[00:13] EMILY BARSON

Hi. Good afternoon everyone. I'm Emily Barson. Executive Director of United States of Care. It's my pleasure to welcome you to this webinar, The Material & Human Costs of COVID-19 on the 50+, sponsored by AARP.

We're so grateful to have AARP as our co-host of today's event.

And now to introduce our guests, joining us as co-host is Bob Stephen, AARP Vice President, Caregiving and Health Programs.

And on our panel today:

Joanne Grossi - USofCare Voices of Real Life and Pennsylvania State President, AARP
Jodi Prohofsky - an experienced health care leader and caregiver
Leigh Purvis - Director of Health Care Costs & Access, AARP
And Dr. Toni Eyssallenne - NY Market Medical Director, Cityblock Health
They'll each share their unique perspective on the topic and I can't wait to hear from each of them.

After each of our guests has presented we'll open the floor for Q&A - you can submit your questions through the Q&A chat at the bottom of your screen.

Before handing it off, I'd like to share a bit about USofCare and our recent work. USofCare was founded in 2018 around the simple yet bold Mission that everyone should have access to quality, affordable healthcare. Our goal - our contribution towards that broader mission - is intentionally two fold.

First, to expand access to quality, affordable health care in the near term -- because we know people can't wait for a perfect solution that may be years down the road. The ripest opportunities for this near term approach are often at the state level, where we can help advance policies that help people now, and build the evidence and momentum for broader change down the line.

And second, to pave a path towards durable, people-centered federal policies that achieve our mission. Because we know actually working to ensure access to quality affordable health care across the country will require federal action, and in order to make those policies durable, we need to work now to build the political will and shift the narrative around health care, to make those changes into a political imperative.

Our mission has never been more important than in the current COVID-19 public health crisis. It isn't enough for us to weather the crisis and go back to "normal" -- We need to build a better, more equitable health care system in the wake of the pandemic.

Durable solutions in response to the pandemic will only be possible if we are centering those solutions around people's shared needs and engaging people in the conversation. To better understand those needs, we have undertaken an ongoing listening project, combining:

- A survey of Americans
- In-depth interviews

- Continuous analysis of public opinion polling related to the impact of the pandemic on the health and health care landscape in the United States.
- These components have helped us understand what Americans are concerned about regarding the pandemic and how the health care sector should be shifting to address those concerns.

Recently we published a guide to humanizing the health care debate and COVID 19 response based on our listening work and our expertise in health care policy.

I am going to share those findings today, including specific analysis for older americans.

After months of ethnographic interviews, in May of 2020, we surveyed over two thousand people across the country, with an oversample for African American women, Republican-identified men and women, and Republican-identified high school-educated white men.
And for this presentation we are highlighting specific data on the response from older americans.

Our research sought to understand how people are doing; their worries, concerns, and needs; as well as what matters most to them and how they are feeling about the health care system.

Contrary to the current national conversation, our findings show many people share common - and in some cases heartbreaking - experiences, even if we each have unique circumstances and inequalities and different political viewpoints.

In several of our survey's open-ended questions, people gave similar responses across a variety of demographics (Republican and Democrat, rural and urban, African American and white).

I will dive into those today before turning it over to our other speakers.

- Before I share the findings – I want to share a reflection. At first these findings may seem remarkably obvious. When we share this work with others, we see head nods of agreement reflecting on how we all feel throughout the day: anxious, concern, and worry mixed with hope and gratefulness; thinking about our loved ones, about our country, our economy and our wallets, about our individual and shared future; and, finally, concurrence on the priorities that our health care system should focus on.

- We wondered when we share our findings if the obviousness of them would undermine the usefulness of this work.

- We soon realized, instead, a disconnect from the national discourse and our findings. We aren't actually having a national conversation which reflects what we have heard from people in our discussion and in our survey. While we watch the news of partisan fights over the backdrop of human loss and a cratering economy, a run up to the elections, we are neglecting to identify what we all have in common right now, and which differences are noteworthy. And while I don't pretend there aren't true differences occurring from all angles – different health needs, financial needs, and partisan differences – it is our intention with this research to nuance the national discourse in a way that resonates with people and humanizes the response to the pandemic.

In our ethnographic 1:1 and small group discussions, and our survey, we first asked “how are you?” And really what we saw is that Americans are feeling a mix of emotions related to the pandemic, and those emotions are overwhelmingly negative. The highest percentages of respondents feel concerned, anxious, uncertain, and frustrated.

Primarily, older adults were concerned about catching COVID-19. Some raised this concern directly about themselves and their status as a high-risk group, while others expressed concern about family and friends becoming sick. But Americans - including older adults - are also finding hope in the midst of crisis – in religion, in their families, and stories of people helping others.

We also asked people’s top concerns. Across the board, when asked to rank different concerns, we found that the public is deeply concerned about their health and financial wellbeing, describing an interconnection of these parts of their life and broader society.

In open-ended responses, a significant number of respondents are putting concerns about their loved ones ahead of themselves and are concerned about their community and those on the frontlines.

