

America CARES Forum

**Cosponsored by Altarum Institute
Center for Elder Care and Advanced
Illness and Caring Across Generations**

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This transcript has been edited for clarity

Jim Lee, Vice President - Altarum Institute

Welcome to the America CARES Forum where we are gathering to build an even larger movement dedicated to improving our nation's paid caregivers and family caregivers' lives as they work hard to serve our loved ones.

I'm Jim Lee, vice president at Altarum Institute and I would like to welcome those of you who came in person and those of you attending via the Web. We want all of you to participate as we share and learn from each other, and identify opportunities to influence the urgent issues facing caregivers and paid care workers, and most importantly the people who need these caregivers.

So, please use the chat function if you are participating remotely to ask questions and we will get to as many as we can. We also have an open-ended question for you to write a response to at any time during the forum. We will analyze the answers along with survey data and exit polls for those of you who are "quants," and for those of you who like stories we will have some stories as well.

We will provide all of this in a summary report available in December and here is our first question. List the top issue you think caregivers and care workers should press for with national, state, and local policy makers.

I would like to extend a warm welcome and hearty thanks to our partner, Caring Across Generations, for helping create this forum for collaboration, advocacy, and action. We are also grateful to the Cambia Health Foundation for helping fund this forum. Thank you.

In a recent survey that Altarum conducted, sponsored by the Robert Wood Johnson Foundation, we learned that family caregivers compared to other adults are twice as likely (about one in six), as those who are not serving as caregivers to state that their stress level is at a 10 out of 10. So, one in six caring for adults have a stress level of 10 out of 10—and even more stress is reported by unpaid caregivers to children—nearly twice that rate with one in four. That is a lot of people in this country.

A particular challenge arises for those families who have modest incomes. Nearly one half of these caregivers struggle to obtain financial support and the types of assistance that they need to make it through every day.

Personally, my father retired early to be a caregiver to my mother, kind of a role reversal that we do not see too often but more frequently. I served in a relief role for him along with some of my siblings. Our experience with the medical care system was quite frustrating and almost fully unsupportive in assisting with a person with serious mental illness.

I also spent two months as a caregiver to my brother where the medical care system was terrific and he—because of his outgoing personality—had a terrific social network of support. But many people do not have the same financial and social capital available to them, and even my family found that very quickly we were testing the limits of those social connections. So, our families' and caregivers' state of affairs can and must be improved now—and we have the money. I am usually the economist pessimist. But we have the money—we just need to forge the will to use it wisely.

I will now turn things over to Sarita Gupta. Sarita has not only helped launch Caring Across Generations with Ai-Jen Poo in 2011, she also serves as executive director of Jobs with Justice. Sarita was recently named an Influencer of Aging by Next Avenue, PBS's Digital Magazine for People Over 50, like most of us. Welcome Sarita.

Sarita Gupta – Co-Director – Caring Across Generations

Thank you. Good morning.

Sarita Gupta

My name is Sarita Gupta and I am the co-director of Caring Across Generations, and I really want to thank Jim, Anne, and others here at Altarum Institute for co-sponsoring this event with us. We are thrilled to be here and I want to thank all of you for being here as well for this really important conversation.

A little bit about Caring Across Generations: We are a national movement of families, caregivers, people with disabilities, and aging Americans working to create a new approach to care—one that supports the dignity and needs of older Americans, their families, and the caregiving workforce for the 21st Century. This will require access to quality, dignified, affordable care choices for families and individuals, more support for families, millions more quality caregiving jobs with adequate training, living wages, and benefits.

Baby-boomers are starting to retire and need care, as many of us know, and millennials are starting to become parents themselves. So, the need for care in this country is just exploding. We are in the midst of an unprecedented elder boom. Every eight seconds another baby-boomer is turning 65—that is four million Americans per year, and almost one in five Americans by the year 2025.

By 2050 the number of us who will require some form of long-term care and support will double to 27 million. This is an issue that impacts all of us. When I go around the country and I talk to people, we share stories, and I have not run into one person who has said “this is not an issue that really is impacting me at all.” *Everybody* has a really important care story to share.

