effects of market entry and competition on drug prices.

MedPAC looks forward to continuing to support the Congress in developing approaches to payment that ensure beneficiary access to important therapies, while reducing costs for the Medicare program and its beneficiaries. I very much appreciate your consideration of this request for this statutory change, and I also appreciate the support that the Congress has long given to the

Drug pricing and rebate data September 4, 2018 Page 3

Commission. Should you have any questions about this request, please contact James E. Mathews, MedPAC's Executive Director, at (202) 220-3700.

Sincerely,

Francis J. Crosson, M.D.

Transis J. Crosson M.D.

Chairman

cc:

The Honorable Kevin Brady Chairman Committee on Ways and Means U.S. House of Representatives 1011 Longworth House Office Building Washington, DC 20515

The Honorable Peter Roskam Chairman, Subcommittee on Health Committee on Ways and Means U.S. House of Representatives 2246 Rayburn House Office Building Washington, DC 20515 The Honorable Richard Neal Ranking Member Committee on Ways and Means U.S. House of Representatives 341 Cannon House Office Building Washington, DC 20515

The Honorable Sander Levin Ranking Member, Subcommittee on Health Committee on Ways and Means U.S. House of Representatives 1236 Longworth House Office Building Washington, DC 20515



Advising Congress on Medicaid and CHIP Policy

Commissioners

Penny Thompson, MPA, Chair
Stacey Lampkin, FSA, MAAA, MPA, Vice Chair
Melanie Bella, MBA
Brian Burwell
Martha Carter, DHSc, MBA, APRN, CNM
Frederick Cerise, MD, MPH
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Charles Milligan, JD, MPH
William Scanlon, PhD
Peter Sziłagyi, MD, MPH
Alan Weil, JD, MPP
Alan Weil, JD, MPP
Katherine Weno, DDS, JD

Anne L. Schwartz, PhD, Executive Director August 30, 2018

The Honorable Greg Walden Chair Energy and Commerce Committee U.S. House of Representatives 2125 Rayburn House Office Building Washington, DC 20515

The Honorable Frank Pallone Jr. Ranking Member Energy and Commerce Committee U.S. House of Representatives 2322A Rayburn House Office Building Washington, DC 20515

Dear Chairman Walden and Ranking Member Pallone:

It has come to our attention that legislation is currently under consideration to permit the Medicaid and CHIP Payment and Access Commission (MACPAC) to access certain data on Medicaid prescription drug rebates that are now statutorily only available to agencies of the U.S. Department of Health and Human Services, the Department of Veterans' Affairs, the U.S. Government Accountability Office, and the Congressional Budget Office. MACPAC would welcome the opportunity to use these data as we develop analyses and provide information to Congress on how to improve the operations of the Medicaid drug rebate program and address broader concerns about expenditures for and access to prescription drugs within the Medicaid program.

MACPAC began a focused inquiry on Medicaid prescription drug spending, pricing, and utilization in late 2016. At that time, MACPAC staff inquired about obtaining access to drug rebate data, noting our longstanding formal agreements with the Centers for Medicare & Medicaid Services (CMS) to use a variety of Medicaid and Medicare data sources. We were informed that the rebate data had specific statutory protections and thus could not be shared.

Since that time, we examined Medicaid drug policy using the limited data available to us. While we have been able to receive some specialized summaries of rebates amounts from CMS, access to actual rebate data (e.g., average manufacturer price and best price) for each drug would significantly enhance our ability to analyze the financial impact of various policy options. In particular, such data elements would be useful in considering policies targeted toward certain types or classes of drugs and their effects on certain manufacturers, drugs, or groups of beneficiaries.

Medicaid and CHIP Payment and Access Commission

1800 M Street NW Suite 650 South Washington, DC 20036 www.macpac.gov 202-350-2000 **** 202-273-2452 **@** For example, there is currently bipartisan interest in looking at ways to address large price increases that occur over time. One option would be to eliminate the cap of 100 percent of average manufacturer price on the Medicaid rebate, an idea included in the Administration's drug pricing blueprint. Another potential option would be to escalate the inflationary penalty so that large price increases over a short period of time would incur additional rebates beyond those currently collected. In examining these options, MACPAC could use the rebate data to identify how many drugs hit the cap and the amount of additional rebate dollars that would be collected if the cap were removed. We could also use the rebate data to estimate how many products had a price increase over a certain threshold (e.g., a 20 percent increase in the past year) and what the rebates are currently for these products. CMS has been able to provide us some summary-level information that gives us a sense of the magnitude of these two options. However, without information at the drug level, we cannot determine whether these policies would have a singular effect or be concentrated on a selected number of manufacturers, drug classes, or beneficiaries.

MACPAC appreciates the concerns of manufacturers about the sensitivity of raw drug rebate data and why the original legislation creating the rebate program included special protections for its use. MACPAC has been a responsible steward of multiple CMS data sources, however, and has a long track record of protecting sensitive information in its work. As an independent agency of the legislative branch, we look forward to having the opportunity to analyze the rebate data as part of our function of advising Congress and assure you that our data storage and analysis procedures would protect the integrity of this data

Thank you for your willingness to consider a statutory change to provide access to these data.

Sincerely,

Penny Thompson

Chair

Medicaid and CHIP Payment and Access Commission



3001 W. Dr. Martin Luther King Jr. Blvd. Tampa, Florida 33607 T. (813) 554-8500

September 5, 2018

The Honorable Greg Walden
Chairman
Committee on Energy and Commerce
U.S. House of Representatives
2125 Rayburn House Office Building
Washington, DC 20515

The Honorable Michael Burgess Chairman Health Subcommittee Committee on Energy and Commerce U.S. House of Representatives 2125 Rayburn House Office Building Washington, DC 20515 The Honorable Frank Pallone, Jr.
Ranking Member
Committee on Energy and Commerce
U.S. House of Representatives
2125 Rayburn House Office Building
Washington, DC 20515

The Honorable Gene Green Ranking Member Health Subcommittee Committee on Energy and Commerce U.S. House of Representatives 2125 Rayburn House Office Building Washington, DC 20515

Dear Chairman Walden, Ranking Member Pallone, Chairman Burgess and Ranking Member Green,

As the President of St. Joseph's Children's Hospital in Tampa, Florida, I am writing to express my strong support for the Advancing Care for Exceptional Kids Act of 2017, often referred to as the ACE Kids Act (H.R. 3325).

This legislation has the opportunity to make a significant, positive impact for millions of medically complex children and their families in the State of Florida and across our country, while also resulting in considerable savings for U.S. taxpayers. I am very pleased to have the opportunity to submit comments in support of its passage as the Health Subcommittee considers its merits.

The ACE Kids Act aims to improve how we deliver critical health care services to children who are among the most medically complex and vulnerable in our country. In doing so, it also has the potential to save the U.S. government billions of dollars over the course of 10 years. It is a win all around – improving care for our most complex children, enhancing the quality of life for these kids and their families, and ensuring more efficient, effective use of limited healthcare resources.

To do so, the legislation utilizes a 'health home' concept, facilitating coordination of care for medically complex children.

Our direct experience with the health home concept at St. Joseph's Children's Hospital of Tampa allows me the ability to share with you first-hand just how impactful this model is for our most complex children and the families who love them. Roughly 16 years ago, a visionary pediatric critical care doctor named Dr. Daniel Plasencia created the Chronic-Complex Clinic, which is located on the campus of St. Joseph's Children's Hospital of Tampa. The Clinic today serves as a health home to approximately 700 children with complicated medical problems and severe disabilities, while additionally providing support to the entire family.

Included among them is 5-year-old Lucia "Lucy" Ferlita, who is the only child living in the United States with a diagnosis of EMARDD, or early onset myopathy with areflexia, respiratory distress and dysphagia. Very little is known about this serious disease, which has left Lucy with low muscle tone and the need for a feeding tube to eat and a ventilator to breathe. Lucy requires nursing care 24 hours a day, seven days a week. The Chronic-Complex Clinic at St. Joseph's Children's Hospital of Tampa coordinates all aspects of her care. Lucy started kindergarten at her neighborhood elementary school just a few weeks ago in good health and good spirits.

Our Chronic-Complex Clinic at St. Joseph's Hospital of Tampa also serves as the medical home of Lakota Lockhart of Plant City, Florida. Now 9 years old, Lakota was born with congenital central hypoventilation syndrome, a central nervous system disorder which causes his breathing to stop every time he falls asleep. The condition is extremely rare, affecting less than 1,500 people throughout the world. Lakota spent the first 68 days of his life in the Neonatal Intensive Care Unit, where he underwent multiple surgeries to insert a feeding tube in his stomach and a breathing tube in his trachea. A team of pediatric specialists at the Chronic-Complex Clinic provides his care, including a pulmonologist, neurologist and gastroenterologist. Lakota is a frequent visitor at the Clinic, where his continued love for his favorite superhero, Batman, remains a primary topic of conversation with those rendering his care.

Finally, members may recall testimony delivered before this subcommittee in July 2016 by Tish West of Tampa, Florida, who is mother to Caroline West. Now 21 years old, Caroline has a rare neurological condition known as Alternating Hemiplegia of Childhood, which is only diagnosed in 800 people worldwide. As Caroline's mother described to this subcommittee, Caroline's condition impacts every aspect of her life. She has seizures, cannot eat by mouth, and is confined to a wheelchair. Caroline is developmentally delayed and has cerebral palsy. A team of nearly 30 different specialists is needed to care for Caroline to ensure her health and wellbeing.

Better than any words I am able to write, Tish's own description to the Health Subcommittee two years ago is able to best convey the life-changing impact of the health home concept offered by the ACE Kids Act: "'We are 'normal' at our Clinic. We are not an outlier. Since coming to the Clinic, Caroline's health has improved and her hospitalizations have reduced tremendously. Our family feels welcome and embraced at the Clinic. All of the nurses and staff know Caroline and our family...our entire family has benefited from this Clinic."

In addition to my role as hospital president, I am also a caregiver – serving for many years as a pediatric and flight transport nurse. I feel passionately about doing all that we can to provide the best possible care for children and their families.

The ACE Kids Act offers a mechanism by which we as a community of health care stakeholders might vastly improve the quality of life for our country's medically complex children and those who love them. I strongly support this legislation and urge the Health Subcommittee to support its passage.

Thank you for your time, consideration and work to improve the health and wellbeing of our children.

Sincerely,

Kate Reed, RN President, St. Joseph's Children's Hospital Tampa, Florida

Enclosures

CC: Members of Energy and Commerce Committee

Lucia Ferlita

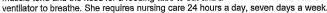
Age: 5

Hometown: Tampa, FL

Hospital: St. Joseph's Children's Hospital

Lucia, aka Lucy, is a bright and social 5-year-old girl who has a natural love for learning and enjoys puzzles, her iPad and being with her mom, dad and little brother. She looks forward to going to her neighborhood elementary school five days a week with her private-duty nurse, where she will attend kindergarten next year.

Lucy is also the only person living in the United States with a diagnosis of EMARDD, or early onset myopathy with areflexia, respiratory distress and dysphagia. Very little is known about this serious disease that has left her with low muscle tone and the need for a feeding tube to eat and a



Lucy appeared healthy at birth but began showing signs of distress when, at 8 weeks old, she stopped eating. Before she was even 6 months old, Lucy had undergone four surgeries to place a feeding tube, get a stomach wrap (Fundo Plication), conduct a muscle biopsy and insert a tracheotomy.

The family searched for medical answers, struggled for resources to cover medical bills, and lived every day just hoping to keep their daughter alive. They truly knew what was at stake; Lucy's older brother, Vincent, was just 6 months old when he died from what doctors

now know was the same disease.