Finally, we asked people what they need from the health care system. Across all demographics, shared needs are emerging in response to the pandemic, including the desire four specific needs:
First, a reliable health care system that is fully resourced to support essential workers and available when it is needed, both now and after the pandemic.
Second, a health care system that cares for everyone, including people who are vulnerable and those who were already struggling before the pandemic hit.
Third, accurate information and clear recommendations on the virus and how to stay healthy and safe.
And finally being able to provide for ourselves and our loved ones, especially as we are worried about the financial impact of the pandemic.

When asked to rank needs that were most important to them, older Americans are fairly evenly divided on these needs, including a health care system that values human life and cares for the most vulnerable, a health care system that is resourced to support front-line workers, and accurate information and recommendations on the virus.

You can check out our guide on Humanizing the Health Care Debate and more of our work on the COVID response on our website @ UnitedStatesofcare.org. And we have resources reflecting these results, including policy recommendations that we made to state and federal leaders grounded in the needs we heard in this listening work.

And now I am pleased to hand it over to Bob Stephen from AARP. Bob.

[08:58] BOB STEPHEN

Great. Thank you, Emily.

You know we’ve all faced unexpected costs and losses due to the pandemic. The great information Emily shared really gets to that. We’ve been working from home, balancing kids (and virtual learning in some cases), supporting and caring for older loved ones - minimizing the time that we have for our friends and feeling really anxious about every step that we take and we could really go on and on.

But you could really argue that the 50+ population has been hit particularly hard by the pandemic. We hear that as we talk to our members and the 50+ at large. The stress and anxiety from health risks that could lead to an early death from COVID complications for themselves or their loved ones is a lot to carry every day.

And seven months into the global pandemic, the situation continues hitting family caregivers. Those who are providing unpaid care for friends, family, parents, spouses even harder. Particularly women. These women are already doing double duty - taking care of their aging family members while raising their own kids. The majority of them, over 60%, are working full time jobs.

While almost all of us have been trying to do the nonstop juggle of work and life balance - some, most specifically women that I mentioned, are having to leave the workforce completely. As we published with S&P Global just a week ago, and the number's been out there - 865,000 women left the workforce in the month of September. And obviously that decision will have a long lasting devastating impact on future career and financial earnings, particularly for those who are over the age of fifty.

But it's not just women who are stressed and having to make these drastic decisions to survive. All family caregivers, and I want to make sure that I point out that family caregivers range from Gen Z all the way up through Boomers and the Greatest Generation, that over half are over the age of 50. They are already stressed, prior to the pandemic, and the research that I just mentioned, we find that during the pandemic, now seventy-five percent of family caregivers say that they are more stressed now than they were prior to the pandemic. And further, over half of them are spending more time on their care responsibilities now versus prior to the pandemic.

AARP has tried to put a much needed spotlight on the needs of the millions of Americans who care for their aging parents, spouses and other loved ones. We've been actively advocating for transparency in virtual visitation for nursing homes across the country, particularly during the pandemic. And we've been continuing to push our efforts to lower prescription drug prices and costs, helping family caregivers address their mental health needs, and helping employers make their workplaces more caregiver friendly.

We now have a chance to seize this moment. As Emily really drew out in the data that she shared with what consumers are looking for, we have a chance to seize this moment to create meaningful long term change in our care system. The work of family caregiving is just one aspect of that. We say that caregivers are the backbone of our long term care system in the country. Caregivers and the care that they provide is also vital to reviving our national economy.

There are many hard and soft costs that the pandemic is amplifying - your mental health, your finances, your own physical health, and the future of your career. I know today we're going to be really focusing on the financial, emotional, mental and health strains from the pandemic among those 50+.

AARP is proud to sponsor this virtual event and to shine a bright light on these issues. We're fighting to address the concerns of the 50+ in our state and federal offices throughout the country and to equip families with the much needed information, resources and support they need to be an advocate for themselves and their loved ones. We've doubled that effort during the pandemic. If you are looking for more information, particularly those things relevant to COVID and the pandemic, please go to aarp.org/covid.

I'm happy to be here with my colleagues Leigh Purvis and Joanne Grossi who is our AARP Pennsylvania State President as was mentioned. We're looking forward to a great, thoughtful discussion with all of our speakers. And finally, I definitely want to give a great big thank you to USofCare for all they do and in particular for pulling together this great webinar. And now, I'd like to turn it over to Joanne.

[13:54] JOANNE GROSSI

Thank you, Bob. Your comments were so relevant because I'm one of those women you were speaking about. So a perfect segue. Good afternoon everyone. I'm really happy to be with you and I'd like to speak to you for a few minutes on two perspectives regarding the emotional and financial strains on the 50+ population during the COVID pandemic. First from a general and then for a personal perspective.

Regarding the general, AARP Pennsylvania actually conducted two polls. One in September and one just last week, on this issue. And I thought two of the results were really striking. First, 58% of respondents told us that they had to contact a creditor to seek relief from paying a bill they couldn't pay. So you see the financial strains on these respondents. And second, in our October poll, 62% of respondents told us that they were worried about getting coronavirus and that was an increase from the 55% in our September poll. So it demonstrates that anxiety is increasing among older Pennsylvanians around COVID. And just an interesting aside, 22% told us that they knew someone that had died due to COVID-19. And I'm actually one of those 22%. So it's clear that older Pennsylvanians are experiencing real financial and emotional strains from the pandemic.