My story of why I am on crutches is actually because I am a family caregiver, my father has Alzheimer’s, my mother has pretty severe arthritis; they both live with me, and I am also raising a 6-year-old daughter—who is very active by the way. One of the ways that I relieve stress in my life—because I also work full-time—is to play soccer, and unfortunately a few weeks back I had a little soccer injury, so I am on crutches for the next few weeks and am certainly appreciating care from a whole new angle as a result.

But all of that to say that I am part of this sandwich generation or—I like to say, “the Panini Generation”—feeling incredibly squeezed in this moment. It is so important for us to be thinking about this issue not only for our aging loved ones, but really for the multitude of people who are in positions like this, trying to manage a whole breadth of care needs.

I believe as a nation we really are at a crossroads right now. We can stay with the status quo patchwork system and let the next economic crisis take place in our homes, or we can take advantage of this tremendous opportunity to build the care infrastructure that we need, and support the realities of 21st century families while meeting the country’s soaring future needs for home-based care and more affordable childcare.

While there is talk about investing in national infrastructure, we need to expand on what this looks like and what the maximum benefit can be for working families. So, beyond our physical infrastructure of roads and bridges, making major investments in our people infrastructure – the millions of family caregivers and professional caregivers, and the millions of new jobs that need to be created in the home care workforce to meet the surging need for care.

This also ties into discussions around the need to create jobs, which have to date fallen short of meeting the need to invest in the fastest growing job sector in the United States—direct care jobs—and in particular those in-home and community-based settings.

This investment in workforce is really a down payment on the future well-being of our families and protection against much higher costs and a lack of home and community-based quality care down the road. At the same time, states can act much more swiftly to directly address the needs of families in their states. Caring Across Generations has thoughtfully analyzed and put forth recommendations for what a state solution could look like, as well as how it can be financed. We are moving this very work in several states.

We have an opportunity right now to strategically push for our recommendations, as the President-elect has highlighted childcare and elder care in his first 100-day plan. The more opportunities we have to come together to share updates on our work and look for the opportunities to cross collaborate, the stronger our organizing and

the stronger the care agenda will be. We are thrilled to be here today and look forward to the conversation. Thank you.

Anne Montgomery – Deputy Director – Altarum Institute Center for Elder Care and Advanced Illness

Thanks so much to Jim and Sarita. That was a terrific opening to our forum. I am Anne Montgomery. I am deputy director of Altarum Institute's Center for Elder Care and Advanced Illness, and in thinking about what to say today, I tried to step back a bit and channel some great thoughts and sharp minds, and how they operate in times of uncertainty. One of the greatest is Eleanor Roosevelt, who in July 1940, on the eve of FDR's third term and set against the chaos and the fear of a war-torn Europe, flew to Chicago to address delegates. Here is what she said:

"We cannot tell from day-to-day what may come. This is no ordinary time, no time for weighing anything except what we can best do for the country as a whole, and that responsibility rests on each and every one of us as individuals."

On November 4th of this year, another time of great uncertainty, *The New York Times* published a column written by an interesting duo: the Dalai Lama and Arthur Brooks of the conservative American Enterprise Institute. They explored why millions of people here, in Britain, and in other prosperous and safe countries are so angry, and here is what they said:

"In America today, compared with 50 years ago, three times as many working age men are completely outside the workforce. This pattern is occurring throughout the developed world, and the consequences are not merely economic. Feeling superfluous is a blow to the human spirit; it leads to social isolation and emotional pain, and creates the conditions for negative emotions to take root."

I think we all know this is no ordinary time and there is no shortage of angry people who are affecting the course of events and the tenor of public discussion. This is a populist era for better or for worse. It is also a moment when movements happen.

We set out a few weeks ago, Altarum Institute and Caring Across Generations, to see if we could combine some thoughts and ideas and come up with an event that would not simply be a one-off, but a kind of launching pad for a whole set of additional work that all of us are doing. With a lot of hard work and determination we put this forum together, which we are calling America CARES. But it is not really about our two organizations. It is about all of you watching online and here today, and everyone that you are connected with, because that is what we are trying to do. We are trying to connect the dots between our initiatives and our collective passions and commitments and networks.

An estimated 90 million Americans care for someone who needs help to function, who is ill, elderly, or disabled, and in effect we represent those people. That is quite a movement.