Fortunately, Lucy has found a medical home in the Chronic-Complex Clinic at St. Joseph's Children's Hospital. As a nationally recognized medical home for children with multiple life-threatening conditions, the Clinic coordinates all aspects of Lucy's highly specialized care. Her mom, Lisa, credits the center for keeping her young daughter in good health and out of the emergency room.

"The team at St. Joseph's Children's Hospital knows Lucy and her very particular, special needs," said Lisa. "Everything about Lucy's medical condition is complicated. Getting out of the house to go anywhere requires a tremendous amount of equipment and brings some risk to her delicate condition. But the progress Lucy has made since we found the Clinic is remarkable. I cannot imagine managing her care without it."

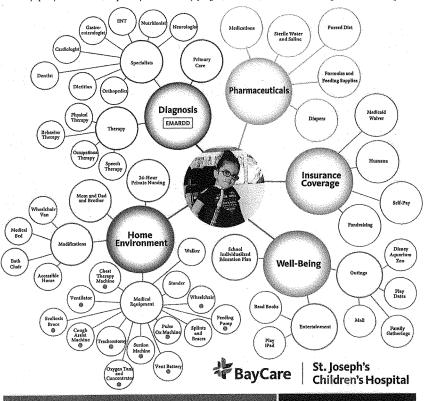




Lucia's Story

A care map by Lucia's parents illustrates the complexity of integrating her health care needs into everyday life.

Lucia's parents mapped out a care web to illustrate the many moving pieces and challenges they face in integrating coordination of her health care into everyday life. Lucia is the only person in the U.S. diagnosed with early onset myopathy with areflexia, respiratory distress and dysphagia (EMARDD). • Red dot = must go wherever Lucia goes



Lakota Lockhart

Age: 9

Hometown: Plant City, FL

Hospital: St. Joseph's Children's Hospital

Lakota is an imaginative and energetic 9-yearold boy who loves to tell stories about his favorite superhero, Batman.

He was born with congenital central hypoventilation syndrome, a central nervous system disorder which causes his breathing to stop every time he falls asleep. The condition is extremely rare, affecting less than 1,500 people throughout the world.



Lakota spent the first 68 days of his life in St. Joseph's Children's Hospital's Neonatal Intensive Care Unit, where he underwent multiple surgeries to insert a feeding tube in his stomach and a breathing tube in his trachea.

He then transitioned to the hospital's Chronic-Complex Clinic, where he receives care from a team of pediatric specialists including a pulmonologist, neurologist and cardiologist. The Clinic serves as a medical home for patients like Lakota, and has been recognized nationally for its innovative work with medically complex children.

"St. Joseph's Children's Hospital has been instrumental in my son's survival," said Lakota's mother, Krystal Lockhart. "From the moment we received the devastating diagnosis six years ago, to the life-saving care Lakota continues to receive today, the hospital's team of specialized caregivers have been there for us every step of the way.



Lakota is typically covered by Medicaid and participates in Florida's Children's Medical Services Program, but is currently covered by commercial insurance. With a lifetime of specialized care and medical equipment in his future, this coverage is a critical lifeline to his family.

St. Joseph's Children's Hospital
BayCare Health System

Lakota's Story

A care map by Lakota Lockhart's parents illustrates the complexity of integrating his health care needs into everyday life.

Lakota's family mapped out a care web to illustrate the many moving pieces and challenges they face in integrating coordination of his health care into everyday life.

• Red dot = must go wherever Lakota goes



Caroline West

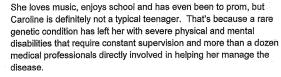


Name: Caroline West

Age: 21

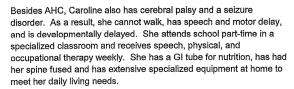
Hometown: Tampa, FL

Hospital: St. Joseph's Children's Hospital





Caroline was born five weeks early, then suffered a seizure and stopped breathing in the first 12 hours of her life. The doctors did not diagnose her for several years because she has an extremely rare neurological disorder, Alternating Hemiplegia of Childhood (AHC), which is only diagnosed in 800 people worldwide. Prior to her diagnosis, Caroline was tested and evaluated extensively at Johns Hopkins, Columbia Presbyterian and Boston Children's Hospitals.





Caroline's medical home is the Chronic-Complex Clinic at St. Joseph's Children's Hospital. The clinic coordinates Caroline's health care needs, which include daily nursing care, physical, speech and occupational therapy, medical supplies, durable medical equipment, medical care and communication between all of her specialists.

See Caroline's story and learn more about the clinic at https://www.youtube.com/watch?v=nsVxl.115]Tk.

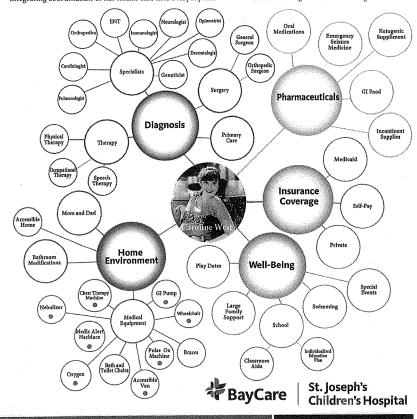


Caroline's Story

A care map by Caroline's parents illustrates the complexity of integrating her health care needs into everyday life.

Caroline's family mapped out a care web to illustrate the many moving pieces and challenges they face in integrating coordination of her health care into everyday life.

• Red dot = must go wherever Caroline goes



Jaden Vidal Velasquez

Age: 10

Hometown: Tampa, FL

Hospital: St. Joseph's Children's Hospital, Tampa, FL

Jaden is a sweet, loving and happy 10-year old who loves swimming, Tae Kwon Do, soccer and going to school. Born with hypoplastic left heart syndrome, a congenital heart defect in which the left side of the heart is severely underdeveloped. At just 4 days old, Jaden underwent open-heart surgery. Since then, he has undergone two additional open-heart surgeries, several catheterizations, the insertion of a gastric feeding tube, and months of physical rehabilitation.



St. Joseph's Children's Hospital has been instrumental in Jaden's diagnosis, treatment and continuous care. His family is extremely grateful to receive all of his specialized care in one facility, and by compassionate caregivers specifically trained to treat Jaden's complex condition.



The Chronic-Complex Clinic at St. Joseph's Children's Hospital is Jaden's medical home. As a nationally recognized medical home for children with multiple lifethreatening conditions, the clinic coordinates all of Jaden's pediatric specialists and care providers.

If it weren't for the scars on his chest, you might never know Jaden was born with a heart defect. "Yes, he was born with half a heart, but it's a strong half a heart and it belongs to an amazing and perfect child," says Jaden's mother, Belkis.

For the first three years of Jaden's life, Medicaid covered nearly all of Jaden's care, including his heart surgeries, hospitalizations, visits to his pediatric specialists, and medical equipment.

Today, Jaden is a national ambassador for Speak Now for Kids, a patient advocacy organization. His family believes this honor gives them the opportunity to speak out on behalf of other children with complex needs as well as the importance of obtaining affordable, comprehensive health care coverage. Jaden and his family understand this all too

Jaden is now covered by the Children's Health Insurance Program (CHIP). With a potential heart surgery in the future and a lifetime of medications, this coverage is a critical lifetime to Jaden's family. To learn more about the Chronic-Complex Clinic please visit: www.sibhealth.org/Chronic-Complex-Clinic.

₹ St. Joseph's Children's Hospital



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EXECUTIVE DIRECTOR
Chris Toth

1850 M Street, NW Twelfth Floor Washington, DC 20036 Phone: (202) 326-6000 http://www.naag.org/ March 28, 2018

Honorable Tim Walberg 2436 Rayburn House Office Building Washington, D.C. 20515

Honorable Peter Welch 2303 Rayburn House Office Building Washington, D.C. 20515

Dear Representatives Walberg and Welch:

As the Attorneys General of our respective states, we write in support of your legislation, H.R. 3891, that would expand the authority of Medicaid Fraud Control Units (MFCUs) to detect, investigate and prosecute Medicaid patient abuse in non-institutional settings.

On May 10, 2017, thirty-eight attorneys general wrote to then-Secretary Tom Price at the U.S. Department of Health and Human Services urging expanded authority for MFCUs to address patient abuse and neglect ("the NAAG letter"). Specifically, the NAAG letter requested HHS alter its regulations implementing the pertinent statutory provisions to broaden the permissible authority for MFCUs, and the associated use of federal financial participation (FFP), in two regards. First, it recommended "allowing the use of federally funded MFCU assets to investigate and prosecute abuse and neglect of Medicaid beneficiaries in non-institutional settings." Second, it recommended "improving detection of abuse and neglect of Medicaid beneficiaries by broadening the permissible use of federal MFCU funds to screen complaints or reports alleging potential abuse or neglect."

On August 7, 2017, HHS Inspector General Daniel R. Levinson responded to the NAAG letter stating "OIG believes that the law should be changed to expand MFCUs' use of FFP to include the detection, investigation, and prosecution of abuse and neglect of Medicaid beneficiaries in non-institutional settings." However, HHS concluded that such a change requires statutory amendment and could not be accomplished solely by regulation.

On September 28, 2017, you introduced H.R. 3891. We are informed that, in the drafting of your legislation, you were mindful of the NAAG letter and that you intended to implement the letter's recommendations. We have reviewed H.R. 3891 and understand that, if adopted, it would enable HHS-OIG to implement all changes requested in the NAAG letter. Your legislation permits, but does not require, each MFCU to exercise the expanded authority the bill proposes, just as current law does with board and care facilities. It is our understanding that States electing to operate under the expanded authority of H.R. 3891 would be able to use their MFCUs to detect, investigate and

prosecute cases of abuse or neglect of Medicaid patients in whatever setting abuse or neglect may occur and to do so without losing federal financial participation. ¹

This change is vitally important because it eliminates the blinders current law places on MFCUs' ability to detect, investigate and prosecute cases of abuse or neglect of Medicaid patients. Since the current statute was enacted decades ago, substantial growth has occurred in home and community-based services, office-based services, transportation services, and other settings that are neither "health care facilities" nor "board and care facilities" but where services are provided and thus patient abuse or neglect may occur. H.R. 3891 proposes a common-sense change that will better protect an often-vulnerable population and will maximize the benefits and efficient use of MFCU assets.

We also note that your bill is particularly timely and important in light of the national opioid epidemic. Consider, for example, a situation in which a Medicaid beneficiary in a home or community-based setting is provided prescription opioid painkillers in an unlawful manner, resulting in death or great bodily harm to the patient. Under current law, although the patient harm caused by distribution of those opioids may have been criminal, our MFCUs would be hampered or prevented from investigating or prosecuting the case of patient abuse because it occurred in a setting other than a health care facility or a board and care facility. Under H.R. 3891, however, MFCUs could exercise clear authority to pursue that sort of investigation and, if appropriate, prosecute that patient abuse, thus bringing more criminal and civil investigation and prosecution assets to bear in the fight against the opioid epidemic.

Thank you for your leadership in proposing H.R. 3891. We hope it can become law soon so our states may have the option to use the important new tools it would make available in the fight

¹ The NAAG letter requested expanded authority for MFCUs to "detect, investigate and prosecute" a wider range of abuse and neglect cases, and Mr. Levinson's response confirms that OIG favors "use of FFP to include the detection, investigation, and prosecution" of such cases. By "detect," the NAAG letter specifically sought broader authority for MFCUs to use FFP to "screen" complaints or reports alleging potential abuse or neglect." Current HHS regulations constrain states' ability to use MFCU assets to review complaints in order to detect which may allege patient abuse or neglect that would warrant investigation or prosecution using MFCU assets. See, e.g., 42 C.F.R. Sec. 1007.19(d)(1)(limiting FFP to "review of complaints of alleged abuse or neglect of patients in health care facilities")(emphasis added); see also 42 C.F.R. Sec. 1007.11(b)(1)(restricting authority of MFCU to "review[ing] complaints alleging abuse or neglect of patients in health care facilities" and to "review[ing] complaints of the misappropriation of patient's private funds in such facilities.")(emphasis added). For states that would choose to exercise the expanded authority in H.R. 3891, we read the bill to require elimination of these and similar regulatory barriers that restrict MFCUs authority to review complaints. Obviously, a review will necessarily precede a determination whether a complaint or report alleges Medicaid patient abuse or neglect that would fall within H.R. 3891's expanded authority to investigate or prosecute, and it would make no sense to arbitrarily limit review to complaints from patients in health care facilities if the authority to investigate and prosecute abuse and neglect is expanded to other settings.

against the abuse and neglect of all Medicaid patients -- wherever that may occur. If we may be of assistance in advancing this legislation, please let us know.