On a personal level, I'm a caregiver for my 90 year old father and we have both certainly felt the emotional strain from the pandemic. First, my father fell in late May and I had to take him to the emergency room. And so I really got to experience, to some degree, what a lot of other families are experiencing because when I brought him to the emergency room I had to leave him there. I actually had to talk my way into going in to a certain spot in the emergency room and speaking to a doctor. Because my dad, on top of everything else, can't hear, even with hearing aids, and so I knew that he wouldn't be able to answer the doctor's questions about what happened to him. So literally had to beg my way in to be able to speak to a doctor to be able to tell them what happened to him and to give some list of medications and give some information, but after that they threw me out of the emergency room and I literally sat outside the hospital for 8 hours while I waited to find out if they were going to admit him, what their diagnosis was, etc. Then they actually did admit him and he was in the hospital for 3 days. And so I also got to feel that frustration, and fear, and anxiety of not being able to be with my dad while they were doing these tests. Again, he can't hear, so I knew conversing with the medical staff was going to be very difficult. The only way we could find out what was going on was by calling and hoping we could get a doctor for an update. And we'd find out things, for example we called be dad and found out they didn't feed him. All these things that would have been handled if we could have been with him. So I got to experience, really firsthand, what it feels like for these people who have had to drop off a loved one with COVID and never get to see them again. Because I can tell you that when I had to leave that hospital that day when they admitted him I really worried - was that the last time I saw my dad and I didn't get to say goodbye. And I get emotional about it, as you can tell, and he actually turned out to be fine, but it really gave me an insight into what some of these families have gone through.

In addition to that, you know, for my dad, he's felt the loss of his social connections. Although he's still seeing his children and grandchildren, he no longer gets to play in his weekly poker group with his buddies. And he's very involved with his church, but his church services were cancelled for months. And other church activities have been cancelled. So again, he's really lost some of his main social connections and I see the effects that has had on him. Fortunately again, he's still seeing his family and that mitigates the social loss for him, but it adds to the strain for me. You know as Bob was talking about a minute ago, as I'm now spending time with him almost daily, which is probably spending at least double what I used to spend with him and that's an emotional and physical strain on me as I have to fit in the drive to his house and carve out time with him among my other responsibilities. I'm a perfect example of what Bob was just talking about.

But I consider us lucky. As I have a few friends who have parents in nursing homes and I've witnessed the stress they've experienced by not being able to see their parents for seven months now. In a few cases their parents got COVID and in one case a parent has died. Alone, of course. So I have seen the toll this has taken when you're trying to navigate a parents care long distance. It has been painful and frustrating for my friend, to say the least. And, of course, here in Pennsylvania, 68% of the 8,800 COVID deaths have been in nursing homes. So this has been the sad reality for thousands of Pennsylvanians.

So to conclude, this pandemic has been a challenge for everyone, but I think it's clear there are some unique stressors for the over 50 population.

And with that, let me turn it over to Dr. Jodi Prohofsky.

[19:03] JODI PROHOFSKY

Thanks, Joanne.

Hello everyone.

My story is not very different from many of yours. Actually, I'm going to say it is rather common today. I am a caregiver!

In all reality, it is an identity that seems to have been part of my birth right. I had great role models of caregivers in my family.

My parents were amazing at supporting their parents through devastating illnesses and the end of life process. My mother provided her brand of caregiving to anyone she called FRIEND, and she called just about everyone Friend. My father cared for my mother through her cancer and through end of life. He was compassionate and loving. He received such positive recognition from the professionals working with my Mom as that was a great source of pride for him. So much so, that he has been volunteering at a hospital every week since Mom passed…until Covid hit.

My Dad lived geographically close to me for 10 years after Mom passed. And then 3 ½ years ago when he had the opportunity to move to senior living community which happened to be closer to my sister. Now he lives 1200 miles. However, it was a good move because he was happy to be around people his own age and have activities geared for him. It allowed him to get the most out of his fixed income AND it helped him managed the social anxiety.

Then March 2020 – in comes Covid. My sister, her husband, and her grown children are all working at jobs that do not afford them to work-from-home. Which meant some of her caregiving of Dad had to be distanced or furloughed.

My Dad's building went into quarantine. All activities where shut down. He was "let-go" from his volunteering duties because the hospital didn't want to put the volunteers at risk for illness. At first, he did not have a mask, or gloves, hand sanitizer…he didn't have anything at home. He didn't know if it was safe to go to the grocery store and quite frankly he vacillated on whether or not he cared. Which of course drove me nuts because I was not there to put a safety plan in place for him.

What did not change was that I could still talk to him every day. But his stress grew, everyone's stress grew, and now I can recognize that even though I tried to ignore it, my ability to employ my usual coping mechanisms were stretched to the max.

Again, not unique, but here's a sample of the initial chaos that was a part of my life as COVID rolled in.

All appointments, activities were cancelled which was more of an annoyance. That seemed to require a PhD in logistics to keep track of and reschedule.

My work moved to home and I wasn't logistically prepared.

My son was moved to at home schooling situation which meant we all were thrust into 11ith grade English class.

My son, who had inherited the family multi-generational anxiety, chose not to leave the house for any reason for fear of getting Covid. Getting him out of the house even for a neighborhood walk has been a challenge.