So, here we all are; an activist subset of those tens of millions, and I think it is fair to say that we are all hopeful people. We care a great deal about the lives of all those families who support someone, and sometimes several people, with a disability. We know that family caregivers have often been ignored, and along with many other wonderful people and organizations, we are here to try to change that. Equally important, we are here to bolster those who care for people for a living as professionals.

On a fundamental level what we have in common is that we want to create a much stronger care economy. What does that mean? Well, for starters, the Dalai Lama-Brooks column argues that to combat anger, social isolation, and feeling useless we must build societies that truly need everyone. Another way of saying that is that we need to create broad-based strategies that include everyone and that care for everyone who needs this.

How do we accomplish such goals? I think each one of us has a piece of the answer and a part of the solution. We are going to be trying to assemble those pieces today into something bigger. It is a lot of work, but we have some of the best people with us in person and online to do it. Of course, we will start today but we will not finish, so that means we will keep working together as a movement.

In a moment, we are going to hear some very interesting data about what voters think and what resonates with them about family caregivers, care workers, and long-term care. As you know we conducted our own survey of those who registered, so thank you very much for filling those surveys out. We tried to drill down on specific possible policy solutions that we can take forward so we will be talking about that, too.

Last week's election results caught an awful lot of people by surprise, and many are still incredibly shocked and some are afraid. Perhaps the most useful response is to get active, kick into overdrive. There is no doubt that we have it within our power to create momentum for change that is wanted and needed, and to take that forward. Our system is designed to make that possible and we know that money does not produce the best ideas; collective work does.

At Altarum, our warm up for this kind of collective work was an initiative we launched in 2015 called the Family Caregiver Platform Project. It aimed to use volunteers to seed state party platforms around the country with language that speaks to the concerns of family caregivers and the kinds of supports they need to keep doing what they do. Of course, these issues intersect and intertwine with those of care workers in long-term care. Happily, we succeeded in getting language submitted in 11 states. In two cases, advocates decided to go through the state legislature with a resolution; one was Mississippi, and Spencer Blalock is here today to talk about that from Jackson, Mississippi.

Before turning it over to Kevin, who will talk about the sweeping and exciting work being done by Caring Across and others in a number of states, I want to say that we are gratified to find that there is support in both the voter polling data and in the survey that we did of those who work on these issues, as well as what AARP has found and many other organizations for financial help for family caregivers, improved access to care workers and in-home services, and for making housing suitable for people with disabilities.

This *is* long-term care, and we are here to talk about it and help make it happen. We are here for the long haul, the major lift. I look forward to hearing about the details from all the different perspectives that we will have here today and thanks for being here. And I look forward to working with you all. I now will turn it over to Kevin.

Kevin Simowitz – Political Director – Caring Across Generations

Hi there, my name is Kevin Simowitz. I am the political director at Caring Across Generations and the Caring Across Action Fund, our 501(c)(4). You are going to hear it in my voice, but I have spent most of the past six days yelling into a megaphone on different streets and street corners, so sorry if I sound a little bit scratchy.

Election results analysis: whew, deep breath. I obviously signed up for this more than a week ago, and the helmet and shoulder pads that I was hoping to wear this morning are not included in the presentation. So, we are just going to go forward, we are going to talk a little bit about what happened and a little bit about what we think could happen next.

I just want to highlight that for us, at Caring Across, we work in culture change, advocacy, and political space, really trying to reimagine the way that we can care in the country. As I speak to the political end I think it is important to note that the work that we are doing in advancing candidates, and kind of the issue environment around care: looking at the two candidates that we had this year at the presidential level, I just do not want to pretend to beat around the bush that we saw two equally compelling visions to advance the care agenda that we believe in.

I think it is really difficult, maybe even a willful misunderstanding, to look at the positions put forward by the incoming Administration and feel particularly hopeful about the core of our care policy. I also think looking at the track record of leadership in the Senate and the House right now, it gets really hard to feel particularly hopeful about legislative progress. This is not going to be all doom and gloom, but I just want to be realistic about our perspective from the campaign.