Sincerely, enk Schmilt Derek Schmidt George Jepsen Kansas Attorney General Connecticut Attorney General Mike Hunter Oklahoma Attorney General Vermont Attorney General Sleven < Steve Marshall a Lindemuth Alaska Attorney General Alabama Attorney General Mark Brnovich Leslie Rutledge Arkansas Attorney General Arizona Attorney General Cynthia H. Coffman Xavier Becerla California Attorney General Colorado Attorney General Matthew P. Denn District of Columbia Attorney General Delaware Attorney General Cuplus Christopher M. Carr Florida Attorney General Georgia Attorney General Russell A. Sugali

Russel A. Suzuki

Hawaii Acting Attorney General

Lawrence Wasden

Idaho Attorney General

Lisa Madigan
Illinois Attorney General

Jon Millar

Tom Miller Iowa Attorney General

Jeff Landry
Louisiana Attorney General

Maura Healey
Massachusetts Attorney General

Lai Suasan

Lori Swanson Minnesota Attorney General

och Hawley Missouri Attorney General

proposition a

Doug Peterson Nebraska Attorney General

Gordon MacDonald New Hampshire Attorney General

Hector Balderas New Mexico Attorney General Curtis T. Hill Jr. Indiana Attorney General

Andy Beshear

Kentucky Attorney General

Brian Frosh Maryland Attorney General

Bill Schuette Michigan Attorney General

Jim that

Jim Hood Mississippi Attorney General

Tim Fox Montana Attorney Genera

Adam Pad Laxalt Nevada Attorney General

Gurbir S. Grewal New Jersey Attorney General

Eric T. Schneiderman New York Attorney General John Sti

Josh Stein

North Carolina Attorney General

Ellen F. Rosenblum Oregon Attorney General

Peter F. Kilmertin

Peter F. Kilmartin Rhode Island Attorney General

Marty J. Jackley South Dakota Attorney General

Sean Reyes Utah Attorney General

Wave R. L

Mark R. Herring Virginia Attorney General

Patrick Morrisey West Virginia Attorney General

Peter K. Michael Wyoming Attorney General Mike DeWine
Ohio Attorney General

Josh Shapiro

Pennsylvania Attorney General

Culan

South Carolina Attorney General

Herburt Slaty 2

Herbert H. Slatery III Tennessee Attorney General

Claude En Warnen

Claude Earl Walker Virgin Islands Attorney General

Robert W. Ferguson Washington Attorney General

Brad Schimel

Wisconsin Attorney General



May 8, 2018

The Honorable Tim Walberg U.S. House of Representatives Washington, DC 20515

The Honorable Peter Welch U.S. House of Representatives Washington, DC 20515

Dear Representatives Walberg and Welch:

On behalf of Families USA, one of the nation's leading health care consumer organizations dedicated to improving the health and health care of all in the nation, I am writing to share our support for your bipartisan legislation, H.R. 3891, which would strengthen the Medicaid program by empowering state Medicaid Fraud Control Units (MFCUs) to better investigate and prosecute Medicaid provider abuse and fraud.

Medicaid is an essential part of America's safety net and is relied upon by tens of millions of working families, children, seniors, and people with disabilities. Medicaid helps kids get a healthy start in life, provides long-term and home care to seniors and people with disabilities, and provides health care to pregnant women and working families.

State Medicaid Fraud Control Units (MFCUs) currently operate in 49 States and the District of Columbia and investigate and prosecute Medicaid provider fraud as well as patient abuse or neglect. H.R. 3891 clarifies the authority of MFCUs to investigate and prosecute cases of Medicaid patient abuse and neglect in non-institutional settings. This commonsense legislation would codify recommendations sent to HHS in a 2017 letter from 38 attorneys general to improve the function of MFCUs.¹

Your bill is an important opportunity for members of Congress to signal their support for bipartisan policies to strengthen Medicaid and protect consumers.

Thank you for your leadership on this issue.

Sincerely.

Frederick Isasi Executive Director

¹ http://www.naag.org/assets/redesign/files/sign-on-letter/Medicaid%20Expanded%20Duties%20final%20NAAG%20sign%20on.pdf



April 13, 2018

The Honorable Tim Walberg United States House of Representatives Washington, D.C. 20515 The Honorable Peter Welch United States House of Representatives Washington, D.C. 20515

Dear Representatives Walberg and Welch:

The Partnership for Medicaid Home-Based Care (PMHC) would like to take this opportunity to express its support for H.R. 3891 and to thank you for your leadership in strengthening the integrity of the Medicaid program.

PMHC was established to advance the delivery of high-quality, cost-effective, and fully-compliant Medicaid home-based care and services. Our members bring to this important quest their experience as home care providers, associations, managed care organizations, and technology providers. While such a diverse membership is somewhat unique, our members came together due to a shared commitment to support legislative and regulatory efforts that improve the quality, accessibility, and integrity of home-based care and services in Medicaid.

PMHC is pleased to endorse this measure, which we believe will strengthen the Medicaid program's ability to protect those served by the program from fraudulent activity. We are particularly grateful for this legislation's focus on streamlining the regulatory process so that Medicaid Fraud Control Units (MFCUs) can better identify, investigate, and prosecute instances of fraud, patient abuse, or neglect.

By cracking down on Medicaid fraud, abuse, and neglect, MFCUs play a vital role in securing the integrity, efficiency, and effectiveness of the Medicaid program. However, MFCUs are restricted under current policy in their efforts to investigate patient abuse and neglect complaints. H.R. 3891 resolves this problem by empowering MFCUs to undertake this activity across all settings and with greater flexibility.

While H.R. 3891 represents an important step forward, we would like to take this opportunity to request consideration of additional measures PMHC has proposed. Specifically, we believe the following reforms could supplement your important efforts to strengthen the integrity of the Medicaid program and foster a universal culture of accountability among Medicaid providers:

- Standardized rules, to ensure hours billed are authorized, match the care/service plan, account for hospitalization days, and prevent banking of hours.
- Establishing conditions specific to eligibility for Medicaid reimbursement for Personal Care Services (PCS) that at a minimum include:
 - Filing an Employer Identification Number (EIN) for all employees of a home care agency;
 - Filing an EIN or a unique identifier provided by the State Medicaid agency by each self-directed provider;

300 New Jersey Avenue, NW * Suite 900 * Washington, DC 20001 Phone: 202.742.5274 * Fax 202-315-3490 * www.medicaidpartners.org

Partnership for Medicaid Home-Based Care April 13, 2018 Page 2 of 2

- Requiring all claims for personal care services include the specific date on which each service is performed and the identity of the home care agency or self-directed care provider rendering each service;
- Prior to award of a new provider number, demonstrate access to capital sufficient to operate for at least six months, exclusive of actual or projected accounts receivable from Medicaid or other sources (exempting self-directed care and agencies or providers in frontier or underserved areas.); and
- On site review within the first year of operation and triennially thereafter to review adherence with minimum business practices; ensure qualifications of staff per state regulation as well as supervision of same staff per waiver requirements; consumer assessment per waiver requirements and any state minimums; and provision of services per plan and respect of consumer rights.
- Guidance to States regarding adequate prepayment controls, including:
 - Claims edits to prevent inappropriate PCS payments during periods when consumers are receiving institutional care;
 - Electronic Visit Verification (EVV)-enabled claims verification;
 - Crosswalk of Medicare and Medicaid data to identify potential instances of fraud, waste, and abuse; and full, timely, and free access to data sources such as Medicare Coordination of Benefits Agreement (COBA); and,
 - Establish minimum federal requirements and guidance for PCS care/service plans, claims documentation, consumer assessments, and attendant supervision appropriate to the scope of the site's authorized services.

We believe H.R. 3891 and reforms such as those proposed by PMHC can greatly strengthen the integrity of the Medicaid program and protect the individuals who depend on it from fraud, abuse, and neglect. In light of the paramount importance of these objectives, we believe such action should be taken as soon as is possible.

For these reasons, PMHC is proud to endorse H.R. 3891 and would be honored to serve as a resource to you in any way that would support your vitally important work.

Sincerely,

David J. Totaro Chairman

David Jo How

cc: The Honorable Greg Walden The Honorable Frank Pallone



AREA AGENCIES ON AGING ASSOCIATION OF MICHIGAN 6105 W. ST. JOSEPH, SUITE 204, LANSING, MICHIGAN 48917

U.S. Representative Debbie Dingell 116 Cannon House Office Building Washington, D.C. 20515

Dear Congresswoman Dingell,

The Area Agency on Aging Association of Michigan (4AM) represents the 16 Area Agencies on Aging serving every jurisdiction in the state of Michigan. Area Agencies on Aging are experts in providing long term support services across Michigan with more than 40 years of experience. We are writing on behalf of our membership to thank you for your sponsorship of H.R. 5306 reauthorizing the EMPOWER Care Act.

As you know, this Money Follows the Person (MFP) program provides an effective and efficient mechanism to help seniors and persons with disabilities to move back to the community they call home from a nursing home setting. This program not only improves the quality of life reported by seniors and persons which disabilities who have returned to the community, but the Home and Community Based Services also provide significant savings over the cost of an institutional setting – Nearly \$1,840 per month less than the cost of an institution according to the Center for Medicare and Medicaid Services.

The reauthorization of the EMPOWER Care Act seeks not only to maintain this quality of life enhancing and fiscally prudent service through FY 2022, but it also seeks to create key improvements. Such improvements include:

- Reducing the number of days someone must be in a nursing home before becoming eligible for the program from 90 to 60;
- Enhances reporting and accountability requirements of the MFP funding;
- Requiring Health and Human Services to conduct a review and share the most effective state strategies for transitioning beneficiaries from an institution to a qualified community setting.

Again, we thank you for your sponsorship of H.R. 5306, the Reauthorization of the EMPOWER Care Act. Please do not hesitate to contact me should you want more information on this key program.

Sincerely,

Ryan Cowmeadow, Executive Director

(517) 886-1029, fax (517) 886-1305, www.mi-seniors.net



NASDDDS



May 1, 2018

Hon. Greg Walden Chairman House Committee on Energy & Commerce

Hon. Michael Burgess Chairman Subcommittee on Health Hon. Frank Pallone, Jr. Ranking Member House Committee on Energy & Commerce

Hon. Gene Green Ranking Member Subcommittee on Health

Dear Representatives Walden, Pallone, Burgess, and Green:

On behalf of the National Association of Medicaid Directors, the National Association of State Directors of Developmental Disabilities Services, and the National Association of States United for Aging and Disabilities, we are writing to you in support of efforts to reauthorize and extend the Money Follows the Person Demonstration Program (MFP). Collectively, our organizations represent the full array of state agencies responsible for delivering long-term services and supports to older adults and individuals with disabilities.