In addition, I am the President of our local Synagogue and I had to stay on top of State mandates and population safety and find new ways to bring the community together for religious services.

Oh…and my job was eliminated. So now I also had to start a new job search.

So…Caregiving for my son, my husband, my community, and my father was not fun – nope it was feeling down-right frustrated. There were moments when I resented being the one everyone looked to for emotional support and solutions.

And, I was definitely losing focus on my own health and wellness.

So… I had to take a deep breath, remind myself that I am wired to help and that I have handled many crisis situations both professionally and personally before. So…what did I do? To manage through this time I needed a plan. I do better with a plan. I know that doesn't work for everyone. But, when I break everything down into edible bites, it allows me to feel like I have a little bit more control. Not to bore anyone with the details but I started to make a list for everything and I mean everything so I could stay focused, connect to the right resources, feel accomplished, and most importantly not lose my "cool" with those I love most.

I had plan for:

· Conversations with Dad – things I had to cover to keep him safe. Ways to manage his stress. Things to stay away from because they triggered a whole bunch of frustration for both of us and I surely didn't want to snap or make him feel like he did anything wrong.

Ways to help him financially if needed. And then tech support for online shopping and Zoom lessons and things that could keep him active.

I had to have a plan for my son's school, AP tests, summer plans, 16th birthday recognition, drivers license test, and of course return to school.

I had to have a plan for health care for the family. Doctor's visits, medication refills (for humans and dogs), flu shots.

I had to have a plan for groceries, cooking, cleaning, laundry, activities and projects.

And I plan for diet and exercise. And even socially distanced socialization, which was also sometimes connected to exercise.

So you can see, my story's not special. I'm a caregiver who in 2020 got extraordinarily overwhelmed by more than my usual share of chaos. I forgot to ask for help and I didn't think I had the right to as many in my circle were dealing with things that were far worse. But there are resources out there. And we're not alone. When I can talk to others and share my frustrations, my stress, my accomplishments, my worries it helps me to think outside of my own box which turns my brain on to new solutions. So I keep regular dates with great friends who help me make more lists and now I have more capacity to be there for everyone I want to or need to. And I know that they're there for me too.

I want to thank you for letting me share my story today.

Now, let's turn this over to Leigh.

[25:12] LEIGH PURVIS

Hi everyone. Thank you for having me here today. I'm going to take a few minutes to talk a little bit more about prescription drugs, which is an area that, as Bob mentioned, is an area of long standing interest for AARP.

So I'm going to start off with a little bit of level setting that will help explain why this area is so important to us. And I think the short answer is the prices. I think if you've been reading the newspaper over the past several years we've been seeing some pretty eye popping prices.

And I always like to try to but that in perspective historically speaking. So about 1990 there was a drug that came out that cost about $10,000 per year and it caused an incredible amount of outrage. And we are now seeing prescription drugs that are on the market with prices that exceed $1M per year.

So we really have seen an incredible amount of price inflation that is having a huge impact on both patients and the health care system more broadly.

Unfortunately, those high drug prices are just the beginning. AARP has been tracking the prices of prescription drugs that are widely used by older Americans since 2005. And we have

consistently seen price treads, where prices have increased substantially faster than inflation. Anywhere from 2x to 100x. Something else that we've noticed is that everyone has kind of become accustomed to that behavior. And so when you see a headline about a drug price increase. A lot of times people won't think about that that's a price increase, on top of a price increase, on top of a price increase. And that really does add up over time. In one of our most recent Rx [inaudible] report we took a look at those high cost specialty groups and we looked at what the price would have been if the price had moved with inflation. And what we found is that on average the price of one specialty prescription drug would have been almost $50,000 lower if that price had stayed with inflation between 2006 and 2017. So again, these price increases that we have kind of become accustomed to really do add up.

Something else we're paying attention to is the price line. If you look at the drugs that are moving through FDA right now a lot of them are drugs that are specialty drugs. The ones that I just mentioned with the average price around $80,000 per year. What we're seeing is a lot of manufacturers focusing their attention on things like biologic drugs which are drugs that are derived from living organisms instead of chemicals. Or orphan drugs, which are designed for patient populations of less than 200,000 people. Or personalized medicine, something else we've been hearing a lot about lately. But the short answer for what all of these products represent is an opportunity to charge incredibly high prices. And of course from AARP's perspective we're looking at the people who are actually using those drugs and older adults, if you've heard us talk about this issue before, use more prescription drugs than any other segment of the population. On average, part D enrollees take between 4 and 5 prescription drugs per month and they often take them on a chronic basis.

So when we talk about people who are facing high prescription drug costs we are not talking about a one time, you're having a bad month, kind of situation. We are talking about people who are facing high prescription drug costs every month for the rest of their lives.

There's also a common misconception that older adults have resources that will allow them to absorb the costs associated with prescription drugs. Take a look at these numbers. Median income is just over $26,000 per year. And a lot of them have relatively limited savings. So they really don't have the ability to absorb high prescription drug costs today much less the even higher prescription drug costs that are coming tomorrow.