I do not want to dwell too much on the possibilities at the federal level, both to avoid repetition, because my family has sort of a history of hypertension and I do not want to exacerbate that this morning so I will try to keep moving. But I also think it is interesting for us to note that in large part, as a result of work done by people

in this room, caregiving entered the presidential campaigns this year in a way that we have not seen it enter before.

I think kind of moving from the outskirts of policy websites to the center of public addresses by candidates is one of the ways that we can measure a little bit of the changing issue environment around long-term care. Of course, one of the spots where we saw that most clearly was in the fact that both of the major parties incorporated long-term care into their party platform really explicitly and really clearly; and again, that does not happen without a lot of the work from people right here in this room.

Of course the Democratic Party in particular expanded on the vision a little bit more, talking about the homecare workforce, and then that showed up in some of Secretary Clinton's campaigning, both early in the campaign when she met with a group of SEIU homecare workers to talk about what that job was like. Then later in the campaign, in early fall she met with a family caregiver backstage at an event in New Hampshire, and then, after hearing that story, incorporated what she heard in the middle of her speech to a crowded room. The Clinton campaign, feeling like that issue resonated, began to incorporate that story and the issue of family caregiving into some of their online communication for the coming couple of weeks. It feels small to look back at that now, but I think it is important to hold onto those moments to see where breakthroughs are possible.

It is also, of course, important to look and see where we did *not* have a breakthrough this year, as we look at 2018 and 2020. Care was noticeably absent from the debates both during the primaries, and when we narrowed down to two candidates. I think a lot of our work looking to 2020 should probably consider how we move from the policy platforms into actually having a public conversation, which most of us are already having, by asking candidates to align their platforms up side-by-side and giving voters a chance to compare.

So, with that, I would like to shift from thinking about candidate campaigns into thinking a little bit about the voters. At the presidential level, if you are anything like me, you have spent a decent portion of the past week or so analyzing exit polls and data, and if you are really like me you have been matching that data up with who is invited to Thanksgiving and trying to figure out where you want to sit and who you want to sit next to. But the reality, from a progressive understanding, of what we saw on Tuesday is there are a lot of things at play, but one is surely that there was a fundamental misunderstanding of who is and who was the Democratic base, and how large the Democratic Party's reliable voters actually can be.

So, I am going to try to resist anything that oversimplifies the election result, because I do think it is complicated, but I also want to highlight one of the stories about the base of the Democratic Party. I think we have all seen this, a lot of people who voted for President Obama once and quite a few people who probably voted for President Obama twice also voted for Donald Trump.

I pull that out because I think that when we think about how care can function in future elections, it really does feel like one of the few issues that can be part of intentional outreach to voters who progressives are going to try to reach. I am thinking especially about white voters in the Rust Belt and in the Midwest, and I am thinking specifically about white low-income and middle-income voters.

Care can be an issue that is both aspirational and honest, since the need for care is practically universal. Our work at Caring Across, as Sarita mentioned, is really right now centered on this idea of universal family care. That is a policy idea that combines childcare, paid leave, and elder care into one policy - understanding those three components not as competing versions of care but rather part of a care continuum that stretches throughout the lives of most families.

If care is going to be an outreach issue beyond the base, one thing that we have noticed from our work both nationally and at the state level is that we have to talk about care as an economic issue, and not solely as a moral imperative. I think that can be a struggle for some of us in this room. It can be a struggle for us at the Caring Across campaign sometimes. It can feel like that is the messaging that we *have* to use rather than the messaging that we want to use. But to continue telling care stories that speak more to the narrative that we want to establish than they do to the needs and desires of the voters that we just heard from just concedes the possibility of any sort of legislative or electoral progress in the next two to four years, and I am not willing to make that concession.

So, I am going to pivot and think specifically about work that happened at the state level this year. I think it provides important lessons about how we incorporate care into progressive electoral work. Again, I just want to highlight that the work from our field partners is largely around winning elections where progressive candidates who share the values of our organizations were at work. There are going to be some inherent tensions between progressive political campaigning and bipartisan policy solutions that are going to be used in state legislative sessions.

So, one highlight is from Maine; you are going to hear more from Ben Chin at Maine People's Alliance later on today. In Maine, where universal family care legislation is going to be introduced in the coming legislative session, Maine People's Alliance, in their candidate questionnaire to everyone who is running for the state House and state Senate this year, asked a question of candidates about their support for universal family care and on a revenue mechanism to pay for it. The candidates who said they supported the policy got a chance to sit down with Maine People's Alliance members and leaders and talk about their support for it as part of the candidate endorsement process.