We strongly support the reauthorization and extension of MFP for the following key reasons:

- MFP has enabled categorically high need, high cost older adults and people with disabilities to transition from costly institutional settings to the community, which enables choice, selfdirection, and integration in civic life;
- MFP has been a leading means of shifting the proportion of Medicaid long-term services and supports (LTSS) spending from expensive nursing homes and chronic disease hospitals to less costly home and community-based waivers, resulting in billions of dollars of savings;
- MFP has represented the leading edge of Medicaid's efforts to address social determinants of health, including housing access and stability;
- MFP's success in systems transformation has been documented longitudinally through years of rigorous data collection and analysis through third-party evaluators; and
- States that are participating in MFP are currently exhausting their allotted funding, and will not
 have the means of ensuring that all those who seek transition will be served.

MFP provides states with flexible funding that allows programs to establish innovative and person-centered approaches to transition individuals from institutional to community-based settings. Although significant progress and success has been made regarding rebalancing to HCBS, almost 60 percent of all Medicaid expenditures for long-term services and supports (LTSS) delivered to older adults and people with physical disabilities are for institutional care. We recognize that there is much more progress to be made for these vulnerable consumers; however, we would like to stress that MFP has provided essential supports that have led to overall improvement on this issue. For example, the recently-

 $^{^{1}\,}https://www.medicaid.gov/medicaid/ltss/downloads/reports-and-evaluations/ltssexpendituresffy 2015 final.pdf$

released MFP evaluation found that 71 percent of the individuals transitioned through the program were older adults or people with physical disabilities. The evaluation also indicated that the aggregate number of transitions is growing. This is likely due to examination of and strategies to address barriers to community living that have been a hallmark of MFP's research orientation. Increasing incidence of transitions is also demonstrably related to partnerships with community-based organizations that facilitate community living. For example, state MFP grantees have reported that partnerships with housing entities are essential due to the lack of affordable, accessible living arrangements for many LTSS participants across the country. 3

The national evaluation also found that MFP deinstitutionalization efforts result in significant cost savings. According to the report, average annual per person spending during the first year following transition declined by over \$20,000 for older adults and people with disabilities, and by over \$48,000 for individuals with intellectual/developmental disabilities.. All told, this resulted in over \$1 billion in savings during the first year of transitions for these individuals alone. The evaluation also estimated that, within 17 states evaluated, roughly one quarter of older adults and one half of individuals with ID/DD would not have transitioned without support from MFP. This substantiates that MFP results in hundreds of millions of dollars in savings during the first year after participants' transitions, and substantial additional savings during subsequent years.

Our experience working with a wide range of LTSS demonstrates that there will continue to be barriers that result in Medicaid-funded individuals living in institutional settings. In many cases, these barriers are beyond the Medicaid program's control. A leading example is that it remains typical for individuals who enter a facility for a Medicare post-acute rehabilitative stay, as well as people who privately pay for nursing home care until they have spent down to Medicaid eligibility, to remain in the nursing home without meaningful consideration of their interest and capacity to move back to the community. Oftentimes, these individuals have lost access to housing and community-based support systems by the time they become Medicaid participants. MFP provides important funding and programmatic flexibility that enables states to move these individuals back into the community. This results in increased participant satisfaction and quality of life with lower overall program expenditures. For example, Connecticut, like all MFP states, administers a quality of life survey to individuals who are able to leave a nursing home and move to a community setting. Across the board, compared to their experiences while living in a nursing home, individuals report higher levels of satisfaction, engagement with their communities and better health status.⁵

We appreciate the bipartisan efforts that have been made to reauthorize MFP, and strongly encourage Congress to quickly pass a bill that continues this crucial program. While we recognize that current legislation proposes a five-year reauthorization, we believe that other timeframes would be appropriate depending upon considerations such as legislative timing, budgetary offsets required for passage, and related policy issues.

² https://www.medicaid.gov/medicaid/ltss/downloads/money-follows-the-person/mfp-rtc.pdf

³ https://www.medicaid.gov/medicaid/ltss/downloads/money-follows-the-person/mfp-2015-annual-report.pdf

⁴ Ibid

⁵ https://health.uconn.edu/aging/wp-content/uploads/sites/6/2017/02/2016 Q4-QOL-Dashboard.pdf

MFP authorization expired over a year ago, and states have been operating through no-cost extensions. Eight states have already run out of MFP grant funds, and the remaining participants will use up their funds by the end of 2018. As a result, these states already are currently scaling back their programs and reducing dedicated staff and resources. We believe Congress should reauthorize and extend this program as soon as possible so that no individuals who could be helped by MFP are instead forced to remain in an institution.

Sincerely,

Mary Lee Fay Executive Director

National Association of State Directors of Developmental Disabilities Services

Martha A. Roherty

Executive Director

National Association of States United for Aging and Disabilities

Martha & Roberty

Mattle Silo

Matt Salo Executive Director

National Association of Medicaid Directors

December 19, 2017

The Honorable Orrin Hatch Chairman Committee on Finance United States Senate

The Honorable Rob Portman Senator Committee on Finance United States Senate The Honorable Ron Wyden Ranking Member Committee on Finance United States Senate

The Honorable Maria Cantwell Senator Committee on Finance United States Senate

Dear Chairman Hatch, Ranking Member Wyden, Senator Portman, and Senator Cantwell:

The undersigned organizations strongly support extension of the Money Follows the Person. We applaud recent introduction of bipartisan legislation (S. 2227) by Senators Portman and Cantwell to do so and urge swift passage.

The Money Follows the Person (MFP) Demonstration – first authorized in the Deficit Reduction Act of 2005 with strong bipartisan support and signed into law by President Bush – was designed to assist states with:

- 1) Supporting Medicaid enrollees who want to transition from nursing facilities and other institutional setting back to community-based settings; and
- 2) Developing infrastructure to promote and enhance access to HCBS.

Impact of Money Follows the Person

Since its inception, 47 states have participated and over 75,000 individuals have been transitioned back to the community. According to independent evaluations by Mathematica:

- Participants report significant and lasting improvements in quality of life and community integration after returning to the community.
- Findings suggest that after individuals return to the community, their overall Medicare and Medicaid expenditures decrease by roughly 23%.

States have made significant progress on "balancing" their long-term services and supports system to enhance access for HCBS, due in part to MFP. In FY05, states only spent approximately 37% of their LTSS expenditures on HCBS. According to the most recent data, states now spend over 53% on HCBS.

Need For Extension

While states have made great progress, more work is needed. Significant variations remain across states and different populations who need HCBS. For example, HCBS accounted for 75% of spending in programs targeting people with developmental disabilities, compared to only 41% of expenditures for programs targeting older people,

people with physical disabilities, and people with serious mental illness. Over 50,000 nursing home residents said they wanted to talk with someone about leaving their facility, but never received a referral to a local agency that could help them, according to recent analyses of Nursing Home Minimum Data Set reporting. States have learned lessons and can share promising practices with other states.

Unfortunately, the program expired on September 30, 2016. While states can continue to use remaining grant funding through 2020, they are currently scaling back their programs and reducing dedicated staff and resources. The most recent national evaluation indicates that last year was the first year that number of new transitions through the program declined. We are beginning to lose the momentum and progress we have made.

We commend you and your staff for the bipartisan process to develop this legislation, which will extend the program through 2022, remove barriers for individuals and states, enhance accountability, and contribute to sharing of best practices across states. This will assist states with achieving cost-efficiencies in their Medicaid programs while simultaneously enhancing opportunities for individuals to live independently and age with dignity in their homes and communities.

We applaud you for your leadership and look forward to working with you on passage.

Sincerely,

National Organizations:

AARP

ADAPT

Alliance for Citizen Directed Supports

Alliance for Retired Americans

Allies for Independence

Alzheimer's Association

Alzheimer's Impact Movement

America's Health Insurance Plans (AHIP)

American Association of People with Disabilities

American Association on Health and Disability

American Civil Liberties Union

American Network of Community Options and Resources (ANCOR)

The Arc of the United States

Association of Programs for Rural Independent Living

Association of University Centers on Disabilities (AUCD)

Autism Society of America

Autism Speaks

Autistic Self Advocacy Network

Bazelon Center for Mental Health Law

Caring Across Generations

Centene Corporation

Center for Public Representation

Community Catalyst

Consumer Direct Care Network

Disability Rights Education and Defense Fund (DREDF)

Easterseals

ElevatingHOME

The Jewish Federations of North America

Justice in Aging

Lakeshore Foundation

LeadingAge

Lutheran Services in America Disability Network

Medicaid Health Plans of America (MHPA)

National Academy of Elder Law Attorneys

National Association for Home Care and Hospice

National Association of Area Agencies on Aging

National Association of Councils on Developmental Disabilities

National Association of Social Workers (NASW)

National Association of State Directors of Developmental Disabilities Services

National Association of State Head Injury Administrators

National Association of State Long-Term Care Ombudsman Programs (NASOP)

National Center for American Indians with Disabilities

National Committee to Preserve Social Security and Medicare

National Consumer Voice for Quality Long-Term Care

National Council on Aging

National Council on Independent Living

National Disability Rights Network

National Down Syndrome Congress

National Health Law Program

National MLTSS Health Plan Association

National Multiple Sclerosis Society

National Organization of Nurses with Disabilities (NOND)

National Rehabilitation Association

National Respite Coalition

Not Dead Yet

Nursing Home Victims Coalition, Inc.

Paralyzed Veterans of America

Partnership for Medicaid Home-Based Care

PolicyWorks, Inc.

ResCare Home Care

Self-Development of People of the United Presbyterian Church

Special Needs Alliance

Special Needs Resource Project

TASH, Inc.

United States Brain Injury Alliance

State and Regional Organizations

Ability360 (Arizona)

Access 2 Independence (Georgia)

Access Alaska, Inc.

Access Center for Independent Living (Illinois)

Access to Independence of Cortland County, Inc. (New York)

Accessible Resources for Independence (Maryland)

The Arc Michigan

The Arc New York

The Arc of Alabama

The Arc of Arizona

The Arc of Illinois

The Arc of Pennsylvania

The Arc of South Carolina

The Arc of Texas

The Arc of the District of Columbia, Inc.

The Arc Tennessee

ADAPT Delaware

ADAPT Montana

ADAPT of Texas

The Adaptables, Inc. Center for Independent Living (North Carolina)

Advocates for Inclusion (Idaho)

Aging and Community Services of South Central Indiana

Aging Life Care Association (Arizona)

AIM Independent Living Center (New York)

Arkansas SILC

Appalachian Center for Independent Living (West Virginia)

Appalachian Independence Center, Inc. (Virginia)

ARISE Independent Living Center (New York)

Brain Injury Alliance of Iowa

Brain Injury Association of Georgia

Bronx Independent living Services (New York)

California Foundation for Independent Living Centers

California Office of the State Long-Term Care Ombudsman

Cape Organization for Rights of the Disabled (CORD) (Massachusetts)

Caring Associates, Inc. (Florida)

Catskill Center for Independence (New York)

Center for Disabilities and Development, University of Iowa

Center for Disability Rights (New York)

Center for Independence of the Disabled, NY (New York)

Center for Living & Working, Inc. (Massachusetts)

Central Wisconsin ADAPT

CIL Western Wisconsin, Inc.