So you'd think, given all that information, that during a pandemic we would see perhaps some changes. Perhaps there wouldn't be as many price increases. As you can tell from these newspaper headlines, unfortunately that is just not the case. We are continuing to see the prices of hundreds of prescription drugs increasing since January of this year. This behavior, again, as I mentioned previously, is pretty consistent with what we've seen for decades at this point, but it does seem particularly egregious in the context of a pandemic.

Even more so when you look at the larger context. There are millions of Americans who have lost their jobs or health coverage or both. You're looking at people who are receiving unemployment. You are looking at people who have lost health coverage. And of course we are looking forward and looking at what could potentially happen with the Affordable Care Act, in which case millions more could lose that health coverage. So this issue is really one that is bad and is unfortunately getting worse because we're looking at millions of people who don't have an income or don't have health coverage or don't have either frankly and the context of high and growing prescription drug prices. And it really is just not a sustainable situation.

So of course we're looking at this and thinking, well what happens next? What happens if we don't adjust this problem? And I use the word sustainable and it's really true for the patient perspective and from the larger health care system, the reality is that prescription drug prices and the costs associated with them are not something that we can continue to pay.

I think it's also really important to keep in mind that this is an issue that people feel directly. Mpt everyone is going to go to the hospital and have heart surgery, but virtually everyone is going to fill a prescription drug at some point and go to the pharmacy and experience the cost associated with that. This really is an issue that they feel personally.

And again as I mentioned, if you look at the larger economic context, this issue is unfortunately not going away anytime soon. We are looking at millions of people potentially facing the possibility of not being able to afford their medications. And I think that one thing people way not recognize is maybe not taking that anti-cholesterol drug today would mean several months down the line you're looking at a much larger heart issue that could potentially be that much more expensive. So it's really important for people to be able to access and afford their prescription drugs because ultimately the health care costs could be even higher down the road.

Again I'm going back to kind of hammering on this. This is really important. People really do need some level of relief from high prescription drug prices. And we are facing the possibility of some serious problems down the road especially in the context of this pandemic. So again, an incredibly important issue for lots of people.

And now for another important perspective, I'm going to had this over to Toni, so she can speak about the on-the-ground provider.

[31:43] DR. TONI EYSSALLENNE

Thanks so much, Leigh. Really important topic.

So as we all heard, COVID-19 has taken a lot from all of us.

It has taken our freedom to come and go to places we never gave a second thought. Our decision making has been complicated to the extent that negotiating the risks, benefits and alternatives for something as simple as going to the grocery store or a walk in the park, must be considered. Many of us listening in on this panel likely have a story about someone they knew and loved or someone they know and love that either lost their battle with COVID or are struggling to recover. They are mothers, they are fathers, they are grandparents whose children and grandchildren have their own families, they have their own lives, they are aunts and uncles and sisters and brothers, and some of them live alone and either qualify for services that they are deathly afraid of procuring because of the exposure risk or they don't qualify at all.

Many gamble with the chance of dying alone or with family members at home with their independence and their dignity rather than being another COVID case in a cold hospital bed. Where if you could see the eyes of the person taking care of you it would be a luxury.

At Cityblock, we know we need to reimagine health care. We need to expand what we care for and we need to expand the modalities for delivering that care. The majority of our members are over the age of 50 and we recognize that their health is not a matter of one size fits all. We are dedicated to caring for our most vulnerable populations, including those with multiple and complex social, medical and behavioral health conditions. And who have historically been

marginalized by our health care system.

New York was particularly affected by this pandemic with the death toll as high as a thousand deaths a day, at one point, with the city reporting half the number of cases statewide. We knew our members were, and still are, at risk for contracting the virus and also becoming seriously ill from it.

So we went to work to ensure we could keep our members healthy and at home and designed a food delivery program. Access to food at the height of the pandemic was a big need. And it was especially stressful for our members who couldn't get to the grocery store safely, didn't have a network to assist them, were experiencing financial hardship due to recent changes in household income, and/or needed to stay isolated to minimize exposure.

We developed a high risk courier program to ensure our members had the supplies they needed to monitor their health at home. With our community health partners and nurses checking in on them oftentimes daily to ensure all of their needs were met. Medications and cleaning supplies and paperwork for applications and medical supplies for home monitoring such as blood pressure cuffs and thermometers and pulse oximeters - they were all delivered.

We developed a rapid response team of nurses and paramedics with the virtual backing of a physician to go see members with concerning symptoms and manage them in the home so they didn't have to go to the emergency room.

In order to respond to the clinical needs of patients throughout the city, many health clinics have turned to virtual health, but this is a technology that many of our elderly need help with. And without that help are effectively denied access.

And finally, the mental health toll on our population cannot be overstated. The anxiety of not knowing who has it at any given time, the isolation, the food insecurity that is already an issue in our elderly continues to be exacerbated. Several of our members during this time have stopped going to their appointments even after clinics reopened. Their were members that we visited who had orders for imaging and for labs that they had never done because they were afraid to leave their home. And by the time we got to them, some of them were in crisis. No one wants to go on public transportation or expose themselves to a health care worker when they've heard on the news about the limited PPE that we're experiencing. If you were lucky enough to survive, you were traumatized by the early and callus discharge that you experienced from the hospitals that were frankly quite overwhelmed. And as a health care worker, you were traumatized by the news that your patient or your friend, your family member died alone.