At the end of the day, more than 70 candidates for the state legislature in Maine expressed a commitment to supporting universal family care in the state legislature. To be able to have that deep conversation with candidates and actually say, "if you want our endorsement this is one of our core values" at the same time that people are knocking on doors and making phone calls were having that conversation in the field we think will really set up a different issue environment around family care in Maine in the coming legislative session—even in a divided legislature.

In Michigan, we're doing a similar type of work: our partners in Michigan endorsed a care champion in the only legislative district in the Michigan House that flipped from red to blue this year. I do not think that it is coincidence that a lot of really deep work happened in a district that has been held by a Republican for the last six years—a white working class district—and where our partners talked with mostly moderate white women about the concept of universal family care. The doors that they knocked on and the conversations that they had were new for both the people knocking and new for the people on the other side of the knock too, but the response was really tremendous.

There were anecdotal stories of people who had this conversation and said "I never thought about combining these things," and a story about one woman who had just moved back home and shot a video with our partners right on her doorstep about how important care was. And then of course, there was the quantitative result of winning by, I think 150 votes or something in that vicinity—a very close election winning on the basis largely of conversations about care with voters who were not engaged by some of the other topics that were out there.

That work matches up with what we saw from polling data earlier in the fall. I am going to give you two numbers from the polling data. I will not throw a whole lot out at you. Then we are going to hear a bunch of good numbers in our next presentation.

One is that after being told about the concept of universal family care, there was bipartisan support for the idea and for the revenue mechanism. Forty percent of people who identified as Republicans and more than 60% of Independents and Democrats said that they supported the idea of universal family care, and that was after a battery of opposition messaging. So, even after you throw in a poll, and everything that could be wrong about this idea out at the respondent, 40% of Republicans and more than 60% of Democrats and Independents still said "yes, this is something that I want to support." I think that is telling.

The other thing that is interesting is that when those voters were asked, "would you be more or less likely to support a legislative candidate who supported universal family care?" in both Maine and Michigan, more than 60% of respondents said, "I would be more likely to support a candidate who voted in favor of universal family care."

This is not nebulous. When this issue is connected to how people understand their votes and their elected officials, we are in a much stronger policy position.

I am going to wrap up with three quick notes about care policy as it relates to integrated voter engagement—which is that super-clunky term where we talk about trying to make sure that our work to build a grassroots base is linked to our legislative advocacy—and then connects to our electoral work.

First, we have seen that to use care effectively in conversations with voters, we have to be super specific. We cannot just talk about care as a value even though it certainly is. We also have to talk about it as a piece of economic policy that puts and keeps money in your pocket and meets a need that you and your family have.

Secondly, we have seen that the strongest case for care policy happens when we actually make a case about revenue. Progressive revenue messaging resonates exceedingly well with the progressive base, and it also resonates with the voters who we are talking about trying to reach. As we talk about universal family care and care policy in general, I think that we should be running *toward* rather than away from conversations about tax fairness.

Lastly, we have seen that care can open conversations with a new set of voters. We saw it in Maine this year, we saw it in Michigan, and I think we are going to see it in more states as we expand the campaign.

As we learned from the polling and the message research, as well as from this cycle, undecided voters can engage on this issue in a way that other issues fall short on. In fact, our partners in Michigan shared a story with me on Election Day: they were talking to people at their doors in that last little push to get turnout, and someone said to one of our partners, canvassers in Michigan, “oh, wow, this candidate cares about these issues! I’ll definitely support him.” That is not bad.

So, I think that is a good spot for me to leave this part of the conversation. I appreciate the time, and I am looking forward to hearing from everyone else today, and just hope that we soon find ourselves on that path to hearing a lot more “oh, wow, someone cares about this, I’ll definitely support that person” conversations in the coming years. Thank you.

Anne Montgomery

Thanks so much. Now we will move to a panel with Celinda Lake, Brian Nienaber, and Josie Kalipeni, and we will hear a lot about data.