Coalition of Texans with Disabilities

Community Resources for Independent Living, Inc. (CRIL) (California)

Connecticut Office of the Long-Term Care Ombudsman

DC Metro ADAPT

Delaware Office of the State Long-Term Care Ombudsman

Disabilities Law Program and Community Legal Aid Society, Inc. (Delaware)

Disabilities Resource Center of Siouxland (Iowa)

Disability Action Center - NW, Inc. (Idaho)

Disability Action Center of Ga, INC (Georgia)

Disability in Action, Inc. (Texas)

Disability Law Colorado

disABILITY LINK (Georgia)

Disability Network Northern Michigan

Disability Policy Consortium (Massachusetts)

Disability Pride NYC, inc. (New York)

Disability Resource Center (Illinois)

Disability Rights California

Disability Rights Maryland

Disability Rights Nebraska

Disability Rights Tennessee

DisabilitySavvy (Michigan)

Faith Hope and Charity (Iowa)

FREED, Center for Independent Living (California)

Full Life Care (Washington)

Governor's Advisory Council for Exceptional Citizens (GACEC) (Delaware)

Hawaii Disability Rights Center

Hills & Dales (lowa)

Houston Center for Independent Living (Texas)

Idaho State Independent Living Council

Illinois Chapter of the National Academy of Elder Law Attorneys

Illinois Iowa Center for Independent Living

Illinois Network of Centers for Independent Living (INCIL)

Illinois Valley Center for Independent Living

IMPACT CIL (Illinois)

Inclusion PAC (Illinois)

Independence Associates, Inc. (Massachusetts)

Independent Connection Inc. a Center for Independent Living (Kansas)

Independent Living Center of Kern County (California)

Independent Living Center of the Hudson Valley Inc. (New York)

Independent Living Center of the North Shore and Cape Ann, Inc. (Massachusetts)

Independent Living of the Genesee Region, Inc. (New York)

Independent Living Resource Center, Inc. (Kansas)

Indiana Association of Area Agencies on Aging

Indiana Statewide Independent Living Council (INSILC)

Institute on Disabilities Temple University (Pennsylvania)

Iowa Statewide Independent Living Council

Iowa Office of the State Long-Term Care Ombudsman

Kansas ADAPT

League of Human Dignity, Inc. (Iowa)

LifeSpan Resources (Indiana)

Linking Employment, Abilities and Potential (LEAP) (Ohio)

Living Independence Network Corporation (LINC) (Idaho)

Living Independently For Everyone, Inc. (Idaho)

Living Independently for Today & Tomorrow (Montana)

Maine Long Term Care Ombudsman Program

Maryland ADAPT

Maryland Developmental Disabilities Council

Maryland Occupational Therapy Association

Maryland Statewide Independent Living Council

Mass Home Care Association

Massachusetts Advocates for Nursing Home Reform

Michigan Protection & Advocacy Service, Inc.

Middle Georgia Center for Independent Living, Inc.

Midwest Military Outreach (Iowa)

Missouri Association of Area Agencies on Aging

Missouri Long-Term Care Ombudsman

Montana Independent Living Project

Montana Statewide Independent Living Council

Muslims for Evidence Based Health Care (Washington)

Nebraska Ombudsman Office

New Hampshire Office of the Long Term Care Ombudman

New River Valley Disability Resource Center (Virginia)

New York Association on Independent Living

New York State Independent Living Council, Inc. (NYSILC)

New York State Office of the State Long Term Care Ombudsman

North Central Independent Living Services, Inc. (Montana)

Northeast Independent Living Program, Inc. (Massachusetts)

Ohio Association of Area Agencies on Aging

Ohio Office of the State Long-Term Care Ombudsman

Old Friends Club (Washington)

Options for Independent Living (Wisconsin)

Paraguad (Missouri)

Personal Attendant Coalition of Texas

Prairie Independent Living Resource Center, Inc. (Kansas)

Progress Center for Independent Living (Illinois)

Progressive Center for Independent Living (New Jersey)

Protection & Advocacy Project of ND (North Dakota)

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Resource Center for Independence Living (New York)

Resources for Independence Central Valley (California)

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Roads to Independence (Utah)

Rolling Start Inc. (California)

SCIL (Missouri)

Senior Advisory Council of King County (Washington)

Service Center For Independent Life (California)

Shepherd Center (Georgia)

Silicon Valley Independent Living Center (California)

Smart Policy Works (Illinois)

Sno-valley Senior Center (Washington)

Southeast Kansas Independent Living Resource Center

Southeastern Wisconsin ADAPT

Southeastern Wisconsin Disability Rights

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Southwest Center for Independent Living (SCIL) (Missouri)

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Star Choices, Inc. (Georgia)

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Stavros Center for Independent Living (Massachusetts)

Sunrise Fiduciary (California)

SWIRCA & More (Indiana)

Syntiro (Maine)

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Texas Parent to Texas

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The IMAGE Center for People with Disabilities (Maryland)

The Resource Center for Accessible Living, Inc. (New York)

Topeka Independent Living Resource Center (Kansas)

Touch the Future Inc. (South Carolina)

Transitions in Dementia Care (Washington)

Vermont Long-Term Care Ombudsman Program

Voices for Quality Care (LTC), Inc. (Maryland)

Walton Options (Georgia)

Washington State Independent Living Council

West Virginia Statewide Independent Living Council

Westchester Disabled on The Move Inc. (New York)

Wisconsin Board for People with Developmental Disabilities

March 5, 2018

The Honorable Greg Walden Chairman House Energy and Commerce Committee

The Honorable Michael Burgess Chairman, Health Subcommittee House Energy and Commerce Committee

The Honorable Brett Guthrie Member House Energy and Commerce Committee The Honorable Frank Pallone Ranking Member House Energy and Commerce Committee

The Honorable Gene Green Ranking Member, Health Subcommittee House Energy and Commerce Committee

The Honorable Debbie Dingell Member House Energy and Commerce Committee

Dear Chairman Walden, Ranking Member Pallone, Chairman Burgess, Ranking Member Green, Representative Guthrie, and Representative Dingell:

The undersigned organizations strongly support extension of the Money Follows the Person. We applaud introduction of bipartisan legislation by Representatives Guthrie and Dingell to do so and urge swift passage.

The Money Follows the Person (MFP) Demonstration – first authorized in the Deficit Reduction Act of 2005 with strong bipartisan support and signed into law by President Bush – was designed to assist states with:

- Supporting Medicaid enrollees who want to transition from nursing facilities and other institutional setting back to community-based settings; and
- 2) Developing infrastructure to promote and enhance access to HCBS.

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- Findings suggest that after individuals return to the community, their overall Medicare and Medicaid expenditures decrease by roughly 23%.

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While states have made great progress, more work is needed. Significant variations remain across states and different populations who need HCBS. For example, HCBS accounted for 75% of spending in programs targeting people with developmental disabilities, compared to only 41% of expenditures for programs targeting older people, people with physical disabilities, and people with serious mental illness. Over 50,000 nursing home residents said they wanted to talk with someone about leaving their facility, but never received a referral to a local agency that could help them, according to recent analyses of Nursing Home Minimum Data Set reporting. States have learned lessons and can share promising practices with other states.

Unfortunately, the program expired on September 30, 2016. While states can continue to use remaining grant funding through 2020, they are currently scaling back their programs and reducing dedicated staff and resources. The most recent national evaluation indicates that last year was the first year that number of new transitions through the program declined. We are beginning to lose the momentum and progress we have made.

We commend you and your staff for the bipartisan process to develop this legislation, which will extend the program through 2022, remove barriers for individuals and states, enhance accountability, and contribute to sharing of best practices across states. This will assist states with achieving cost-efficiencies in their Medicaid programs while simultaneously enhancing opportunities for individuals to live independently and age with dignity in their homes and communities.

We applaud you for your leadership and look forward to working with you on passage.

Sincerely,

National Organizations:

AARP

ADAPT

Alliance for Citizen Directed Supports

Alliance for Retired Americans

Allies for Independence

Alzheimer's Association

Alzheimer's Impact Movement

America's Health Insurance Plans (AHIP)

American Association of People with Disabilities

American Association on Health and Disability

American Civil Liberties Union

American Network of Community Options and Resources (ANCOR)

The Arc of the United States

Association of People Supporting Employment First

Association of Programs for Rural Independent Living

Association of University Centers on Disabilities (AUCD)

Autism Society of America

Autism Speaks

Autistic Self Advocacy Network

Bazelon Center for Mental Health Law

B'nai B'irth International

Caring Across Generations

Centene Corporation

Center for Public Representation

Christopher & Dana Reeve Foundation

Community Catalyst

Consumer Direct Care Network

DQIA: Disabled Queers in Action!

Disability Rights Education and Defense Fund (DREDF)

Easterseals

ElevatingHOME

The Jewish Federations of North America

Justice in Aging

Lakeshore Foundation

LeadingAge

Little Lobbyists

Lutheran Services in America Disability Network

Medicaid Health Plans of America (MHPA)

Medicare Rights Center

National Academy of Elder Law Attorneys

National Association for Home Care and Hospice

National Association of Area Agencies on Aging

National Association of Councils on Developmental Disabilities

National Association of Social Workers (NASW)

National Association of State Directors of Developmental Disabilities Services

National Association of State Head Injury Administrators

National Association of State Long-Term Care Ombudsman Programs (NASOP)

National Center for American Indians with Disabilities

National Center for Environmental Health Strategies

National Committee to Preserve Social Security and Medicare

National Consumer Voice for Quality Long-Term Care

National Council on Aging

National Council on Independent Living

National Disability Rights Network

National Down Syndrome Congress

National Health Law Program

National MLTSS Health Plan Association

National Multiple Sclerosis Society

National Organization of Nurses with Disabilities (NOND)

National Rehabilitation Association

National Respite Coalition

Not Dead Yet

Nursing Home Victims Coalition, Inc.

Paralyzed Veterans of America

Partnership for Medicaid Home-Based Care

PolicyWorks, Inc.

Program to Improve Eldercare, Altarum

ResCare Home Care

Self-Development of People of the United Presbyterian Church

Service Employees International Union (SEIU)

Sibling Leadership Network

Special Needs Alliance

Special Needs Resource Project

TASH, Inc.

United States Brain Injury Alliance

Women's Institute for a Secure Retirement (WISER)

State and Regional Organizations

Ability360 (Arizona)

The Ability Center of Greater Toledo (Ohio)

Ability now Bay Area (California)

Able South Carolina

Access 2 Independence (Georgia)

Access Alaska, Inc.

Access to Independence, Inc. (Wisconsin)

Access Center for Independent Living (Illinois)

Access to Independence of Cortland County, Inc. (New York)

Access Support Network of San Luis Obispo and Monterey Counties (California)

Accessible Resources for Independence (Maryland)

The Arc Michigan

The Arc New York

The Arc of Alabama

The Arc of Arizona

The Arc of Illinois

The Arc of Pennsylvania

The Arc of South Carolina

The Arc of Texas

The Arc of the District of Columbia, Inc.

The Arc Tennessee

Area Agency on Aging Association of Michigan, Inc.

ADAPT Delaware

ADAPT Montana

ADAPT of Texas

The Adaptables, Inc. Center for Independent Living (North Carolina)

Advocacy Center of Louisiana

Advocates for Inclusion (Idaho)

Aging and Community Services of South Central Indiana

Aging Life Care Association (Arizona)

AIM Independent Living Center (New York)

Alliance of People with disAbilities (Washington)

Arkansas SILC

Appalachian Center for Independent Living (West Virginia)

Appalachian Independence Center, Inc. (Virginia)

ARISE Independent Living Center (New York)

Association of California Caregiver Resource Centers

Atlantis Community, Inc. (Colorado)

Austin Resource Center for Independent Living, Inc. (Texas)

Blue Ridge Independent Living Center, Inc.

Brain Injury Alliance of Iowa

Brain Injury Association of Georgia

Brain Injury Association of Kansas and Greater Kansas

Brain Injury Association of Massachusetts

Bronx Independent living Services (New York)

California Children's Services Transition Program

California Foundation for Independent Living Centers

California Office of the State Long-Term Care Ombudsman

California Supported Living Network

Californians for Disability Rights Inc.

Cape Organization for Rights of the Disabled (CORD) (Massachusetts)

Caring Associates, Inc. (Florida)

Catskill Center for Independence (New York)

Center for Accessible Living (Kentucky)

Center for Disabilities and Development, University of Iowa

Center for Disability Rights (Connecticut)

Center for Disability Rights (New York)

Center for Independence (Washington)

Center for Independence of the Disabled, NY (New York)

Center for Living & Working, Inc. (Massachusetts)

Central Wisconsin ADAPT

Choice in Aging (California)

CIL Western Wisconsin, Inc.