We expanded our mental health capacity to help folks with the increased COVID anxiety that many were dealing with on top of their comorbidities. And oftentimes our care teams were the only family that some of our members even had. The folks in our community, to be clear, are not looking for pity or for charity. They want what any one of us would want - and that is the freedom to live in a world where the decisions about their health are not driven by fight or flight, but it's driven by justice.

And so with that, I will pass it off to Emily so we can take some questions.

[36:54] EMILY BARSON

Great, thank you Toni and thanks to all our speakers and panelists today.

There's been a great sharing of perspectives across the board that we're all experiencing in this pandemic and I really appreciate everyone joining and especially sharing your personal stories.

I do want to open it up, if folks have questions, you can use the Q&A chat box at the bottom of your Zoom screen and enter your questions.

And I'll start us off. Toni you shared a number of the challenges that your populations are encountering and I think a lot of these are overlapping crises - wondering what policies or solutions you think the government can offer to help right now as well as strengthening for the longer term? Certainly for others as well, but we'll start with you Toni.

[38:01] TONI EYSSALLENNE

Yah, great question. I think these are things that all of us are thinking about. How can we strengthen the system so that we're not trying to catch people with nets when it's too late. And I think that one of the things that we have to do is we have to think about where we are investing our resources. How we are going to make sure everyone has access to health care. We heard earlier that the ACA's at risk. And so that's something that's going to incredibly affect the members that we're talking about. The population that we're talking about, if you don't even have access to being covered with insurance, how are you going to be able to access those services? And so I really think we need to take a close look as to how we are providing health care to our population. I think that's an incredible question and I think that the fact that some people have under insurance, we don't talk about those folks a lot. Those folks who are underinsuranced they suffer a lot. They almost are able to get a service. I had mentioned that we have members who don't even qualify. They'll have insurance but they won't even qualify for extra services based on some bureaucratic loopholes. That stops them from being able to get access to the full gamut of services. So I think that we really have to think about from a governmental perspective what are we trying to do with our population and what do we want to support them. And make sure that health is actually supported as a human right. As opposed to a privilege. And it shouldn't be. It should be access for all and I think that's where we need to start the conversation.

[39:40] EMILY BARSON

Great thanks so much. Would any of the other panelists like to chime in with your thoughts on that? Great, well will continue, we got a question from a participant, what creative and safe ways are you seeing older adults fulfill their social needs and how will these be impacted by winter and do you have any other recommendations? Um Joanne I know you spoke a little about this with your dad do you want to start?

[41:13] JOANNE GROSSI
Yeah I mean I don't think I'm going to say anything that's earth shadowing you know different than what people thought of you know. I know for my dad even just you know doing FaceTime with his great-grandchild you know who lives in Virginia that's really important to him we make sure we do that weekly so you know he can get to see her you know and see how she's developing even though he can't be with her. And I think you know unfortunately given his age, he's 90 years old, he can't do FaceTime with his friends, they don't know how to do it. You know no matter how many times we told my dad, he can't do it if we're not there and his friends can't either. So it's it's funny there's something that technology can help when you're really elderly, but I think there's some limitations to it but you know obviously all the things that you would think

of you know making sure you're calling and checking in, you know we even have some people who will drop by food and leave it outside you know some neighbors or you know family friends who won't you know take the risk of exposing him, but certainly will leave some you know food outside his door or call him and you know again checking in. The church actually checks in with him a lot, they've got a system set up where they check in and even one of the things we are doing, and then I'll turn it over to someone else, but even one of the things we are doing at AARP in Pennsylvania that I really like we've gotten volunteers who now can't do any outside activities we have them actually calling people who used to go to senior centers so we've actually kind of gotten all of our army, our volunteers, a list for them from, we partnered with the Pennsylvania Corporation on Aging, and we got a list of people who actually normally go to senior centers who can't go now so our volunteers are actually calling them. So, again I don't think these are any ideas that maybe no one else would think of, but I'm just definitely ways to make sure are staying connected and staying in touch with.

[42:03] EMILY BARSON

Great, thank you. Any other ideas or creative thoughts to share with our audience?

[42:12] JODI PROHOFSKY

I'll just add, you know I think back to when the pandemic started and we were all trying to figure out ways to socialize, but distance and it was still a bit colder then so as the summer has been ending and fall is coming to an end we start thinking like all that's going to get cut off so we've been trying to creatively think about how do we go back to those drive by conversations, where we find parking lot that we could park you know 6, 12 feet away, roll down windows, but be in the warmth of the car, but still you know visit. So I think it's just going back and again working with everybody you know to figure out how do you do it so it's comfortable and where you don't have to cut everybody off from one another.

[43:02] EMILY BARSON
Great, great thanks. Bob were you jumping in there as well?

[43:08] BOB STEPHEN

I was just going to mention actually coming up we we got the holidays and the holidays are going to be completely different and it is something that is going to be potentially very difficult for folks. That's one of things that we're trying to compile a lot of these really great ideas and actually are trying to encourage the idea of friendsgiving, that not just for family, but reaching out to those who you know who are caring for someone and they may be feeling isolated that even if you can't see them, and I love the parking lot idea I should say that, maybe you find a way to maybe cook together from a distance. I think the holidays are going to be very tough and different for us this year.