Josephine Kalipeni – Director of Policy and Partnerships – Caring Across Generations

Good morning. I am incredibly excited about this conversation, and really happy to be here on behalf of Caring Across. I will do some quick introductions of Brian and Celinda, and let them take it away with some incredible and exciting conversations that I think will have a lot of nuggets for us to think through and apply to our work moving forward.

Brian is the VP at the Tarrance Group and a highly respected Republican researcher and strategist. Brian has worked on various political campaigns at all levels, including ballot initiatives and lobbying campaigns.

Celinda is the founder of Lake Research Partners and is a nationally renowned Democratic political strategist. She has led cutting-edge research and data on a myriad of issues including health care.

Celinda Lake – President – Lake Research Partners

Thank you. I am delighted to be here, and I am delighted to be here with Brian, because this issue is, as the previous data suggested, very much a bipartisan issue. It is not a partisan issue in any way. The next presentation also, the AARP survey, which is the first of its kind in-depth look at women over 50, really shows the power of this issue electorally and to women voters, to male voters, to millennials, to people of color, to women over 50, to white women—key groups out there.

This is data that we are going to share with you from an election eve survey—really an exit poll—of 2,400 likely voters nationwide. It includes cell and landlines, and you will see both some insights into the elections and some insights into this issue in the elections.

First of all, the elections: If we can stand to—now, no crying in the middle of the presentation, okay, but I can appreciate the sentiment—the Democratic voters in the last election tended to be female African-American, Latino, millennials and college-educated. Although, as you know, white women went Republican, and white women have gone Republican since 2004, so this was not a new development.

Secondly, while we split married women—and actually Democrats won them by two points—Obama lost married women in 2008 and 2012—they were split this time. We did not have the margin, and we only won college-educated women by six points. At one point they had looked like they would be 2:1 for the Democrats.

Republican voters tended to be men—white, seniors, and non-college educated. The older you were, the more likely you were to vote for the Republicans. There was a big gender gap—in fact depending on how it is calculated, the biggest gender gap we have had in a couple of decades—and of course everyone has paid a lot of attention to the enormous margins among white blue-collar voters. Also, rural voters who turned out in record numbers and rural voters, who in 2008 voted 8 points Republican, voted 28 points Republican in this election.

The reason I lay out these coalitions is frankly not to talk about a polarized America, but in fact to do the exact inverse of that and to say, when you look across these demographics, this [caring] issue has major salience to groups in both coalitions. Women care particularly intensely about this issue; so do seniors.

When we asked people, “When do you think you might have responsibility for caring for an aging family member?” among whites, the average estimate is 45 or 50; among Latinos the average estimate is 23. So, college-educated people often feel like they will have the resources to deal with this issue, although no one has the resources to deal with this issue. For non-college educated whites—this is part of the economic pressure that they are under, and they are feeling the pressure both multi-generationally—their kids are back home, their parents are back home.

Senator Debbie Stabenow used to say this on the campaign stump, “The question in my family is ‘who is in the extra bedroom? Is it my college kid who can’t get a job, or my mother who needs care?’”

Voters who said that terrorism, federal budget deficit taxes, and dysfunctional government were major issues voted for Donald Trump. Voters who said the environment, climate change, education and prescription drug costs, Social Security, and Medicare were issues deciding their vote tended to vote for Hillary Clinton.

Hillary Clinton did use this [caring] issue, but the one thing that I noted in the previous two speaker’s remarks that I think that was really right is, this issue needs to be embedded in a broader economic frame. We are talking about it in too minor a way. We do not have a major economic frame out there on the progressive side, and this is a major component of an economic agenda.

This is in fact—I will tell you what I think—a sleeper issue for 2017/2018 and 2020. It is a major *economic* issue for people. It is a major *time* issue for people. It is a major *health care* issue for people. It is a major *retirement* issue for people. It cuts across the board.

As we think about activating this issue politically, think about also the fact that there are 47 mayoral elections up in 2017 and 34 gubernatorial races up in 2018. We should think about how to make this agenda actionable at the governor’s level and at the mayor’s level, because in some ways we may have a better hearing, at least initially. I thought Kevin was great in terms of talking about how this issue really got implemented at more of the state and local level.