Coalition of Texans with Disabilities

Colorado Springs Independence Center (Colorado)

Community Resources for Independent Living, Inc. (CRIL) (California)

Connecticut Office of the Long-Term Care Ombudsman

Connecticut State Independent Living Council

Dayle McIntosh Center (California)

DC Metro ADAPT

Delaware Office of the State Long-Term Care Ombudsman

DIRECT Center for Independence (Arizona)

Disabled Rights Action Committee (Utah)

Disabilities Law Program and Community Legal Aid Society, Inc. (Delaware)

Disabilities Resource Center of Siouxland (Iowa)

Disability Action Center - NW, Inc. (Idaho)

Disability Action Center of Ga, INC (Georgia)

Disability in Action, Inc. (Texas)

Disability Law Colorado

disABILITY LINK (Georgia)

disAbility Solutions for Independent Living (Florida)

Disability Network Northern Michigan

Disability Policy Consortium (Massachusetts)

Disability Pride NYC, inc. (New York)

Disability Resource Center (Illinois)

Disability Rights Arkansas

Disability Rights California

Disability Rights Maryland

Disability Rights Nebraska

Disability Rights Tennessee

Disability Rights Washington

DisabilitySavvy (Michigan)

East Bay Innovations (California)

Empower Tennessee

Faith Hope and Charity (Iowa)

Family Voices New Jersey

FREED Center for Independent Living (California)

The Freedom Center, Inc. (California)

Full Life Care (Washington)

Georgia ADAPT

Georgia Council on Developmental Disabilities

Governor's Advisory Council for Exceptional Citizens (GACEC) (Delaware)

Granite State Independent Living (New Hampshire)

Hawaii Disability Rights Center

Hawaii State Council on Developmental Disabilities

Hills & Dales (lowa)

Houston Center for Independent Living (Texas)

Idaho Council on Developmental Disabilities

Idaho State Independent Living Council

Illinois Chapter of the National Academy of Elder Law Attorneys

Illinois Iowa Center for Independent Living

Illinois Network of Centers for Independent Living (INCIL)

Illinois Valley Center for Independent Living

IMPACT CIL (Illinois)

Inclusion PAC (Illinois)

Independence Associates, Inc. (Massachusetts)

Independence First (Wisconsin)

Independence Unlimited (Connecticut)

Independent Connection Inc. a Center for Independent Living (Kansas)

Independent Living Center of Kern County (California)

Independent Living Center of the Hudson Valley Inc. (New York)

Independent Living Center of the North Shore and Cape Ann, Inc. (Massachusetts)

Independent Living Council of Wisconsin, Inc.

Independent Living of the Genesee Region, Inc. (New York)

Independent Living Resource Center (California)

Independent Living Resource Center, Inc. (Kansas)

Indiana Association of Area Agencies on Aging

Indiana Statewide Independent Living Council (INSILC)

Inland Empire Coverage and Health Institute (California)

Institute on Aging (California)

Institute on Disabilities Temple University (Pennsylvania)

Iowa Statewide Independent Living Council

Iowa Office of the State Long-Term Care Ombudsman

Kansas ADAPT

LeadingAge California

League of Human Dignity, Inc. (Iowa)

LifeSpan Resources (Indiana)

LINK Inc. (Kansas)

Linking Employment, Abilities and Potential (LEAP) (Ohio)

Living Independence Network Corporation (LINC) (Idaho)

Living Independently For Everyone, Inc. (Idaho)

Living Independently for Today & Tomorrow (Montana)

Los Angeles Aging Advocacy Coalition (California)

Maine Long Term Care Ombudsman Program

Marin Center for Independent Living (California)

Maryland ADAPT

Maryland Alliance of Disability Commissions and Committees

Maryland Association of Centers for Independent living

Maryland Developmental Disabilities Council

Maryland Occupational Therapy Association

Maryland Statewide Independent Living Council

Mass Home Care Association

Massachusetts Advocates for Nursing Home Reform

Memphis Center for Independent living (Tennessee)

Michigan Disability Rights Coalition

Michigan Elder Justice Initiative

Michigan Health Link Coaliton

Michigan Long Term Care Ombudsman Program

Michigan Olmstead Coalition

Michigan Protection & Advocacy Service, Inc.

Midstate Independent Living Choice, Inc. (Wisconsin)

Middle Georgia Center for Independent Living, Inc.

Midwest Military Outreach (Iowa)

Missouri Association of Area Agencies on Aging

Missouri Developmental Disabilities Council

Missouri Long-Term Care Ombudsman

Montana Independent Living Project

Montana Statewide Independent Living Council

Muslims for Evidence Based Health Care (Washington)

NAMI Connecticut

National Federation of the Blind of Maryland

Nebraska Ombudsman Office

New Hampshire Office of the Long Term Care Ombudman

New River Valley Disability Resource Center (Virginia)

New York Association on Independent Living

New York State Independent Living Council, Inc. (NYSILC)

New York State Office of the State Long Term Care Ombudsman

North Central Independent Living Services, Inc. (Montana)

North Country Independent Living, Inc. (Wisconsin)

Northeast Independent Living Program, Inc. (Massachusetts)

Northern Regional Center for Independent Living (New York)

Ohio Association of Area Agencies on Aging

Ohio Office of the State Long-Term Care Ombudsman

Old Friends Club (Washington)

Options for Independent Living (Wisconsin)

Paraquad (Missouri)

Partners in Care Foundation (California)

Pennsylvania ASPE

Personal Assistance Services Council (California)

Personal Attendant Coalition of Texas

Placer Independent Resource Services (California)

Public Health Advocates (California)

Prairie Independent Living Resource Center, Inc. (Kansas)

Progress Center for Independent Living (Illinois)

Progressive Center for Independent Living (New Jersey)

Protection & Advocacy Project of ND (North Dakota)

Protection and Advocacy for People with Disabilities, Inc. (South Carolina)

RAMP Center for Independent Living (Illinois)

REAL Services, Inc. (Indiana)

Resident Councils of Washington

Resource Center for Accessible Living (New York)

Resource Center for Independence Living (New York)

Resources for Independent Living, Inc. (Virginia)

Resources for Independence Central Valley (California)

RI long Term Care Ombudsman (Rhode Island)

Roads to Independence (Utah)

Ron Yost Personal Assistance Services Board (West Virginia)

Rolling Start Inc. (California)

San Antonio Independent Living Services (Texas)

San Diegans for Healthcare Coverage (California)

SCIL (Missouri)

SECC, Washington DC/Maryland

Senior Advisory Council of King County (Washington)

SeniorServ (California)

Service Center For Independent Life (California)

Shepherd Center (Georgia)

Silicon Valley Independent Living Center (California)

Smart Policy Works (Illinois)

Sno-valley Senior Center (Washington)

Society's Assets, Inc. (Wisconsin)

Sources for Community Independent Living Services (Arkansas)

Southeast Kansas Independent Living Resource Center

Southeastern Wisconsin ADAPT

Southeastern Wisconsin Disability Rights

Southern Adirondack Independent Living Center (New York)

Southern Tier Independence Center (New York)

Southwest Center for Independence (Colorado)

Southwest Center for Independent Living (SCIL) (Missouri)

Southwest Louisiana Independence Center

Spa Area Independent Living Services, Inc. (Arkansas)

St. Barnabas Senior Services (California)

Star Choices, Inc. (Georgia)

Statewide Parent Advocacy network (New Jersey)

Statewide Independent Living Council of Georgia

Statewide Independent Living Council of Illinois

Statewide Independent Living Council of Tennessee

Stavros Center for Independent Living (Massachusetts)

Sunrise Fiduciary (California)

SWIRCA & More (Indiana)

Syntiro (Maine)

Texas Advocates

Texas Association for Home Care & Hospice

Texas Parent to Texas

The Freedom Center, Inc. (Maryland)

The IMAGE Center for People with Disabilities (Maryland)

The Resource Center for Accessible Living, Inc. (New York)

Topeka Independent Living Resource Center (Kansas)

Touch the Future Inc. (South Carolina)

Transitions in Dementia Care (Washington)

UDW/AFSCME Local 3930 (California)

University of Cincinnati Center for Excellence in Developmental Disabilities

Utah Developmental Disabilities Council

Vermont Long-Term Care Ombudsman Program

The Viscardi Center (New York)

Voices for Quality Care (LTC), Inc. (Maryland)

Walton Options for Independent Living, Inc. (Georgia and South Carolina)

Washington State Independent Living Council

West Virginia Statewide Independent Living Council

Western Center on Law and Poverty (California)

Western Reserve Independent Living Center (Ohio)

Western New York Independent Living

Westchester Disabled on The Move Inc. (New York)

Wisconsin Board for People with Developmental Disabilities

Wisconsin Coalition of Independent Living Centers

PillPack, Inc. 250 Commercial Street Manchester NH 03101



September 4, 2018

The Honorable Michael Burgess Chairman House Energy and Commerce Committee Subcommittee on Health 2336 Rayburn House Office Building Washington, DC 20510

Dear Chairman Burgess,

In regard to the hearing scheduled for Wednesday, September 5, 2018, entitled "Opportunities to Improve Health Care", I write to extend my strong support for your discussion draft that will prohibit the use of "gag clauses" in Medicare and certain private health insurance plans.

As a licensed pharmacist and CEO of PillPack, Inc., I share the Subcommittee's desire to promote transparency in our Nation's medical system. Prohibiting pharmacy benefit managers (PBMs) from utilizing "gag clauses" on pharmacists will ensure proper disclosure of the best available price for each insured enrollee. Today, pharmacists have limited ability to help patients understand the total cost of their medications because pricing information is closely held by PBMs. We advocate full drug price transparency for consumers and support this effort as a step towards that goal.

PillPack is an independently operated national pharmacy, licensed and providing home delivery to customers in every state except Hawaii. We offer unique services designed to support medication adherence for customers who take multiple medications every day. Home delivery is a core component of our services, making it possible for anyone to receive their medications without time-consuming and burdensome trips to the pharmacy. This is particularly important for customers who have mobility restrictions or lack consistent access to transportation.

Since our launch in 2014, PillPack has grown to serve tens of thousands of customers and employs approximately 800 professionals in six locations, including our headquarters in Manchester, NH. We are fully compliant with all federal and state regulations and have earned rigorous private accreditations. PillPack is currently the only independently operated pharmacy of our scale to offer home delivery nationwide.

Prohibiting "gag clauses" and providing transparency will send a strong signal in support of innovative efforts to put patients first. It will benefit customers seeking high quality medical care and encourage new patient-centric pharmacy business experiences. Thank you for your leadership.

Sincerely,

TJ Parker Co-founder & CEO, PillPack, Inc.



LeadingAge Statement The Money Follows the Person Program and the EMPOWER Care Act House Energy and Commerce Committee Subcommittee on Health

September 5, 2018

Leading Age, an association of not-for-profit aging services providers, appreciates the opportunity to comment on the Money Follows the Person (MFP) Program and the *EMPOWER Care Act*. We are pleased that the Subcommittee on Health is focusing attention on "opportunities to improve health care" which includes legislation that helps provide resources to State Medicaid programs to help transition older adults and individuals with chronic conditions and disabilities from nursing homes back into local communities.

The mission of LeadingAge is to expand the world of possibilities for aging. Our membership has a service footprint of 4.5 million and includes a community of 6,000 members representing the entire field of aging services, including not-for-profit organizations, state partners, and hundreds of businesses, consumer groups, foundations, and research partners. LeadingAge is a tax-exempt charitable organization focused on education, advocacy, and applied research.