[44:50] EMILY BARSON

Yeah thanks. I think this is absolutely just demonstrating the overlap of the caregiving and the mental health challenges and it's not just about getting people to their physical health appointments, but really making sure that they're some of those social connections, especially for those of us who experience winter and are looking ahead. We have another question that I am certain my friends at AARP have thoughts on. How can we provide healthcare to the 50 plus

populations in an equitable manner, keeping in mind those with multiple intersecting identities in addition to their age.

[44:30] BOB STEPHEN

I may actually put it first to Leigh because I think certainly the pharmaceutical, the drug cost is a big part of that.

[44:44] LEIGH PURVIS

Yeah, absolutely correct. Even if you do have health coverage at this point, a lot of what we're hearing from our members is they still can't afford their prescription drugs and unfortunately that can apply to a lot of different healthcare services. It is definitely a challenge to provide good health care coverage to a wide swath of the population, but that is certainly something that AARP has been fighting for for a very long time and is why we are very supportive of the Affordable Care Act to the extent that it has kind of strengthened some markets that our members are particularly involved in. Again, we want to make sure that those protections remain in place so definitely a challenge. Unfortunately our health care system is complicated and we have a lot of very expensive services that we are using, but we are using but we are definitely working to make sure they're available to everyone and also affordable.

[45:35] BOB STEPHEN

Yeah, and I would add in, and my perspective comes from where I sit within AARP and the long-term care caregiving side of things, which is that we need to make sure that there are options available to everyone that are both that are affordable, they're high-quality, but they're also acceptable. And I think the question also talked about the multiple identities and that's an issue for so many as we age is that there may not be the options in my community that are culturally appropriate for me and so that's really one of the things that we're fighting for is to make sure that everyone has the options that they want, that are acceptable to them, that are affordable, because that care that long-term care part of things is a critical part of it as you get older, the health care in your life.

[47:19] JOANNE GROSSI

Could I just add two quick comments to what both Leigh and Bob said is you know especially on prescription drugs you know I know it's one thing to say it you know that people are making choices between rent and you know or mortgages and buying prescription drugs, but last year in Pennsylvania, and we did it nationally too, but we actually had Town Halls all across the Commonwealth you know inviting people to come and telling us their personal stories about you know how they're dealing with prescription drug prices and it's one thing to have us kind of say this academically, but when you've had you know a hundred people in a room and they're telling you their personal story that they've had to leave you know a drug at a counter and walk away because they couldn't afford it, I mean it's real for people. There really are people out there and we got to hear from thousands of them last year telling us that they really have to make decisions about are they going to buy food or are they going to get this prescription. So I have to echo Lisa about this is just got to be an issue that changes and secondly you know for to Bob's point I mean here in Pennsylvania you heard me mention that 68% of the people who have died from COVID have been in nursing homes and I think that's been a real wake-up call at least in the Commonwealth that we have got to do a better job about how people have have their end-of-life either you know can they have end-of-life in their home, which is ideal it’s what my

dad is trying to do, or you know, they've got to have better care in nursing homes. I mean this has just put a spotlight on the inadequate care we are getting in our nursing homes.

[47:45] EMILY BARSON

Great, thank you. And that may….

[47:50] DR. TONI EYSSALLENNE

I'm sorry I just wanted to add like just from the perspective I mean we see so many so many patients who are coming in crisis because they can't afford their medications. I mean everybody has a story of somebody who died or was in dka because of the insulin situation and these things are just just incredible injustices that are happening to human beings in our population and I think you know in terms of representation and multiple identities and making sure that everybody everybody is represented properly it's really being able to like when you get a seat at the table looking around at the table and who is sitting there, who is sitting there. Who is making those decisions. Who is, who is amplifying the voices of those folks who are the most vulnerable and I think that's what we don't… we need to do a better job of being able to do that and having organizational leadership where they are taking an active look at who's on my board, who are, who are making the decisions so that we can actually drive these policies forward.

[48:49] EMILY BARSON

Thank you. Thanks for those perspectives. Our next question and I think I'll maybe ask Toni first, but I'd love to hear from others. You know how has the pandemic made us rethink wellness versus illness care and how can we you know switch that thinking in the future around you know wellness and sick care.

[49:13] DR. TONI EYSSALLENNE

I think if you're in public health if you care about public health you're always trying to figure out how you can maximize wellness over illness because you don't want them to get there. We don't want folks to we don't want to have to treat the crisis right? We want to be able to prevent the crisis. It's so much more it is so much more cost effective to do that. And so I think for me and I can only speak for myself personally, I don't think it has changed my mind at all if anything it's made me more vigilant about about wellness care and making sure that people are in a position where they're healthy and not going to be vulnerable to something as devastating as COVID can be.

[49:50] JOANNE GROSSI

Yeah, can I add in on that? Emily I mean as you know I used to be with the U.S. Department Health and Human Services when we implemented the Affordable Care Act and as you know prevention with such a cornerstone of the Affordable Care Act, preventive services. And I do think this really highlights for everyone what we're going through now, how important prevention is. You know vaccines, exercising, staying at a normal weight, you know keeping diabetes under control, so you know I really want to say I hope we make sure we really give more you know you know we really speak more. I don't think we… I used to be a public health official for 30 years. I don't think we ever get the message across well enough about prevention and what an important role that plays in people's lives. So I do agree with Toni that I think you know going forward I hope you know, like even in this country only 65% of people get their flu vaccine right.