The Money Follows the Person (MFP) demonstration program is a Medicaid initiative designed to expand community-based long-term services and supports (LTSS) options. MFP, first authorized in the *Deficit Reduction Act of 2005*, was extended until 2016 under the *Affordable Care Act*. To be eligible for MFP, Medicaid beneficiaries must reside in a nursing home or similar facility, for at least 90 days prior to transitioning to a community residence (e.g., house, apartment, small group home). Under MFP, a participant receives home and community-based services for which the state receives enhanced federal matching funds during a beneficiary's participation year. States began operating in MFP in 2007, and between 2007 and 2017 forty-three states transitioned over 75,000 individuals into the community. The EMPOWER Care Act extends funding for the 5-year MFP demonstration to 2022.

For the purposes of this demonstration, participants must move to a qualified residence in the community, which include homes either owned or leased by the participant or a family member, individual apartments or small group homes. Once transitioned to a qualified residence in the community, participants are eligible for MFP for a year, or 365 days. During this time MFP demonstrations may provide up to three categories of services: (1) qualified home and community-based LTSS; (2) demonstration services that help people adjust to community living; and (3) supplemental services that are not reimbursable outside waiver programs. States receive

 $^{^{1}\,\}underline{\text{https://www.medicaid.gov/medicaid/ltss/money-follows-the-person/index.html}}$

an MFP-enhanced Federal Medical Assistance Percentage (FMAP) for either the qualified or demonstration home and community-based LTSS.²

LeadingAge strongly believes the MFP program represents a major step forward to give people needing LTSS more choice about where they live and receive care. We support the program's intent to: (1) increase the use of home and community-based, rather than nursing home long-term care services; (2) eliminate barriers whether in state law, the state Medicaid plan, and the state budget, or otherwise, that prevent or restrict the flexible use of Medicaid funds to enable Medicaid-eligible individuals to receive support for appropriate and necessary long-term services in the settings of their choice; (3) increase the ability of Medicaid programs to assure continued provision of home and community-based long-term care services to eligible individuals who choose to transition from a nursing home to a community setting of their choice; and (4) ensure that the procedures are in place (at least comparable to those required under the qualified HCBS program) to provide quality assurance for eligible individuals receiving Medicaid home and community-based long-term care services and to provide for continuous quality improvement in such services.

The MFP demonstration has allowed states to provide a richer mix of services that allow beneficiaries to access home and community-based LTSS, including home health care services, personal care assistance services; in-home private duty nursing, hospice, employment support services, and adult day services.

We greatly appreciate the Subcommittee on Health's attention to an issue that is becoming ever more urgent, and we congratulate the committee's leadership for their foresight. We look forward to working with the committee on solutions to implement programs that assist with helping to move older adults receive care at home or in a community-based setting.

 $^{^2\,\}underline{\text{https://www.medicaid.gov/medicaid/ltss/downloads/money-follows-the-person/mfp-rtc.pdf}}$



September 5, 2018

Hon. Michael Burgess Chairman Energy and Commerce Committee Subcommittee on Health U.S. House of Representatives Washington, DC 20515 Hon. Gene Green Ranking Member Energy and Commerce Committee Subcommittee on Health U.S. House of Representatives Washington, DC 20515

Dear Mr. Chairman and Ranking Member,

Thank you for the opportunity to submit testimony for the record for the Health Subcommittee's September 5th hearing "Opportunities to Improve Health Care" regarding H.R. 3325, the ACE Kids Act.

Medicaid Health Plans of America (MHPA) member plans are committed partners with Congress, the Administration and the states in strengthening Medicaid and ensuring that the program improves the delivery of care for beneficiaries.

MHPA is the national trade association representing more than 90 managed care health plans that contract with state Medicaid agencies in 39 states plus DC to provide comprehensive, high-quality health care to nearly 25 million Medicaid enrollees in a coordinated and cost-effective way. The number of Medicaid beneficiaries who receive their care through managed care plans continues to rise annually, in part, as more states turn to the expertise of managed care plans to help coordinate, manage and integrate health care for growing numbers of populations of Medicaid enrollees, including Children with Special Health Care Needs (CSHCNs).

We appreciate that the legislation has been significantly improved since the $114^{\rm th}$ Congress to address some of the concerns expressed by MHPA and other stakeholders. However, it continues to rely on a model that would create silos that fragment the medical care and support services that are essential for these children.

Under current law States already have the ability to deploy various medical home and care-coordination models¹ to meet the needs of CSHCNs and most

¹ Several pathways already exist for states to create provider led medical homes and health plan led care coordination programs for CSHCN's, including, for example, ACA Sec.



of them have chosen not to deploy provider-led models for sound policy reasons. This calls into question the appropriateness of creating a substantial financial inducement to the states² for programs and mechanisms states already have the ability to implement.

Impact on beneficiaries: MHPA is concerned that in states with managed care systems for Medicaid that adoption of a provider-led model outside of managed care networks would negatively impact the health and wellbeing of children and their families while simultaneously increasing the cost of care.

As you know, three states³ have implemented MMCO operated specialized plans for CSHCNs. In about half of the other 36 states that utilize managed care plans for Medicaid, state contracts with MMCOs contain a variety of provisions requiring MCOs to maintain specific specialized capabilities, networks, procedures and protocols to meet the needs of CSHCN's. These special plans cover the comprehensive range of services these children need, and the MMCO networks include the best pediatric hospitals in the state and offer access to national "super-specialists" as needed.

These managed care contracts also create important operational safeguards to ensure the solvency and sustainability of MMCOs and the care they manage. While the proposal strives to allow states to give provider-led health homes much of the responsibilities of an MMCO, we should be careful that it also assures a commensurate level of oversight and minimal operational standards to protect states and beneficiaries.

States already have the ability, to create a variety of care coordination mechanisms, including pediatric health homes:

Additional federal legislation is not required for states to create either provider-led or managed care based enhanced pediatric health homes. Through specialized managed care contracts or under pilots and waivers, states are increasingly adding CSHCNs into managed care plans, opting for the comprehensive and effective model that MMCOs provide. MMCOs already routinely meet and far exceed the capabilities mandated under the proposal's "Health Home Qualification Requirements". States already have the ability to create health homes serving children under current law⁴.

²⁷⁰³health homes, waivers, specialized managed care plans and special provisions in managed care contracts.

² The Enhanced FMAP proposed in the legislation

³ CA, FL and DC

⁴ For example, through ACA Sec. 2703, state waivers, or alternative payment arrangements.



Out-of-state care: In rare instances where the necessary specialist care is not available in-state, MMCO's send the child and family to "superspecialists" in various locations across the country, negotiating one-off contracts and relying on pre-established reimbursement rates⁵.

Identifying and utilizing these "super-specialists" does not create an operational challenge for MMCOs, however we understand that CMS-State provider enrollment procedures may represent a challenge for fee-for-service programs. MHPA strongly supports efforts to streamline the process for CMS-State enrollment of providers.

Medicaid is not just medical care: MMCO's operating either special plans for CSHCNs or plans with special provisions have developed networks and capabilities to efficiently and effectively provide, integrate and manage a wide and comprehensive range of both medical and non-medical support services for children and their families. This is not a core capability of a hospital-based medical home.

Often times the most challenging part of managing care for CSHCNs is managing homecare, transportation, prescription drugs, nutrition assistance, and a wide variety of other medical and non-medical services. The variety of services MMCOs offer for CSHCNs can be far broader than what a hospital system provides.⁶

Ability to take and manage cost risk: CMS experience with ACOs in recent years has demonstrated the inability or unwillingness of provider led entities to take and manage full-risk. The proposal removes this important incentive to keep patients healthy and out of the most expensive care setting – the hospital.

While the legislation does encourage exploration of various alternative payment models, it does not require EPHH's to operate under a full-risk capitation model. Given the reluctance of provider-led models to take the kind of risk that MMCO's routinely take, the proposal removes incentives for effective cost containment and creates incentives for fee for volume.

Conflict of interest: The proposal gives the provider control over where a patient will receive their care. When a provider-led entity routinely determines where a child will receive care, it creates an inherent conflict of interest that may result in suboptimal care decisions as EPHH hospitals seek

 $^{^{\}rm 5}$ Either the state established fee for service rate, or the rates negotiated by the MMCO if it operates in the destination state.

⁶ SEE Appendix 1 "Examples of Services Provided by Managed Care to CSHCN's"



to retain revenue by keeping children "in house" rather than sending them to the most appropriate pediatric specialist, or to a less cost-intensive service provider.

Efficiency: Many routine, non-critical services that don't require treatment by high cost specialists or in high cost institutional settings would often cost many times more through a provider-led EPHH than they cost through an MMCO network⁷, which utilizes a comprehensive network of providers to deliver care most efficiently and effectively. These lower intensity cost providers are often also more convenient and accessible for families than a hospital-based health home.

We share concerns that by increasing federal matching funds offered to states implementing EPHH's the proposal will create perverse incentives to states to abandon innovative and effective managed care-based approaches to caring for these children. While intending to advance care for CSHCN's, the proposal, for the reasons we mention, is likely to reverse recent progress in several states.

Access to Care: It is reasonable to assume that provider-led EPHH's will routinely steer CSHCNs into their EPHH even if the engagement with the provider entity is minimal or occasional, even if adequate care is available closer to home. This steering could have negative consequences for local health care providers, FQHCs, rural hospitals, and other community-based providers, driving them out of business and leaving those communities without access to services. The resulting hospital consolidation would not only limit access to care but would also have the unintended consequence of reducing the ability of individual states to manage costs effectively, unnecessarily driving up program costs.

Separate coverage for family members: From experience, we know that keeping families together under the same insurance plan and provider network improves access to care and results. The proposal would have the effect of moving children out of their family or caregiver's Medicaid plan and into an EPHH, greatly complicating compliance with treatment and care regimens for both CSHCN's and family members. As such, the model proposed would fragment the care provided to the child in need of extraordinary services from their family and/or other caregivers. Creating a dynamic that separates the child from their parents via different service

⁷ Some states, such as Florida, limit reimbursement to providers for services to a percentage of Medicaid fee for service rates, but in most states is it common for routine visits, vaccines and other services to cost several times more than they would at a lower cost-intensive provider such as a CHC/FQHC.



providers is likely to add to, rather than reduce, the scheduling and other service difficulties the families already face. Because many of these children's parents are low-income or otherwise disadvantaged, this increased complexity is likely to create additional barriers that would be even harder to overcome.

Legislation creates a federal definition of CSHCN: This is an important definition that has additional implications for states and should be given thorough consideration.

Thank you again for the opportunity to comment on the legislation and suggest improvements. The most important change we can recommend to the legislation to ensure that the full capabilities of both provider-led entities and managed care are brought to bear to meet the needs of CSHCNs is to modify the legislation to require that, if implemented in a state with Medicaid managed care, that an Enhanced Pediatric Health Home must operate as a network element in the MMCO's network and that payments to the EPHH be included in the MMCO's capitated full risk payment rates established by the state.

All the best,

Francis J. Rienzo

Vice President for Government Relations and Advocacy



Appendix 1

"Examples of Services Provided by Managed Care to CSHCNs"

Behavioral health services

In home care

Prescription drugs and medication management

Lab testing

Vaccines

Equipment and supplies

Family transportation and lodging for out of town/state specialist visits

Care coordination for low-income or geriatric patients/members

Nutrition education

Transportation to and from medical appointments

Parent education

School-based healthcare services



Association of American Medical Colleges 655 K Street, NW, Suite 100, Washington, DC 20001-239 7 202 828 0400

September 5, 2018

The Honorable Charles Grassley 135 Hart Senate Office Building United States Senate Washington, DC 20515

The Honorable Joe Barton 2107 Rayburn House Office Building United States House of Representatives Washington, DC 20515 The Honorable Michael Bennett 548 Russell Senate Office Building United States Senate Washington, DC 20515

The Honorable Kathy Castor 2052 Rayburn House Office Building United States House of Representatives Washington, DC 20515

Dear Senators Grassley and Bennett and Representatives Barton and Castor:

On behalf of the Association of American Medical Colleges (AAMC), I am writing to express support for The Advancing Care for Exceptional Kids Act of 2017 (ACE Kids Act, S. 428, H.R. 3325). Thank you for your leadership in introducing this bipartisan legislation to improve health care for children with complex medical conditions on Medicaid.

The AAMC is a not-for-profit association dedicated to transforming health care through innovative medical education, cutting-edge patient care, and groundbreaking medical research. Its members are all 151 accredited U.S. medical schools; nearly 400 major teaching hospitals and health systems, including 51 Department of Veterans Affairs medical centers; and more than 80 academic societies. Through these institutions and organizations, the AAMC serves the leaders of America's medical schools and teaching hospitals and their more than 173,000 full-time faculty members, 89,000 medical students, 129,000 resident physicians, and more than 60,000 graduate students and postdoctoral researchers in the biomedical sciences.

The ACE Kids Act is an important piece of legislation that creates a patient-centered delivery system for a unique population of children to help ensure access to care across state lines and reduce the burden on these children's families. Under this legislation, specially-designed health homes created for children with complex medical conditions would employ national quality standards and coordinate care, which are both essential to improving quality of care and reducing costs.

The ACE Kids Act, which is voluntary for states, families, and providers, would create savings to Medicaid by reducing hospitalizations and emergency room visits while providing essential services and supports for these children. As such, the AAMC is happy to support this legislation.

Thank you for your leadership in introducing this critical legislation – we look forward to working with you to advance this bill this year. If you have any questions, please contact Len Marquez, AAMC Senior Director of Government Relations, at lmarquez@aamc.org.

Sincerely,

Karen Fisher, JD Chief Public Policy Officer

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GREG WALDEN, OREGON CHAIRMAN FRANK PALLONE, JR., NEW JERSEY
RANKING MEMBER

ONE HUNDRED FIFTEENTH CONGRESS

Congress of the United States

House of Representatives

COMMITTEE ON ENERGY AND COMMERCE

2125 RAYBURN HOUSE OFFICE BUILDING WASHINGTON, DC 20515–6115

September 26, 2018

Mr. Hugh Chancy Member, Board of Directors National Community Pharmacist's Association 100 Dangerfield Road Alexandria, VA 22314

Dear Mr. Chancy:

Thank you for appearing before the Subcommittee on Health on September 5, 2018, to testify at the hearing entitled "Opportunities to Improve Health Care."

Pursuant to the Rules of the Committee on Energy and Commerce, the hearing record remains open for ten business days to permit Members to submit additional questions for the record, which are attached. To facilitate the printing of the hearing record, please respond to these questions with a transmittal letter by the close of business on October 3, 2018. Your responses should be mailed to Dan Butler, Legislative Clerk, Committee on Energy and Commerce, 2125 Rayburn House Office Building, Washington, DC 20515 and e-mailed in Word format to dan.butler@mail.house.gov.

Thank you again for your time and effort preparing and delivering testimony before the Subcommittee.

Chairman

Subcommittee on Health

cc: The Honorable Gene Green, Ranking Member, Subcommittee on Health

Attachment



WWW.HCPAHET.ORG

Hugh Chancy's Answer to The Honorable Earl L. "Buddy" Carter

 In your interactions with Pharmacy Benefit Managers (PBMs), are you able to negotiate with PBMs to have provisions altered or removed from contracts such as non-disparagement clauses? If not, why do you feel required to sign these contracts?

No, I am not able to negotiate with PBMs to have provisions altered or removed from contracts such as non-disparagement clauses because PBM contracts, especially those with the largest PBMs in the market, are non-negotiable.

Three large companies lead the PBM market: Express Scripts, CVS Caremark, and OptumRx.¹ A recent report from the Council of Economic Advisers found that these PBMs account for 85 percent of the PBM market. More so, these three PBMs cover a significant level of insured lives. Of note, CVS Caremark has recently stated that it covers approximately 34 percent of covered lives.² This significant market share from just three PBMs allows them exercise undue market leverage in negotiating contracts with community pharmacies like mine.

The default practice in contracting with these PBMs is that there is no opportunity to red-line these contracts which often include non-negotiable blind price terms, overly broad non-disparagement clauses, and other provisions that disadvantage community pharmacies. In fact, community pharmacies like mine routinely must agree to non-negotiable contracts from these PBMs just to continue to serve my longstanding patients. More so, from a business standpoint, community pharmacies cannot just walk away from most PBM contracts because if we did, we would lose a significant amount of our prescription revenue given the large share of covered lives these PBMs represent. We are in a no-win situation.

PBMs often cite community pharmacies' reliance on a Pharmacy Services Administrative Organization or a PSAO to contract on their behalf to demonstrate a level playing field between PBMs and community pharmacies. In short, PSAOs are no match for the PBMs. In 2013, the Government Accounting Office (GAO) conducted a study on the role and ownership of PSAOs and stated:

In addition, according to some PSAOs that we spoke with, reimbursement rates to pharmacies have decreased over time, and PSAOs and other sources we spoke with reported that PSAOs' ability to negotiate reimbursement rates has also decreased over time. Over half of the PSAOs we spoke with reported having little success in modifying

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¹ Council of Economic Advisers, Reforming Biopharmaceutical Pricing at Home and Abroad, Feb. 2018, available at https://www.whitehouse.gov/wp-content/uploads/2017/11/CEA-Rx-White-Paper-Final2.pdf.

² According to CVS Health, it has 94 million PBM Plan Members. See CVS Health, available at https://cvshealth.com/about/facts-and-company-information. The Pharmaceutical Care Management Association testified that PBMs administer drug plans for more than 266 million Americans. See Testimony of Mark Merritt, Pharmaceutical Care Management Association, United States House of Representatives Energy and Commerce Committee, Subcommittee on Health, Examining the Drug Supply Chain, Dec. 13, 2017.

certain contract terms because of negotiations. This may be due to PBMs' use of standard contract terms and the dominant market share of the largest PBMs. Many PBM contracts contain standard terms and conditions that are largely nonnegotiable. According to one PSAO, this may be particularly true for national contracts, in which third-party payers or their PBMs have set contract terms for all pharmacles across the country that opt into the third-party payers, or its PBM's network. For example, a national contract exists for some federal government programs, such as TRICARE. In addition, several sources told us that the increasing consolidation of entities in the PBM market has resulted in a few PBMs having large market shares, which has diminished the ability of PSAOs to negotiate with them, particularly over reimbursement rates.³

In conclusion, I am not able to negotiate with PBMs to have provisions altered or removed from contracts such as non-disparagement clauses. I must sign these contracts to serve my patients and to keep my small business open.

³ See United States Government Accountability Office, Report to the Ranking, Member, Committee on Energy and Commerce, House of Representatives, *Prescription Drugs: The Number, Role, and Ownership of Pharmacy Services Administrative Organizations*, Jan. 2013, available at https://www.gao.gov/assets/660/651631.pdf.

GREG WALDEN, OREGON CHAIRMAN FRANK PALLONE, JR., NEW JERSEY
RANKING MEMBER

ONE HUNDRED FIFTEENTH CONGRESS

Congress of the United States

House of Representatives

COMMITTEE ON ENERGY AND COMMERCE 2125 RAYBURN HOUSE OFFICE BUILDING WASHINGTON, DC 20515–6115

> Majority (202) 225-2927 Minority (202) 225-3641

September 26, 2018

The Honorable Derek Schmidt Attorney General State of Kansas 120 Southwest Tenth Avenue, Second Floor Topeka, KS 66612

Dear Mr. Schmidt:

Thank you for appearing before the Subcommittee on Health on September 5, 2018, to testify at the hearing entitled "Opportunities to Improve Health Care."

Pursuant to the Rules of the Committee on Energy and Commerce, the hearing record remains open for ten business days to permit Members to submit additional questions for the record, which are attached. To facilitate the printing of the hearing record, please respond to these questions with a transmittal letter by the close of business on October 3, 2018. Your responses should be mailed to Dan Butler, Legislative Clerk, Committee on Energy and Commerce, 2125 Rayburn House Office Building, Washington, DC 20515 and e-mailed in Word format to dan.butler@mail.house.gov.

Thank you again for your time and effort preparing and delivering testimony before the Subcommittee.

Michael C. Burgess M.I Chairman

Subcommittee on Health

cc: The Honorable Gene Green, Ranking Member, Subcommittee on Health

Attachment



STATE OF KANSAS OFFICE OF THE ATTORNEY GENERAL

DEREK SCHMIDT ATTORNEY GENERAL MEMORIAL HALL 120 SW 10TH AVE., 2ND FLOOR TOPEKA, KS 66612-1597 (785) 296-2215 • FAX (785) 296-6296 WWW.AG.KS.GOV

October 2, 2018

Michael C. Burgess, M.D. Chairman, Subcommittee on Health Committee on Energy and Commerce 2125 Rayburn House Office Building Washington, DC 20515-6115

Dear Chairman Burgess:

Please find attached my response to the Additional Questions for the Record transmitted to me in your letter dated September 26, 2018. Insofar as some questions request information that is beyond my personal knowledge, please be advised that I have consulted with staff at the National Association of Attorneys General and, through them, the National Association of Medicaid Fraud Control Units. As indicted below, my responses are reliant upon advice they have provided to me.

I appreciated the opportunity to testify and provide this additional information in support of H.R. 3891. Please let me know if I may be of further assistance.

Derek Schmidt

Kansas Attorney General

ce: Hon. Gene Green, Ranking Member, Subcommittee on Health

Attachment

Additional Questions for the Record

- 1. What protections do patients currently have when Medicaid Fraud Control units detect abuse in a non-institutional setting?
- a. Are there any other settings that Medicaid Fraud Control Units are prohibited from addressing patient abuse?

If a facility receives Medicaid funds, it will be included in a MFCU's jurisdiction when investigating patient abuse. Neither a facility that is not a Medicaid funded nor a non-institutional setting would fall under the jurisdiction of a MFCU for patient abuse cases.

b. Can Medicaid Fraud Control Units detect, investigate and prosecute fraud in Indian Health Service Facilities?

I am advised that a MFCU would not typically investigate an IHS facility due to jurisdictional issues. A federal agency could investigate an IHS facility with support from a state MFCU, but the MFCU would generally not be able to conduct the investigation on its own. This question might better be addressed to HHS-OIG, which is charged with enforcing the limitations on MFCU jurisdiction through administration of Federal Financial Participation.

c. Can Medicaid Fraud Control Units pursue cases of patient abuse in IHS facilities?

I am advised that if an IHS facility were funded by Medicaid, a MFCU could pursue the case though it would have to be acting jointly with federal agencies due to jurisdictional issues over the IHS. This question might better be addressed to HHS-OIG, which is charged with enforcing the limitations on MFCU jurisdiction through administration of Federal Financial Participation.

d. Does the jurisdiction of the Medicaid Fraud Control Unit change dependent upon if the hospital is a direct service hospital versus a 638-contract hospital?

I am advised that there are many factors regarding jurisdiction over both 638-contract hospitals and direct service hospitals. Regardless of either type of hospital, a MFCU would examine each situation on a case by case basis and coordinate an investigation with appropriate federal authorities. This question might better be addressed to HHS-OIG, which is charged with enforcing the limitations on MFCU jurisdiction through administration of Federal Financial Participation.

e. Do you believe that MFCU's should be able to investigate federally run direct service facilities?

I have no opinion on this question.

f. Do you believe that MFCU's should be able to investigate 638 contract facilities?

I have no opinion on this question.

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