So you know just making sure people do all the preventive measures they can to make themselves stay healthy so that when you know something happens they're in better shape to survive something.

[50:55] EMILY BARSON

Absolutely. Um thanks for that. Another question we got is do the panelists have thoughts about changes that can be made to Medicare and Medicaid to improve services and provide support to elderly and or low income people. Bob…

[51:18] JOANNE GROSSI

I was gonna say I don't want to keep being, monopolizing here, but just a couple quick thoughts because I'm living it with my father right and actually I stood on a Medicaid managed-care board so the two things I would say is you know I think we've really seen importance of home health care you know Telehealth, you know visiting nurses. I hope we can get to a place where doctors actually come back to the home because we know people want to (inaudible) in place and seeing the experience with my father having been in the hospital I saw how much he was able to recover because he did get home health services, um but I think you know there was a very limited amount of home health services and I think you know expansion of that making telehealth you know permanent, by the way this is my personal opinion. I'm not speaking officially you know the AARP point of view on this, but in my own personal opinion you know I think we have to make telehealth permanent and actually increase the services people get at home, including things like transportation that people really know a lot of people really need transportation services to get to their doctor's appointments. I don't know what my dad will be doing right now if I wasn't taking him to all of his appointment so there's just a couple of comments I would make about the changes I think we need to make.

[52:27] BOB STEPHEN

And I would echo that. Joanne said it much better than I could, but yeah we look at it from a consumer standpoint and what they're telling us and just data that we're going to publish in another week or so. 93% of those that we talked to over the age of 40 say that they really want to be able to stay in their home as they they get older, but they're not they're not taking the steps to do that so the more that we can make it easier to do that, everything from telehealth to have that option instead of going to rehab in a facility to do it at home, is really going to help. That's what individuals want.

[53:10] JODI PROHOFSKY

And Bob if I can add, I think where plans do have those programs and many do, I think we need to do a better job of people understanding what their benefits are. It's hard to navigate even if you've been in the business for a long time. If you've not, it's next to impossible. So those programs all need to be really set so that the communication and the orientation to what is available to you is at your fingertips when you need it, not when you sign up for the benefit only.

[53:41] BOB?

That's an excellent point. I agree.

[53:45] DR. TONI EYSSALLENNE

I would agree with all of those sentiments and you know at City Block our care model is actually like based on everything that you guys have talked about. We have community health partners who are representatives of the community, who go out to the home, call folks on the phone, and try to build that bridge of trust so that we can get to them from the medical and behavioral health side and provide those services, and make sure that they have the social services that they need, providing transportation to get to their appointments, making sure that they understand what they need to get to an appointment, and what do they need to do after an appointment. Like you said, you would be surprised at how much the gaps are with people going to their appointment and then coming away, they're confused. And so making sure that people understand that and you meeting people where they are and I agree Joanne with regard to making sure people are at home, you know you were saying about the getting the doctor back in the home, that's what we do with City Block is we go back we go into the home and we take care of folks in the home and see them and do our full physical exam making sure that their home is safe and making sure that they don't need any other type of devices to help them walk around. And so I think we need more of that right, we need more flexible health care and meeting people we they are as opposed to this stringent, protocolized, this is the way we do it all the time, in this is just a history, it's time to it's time to shake it up.

[55:05] JODI PROHOFSKY

And you know Toni, Emily can I add one more thing? I have to agree with something you just said wholeheartedly I mean you know my dad would not understand his doctor's appointments if I were not with him and you know taking notes and explaining it later. And you know not everybody has someone that can go with them though. So I really wish we could come to a place where Medicare especially would have a program where you get assigned almost you know someone who goes with you into the appointment and you know either takes the notes for you or you know makes sure you understood it, follows up with you later to make sure you understood what happened. You know I'd I just have seen way too many times where older people go to a doctor's appointment and they they couldn't hear what they were being told, they don't understand what was being told, and and so that affects obviously their health outcomes you know including medication. The last thing I'll say is you know if I didn't put my dad's medicine in a box with each day on it for AM,PM, etc. and then looked the next day to make sure he took it all at the right time he would absolutely not be adhering to his medications properly either. So I just think you know we are really falling short in understanding that older adults you know really need much more assistance to stay healthy than we're giving them right now.

[56:18] EMILY BARSON

Well thank you. Thanks for this great discussion I know we had a couple more questions we didn't quite get to. We are right at the top of the hour and want to be mindful of our time so I really just want to thank everyone for joining us this afternoon and special thanks again to all of our speakers and to our sponsor, AARP. As a nonprofit organization we are, work like we shared today with all of you, relies on the donations that we receive from individuals, foundations, and businesses. If you would like to join our community, you may make a gift directly on our website at United States of Care and you may also find other resources, including what we discussed today, a guide to humanizing covid-19, as well as a slew of other resources around the pandemic response at unitedstatesofcare.org/covid-19. Please follow us on Twitter and other channels, @usofcare. Thank you again and have a great afternoon. Thank you.