As we move then to the caregiving survey that we did: 1 in 5 voters, 20%, believe both financial help for family caregivers and easier access to care workers and in-home services would be the most helpful to families who are supporting someone who is ill, elderly, or disabled.

In the data you are going to see in the next presentation, you will see that everybody is adamant about staying home. This is the new agenda. A plurality of voters—41%—believe that *all* proposed pieces of assistance are needed: financial help, easier access for in-home, and making housing suitable for people with disabilities.

One of the things that is interesting is how make this actionable, because it can be overwhelming to people pretty fast. In fact, in some focus groups that we did for some of the folks in this room, when we started to talk about this issue, people got overwhelmed pretty fast in terms of the economics of it. We asked people, “Well, what would you do?” and they said, “Well, we would just make it through, we would believe in the power of prayer”—and they did not mean that facetiously. They said, “we would try to pull resources from across the family, but we just have to make it through.”

Caring is also becoming increasingly not just a women’s issue, although it dominates women’s concerns, but a family issue as well,—we had some really eloquent people in the focus groups—husbands talking about the fact that, because “my wife is the only girl in the family, she is taking care of Mom and Dad, my mother-in-law and my father-in-law, and the brothers aren’t helping. That means I get the ‘sure honey list’ every weekend for taking care of my wife’s family as well as my own family.”

A quarter of voters believe providing opportunities for skills training and career advancement would be the most helpful for expanding the number of paid care workers. And of course you have probably heard, on NPR this morning coming to this meeting as I did, the real crisis is in [the looming shortage of] care workers and nurses out there, when you are going to have a record number of people needing these kinds of services.

And of course while childcare is a major issue agenda, and that was one that actually both candidates— they may have disagreed about how to do it, but both of them agreed to do something about it—childcare in people’s minds is a relatively constrained problem that gets better every year. Caring for someone ill, disabled, or elderly in your family is unconstrained. It is an ever-expanding issue that gets worse every year and often occurs 2,000 miles away from where you live.

Some of these slides—and you can have all of these slides by the way—some of these slides are just showing the vote. It was a very, very tight election...showing you some of the coalitions we have talked about, showing also Democrats and Republicans...the congressional vote.

Here is the issue agenda. The first thing you note is that Americans have a lot of ability to be worried about a lot of things. There are a lot of things on people’s minds (and women in particular are especially good at that), so people are not looking for your problems. They already have enough of their problems. One of the hardest things we have to break through right now is we start with messaging that revolves around crisis, but people do not want more intractable problems that they cannot solve, they already have enough on their list. They are not looking to buy chairs on the Titanic here.

So, if you discuss a problem, you had better have a solution very close to it and very often this conversation does not have the solution linked to the problem.

Health care is a major issue, and it is not just Obamacare. We know the dialogue about Obamacare and I am glad to talk about that in Q&A, but health care includes the rising costs of prescription drugs, which until about August of last year the rising cost of prescription drugs—even among Republicans—beat out repealing ACA as the number one issue. With the course of the campaign and polarization, ACA jumped ahead of it, but it is right up there and prescription drugs is very, very much a bipartisan issue.

Security and stability are the watch words. They are particularly the watch words for women. There was a time when women wanted respect, then we wanted equality, now the number one value that women want is control. When you go home tonight, for a fun exercise, look at the number of popular advertisements that try to sell the value of control to women; it’s everything from Cialis to Lexus that tries to sell the value of control to women.

That said, what is one of the major things that puts a woman’s life completely out of control? Caregiving responsibilities--and they change every day and they are unpredictable. Then when you try to get your mind off of it you have a soccer accident. So, it is the embodiment of this exact problem.

Then finally, the other issue I want to point to is dysfunction of government. One of the biggest problems that we have right now is people do not believe their political system will respond to anything that they care about. Overcoming voter cynicism and people’s cynicism is one of the hardest things that we have. So, as you are

thinking about your message, think one-third problem, two-thirds solution. Be aspirational and positive; do not be negative. Think about how you can help be part of the solution and that people joining together can be part of the solution.

Here, you see the vote by the issue that you cared most about, and you will see that the Trump coalition and the Clinton coalition were both concerned about the economy, both concerned about health care. There were some differences later on in terms of national security, dysfunction in government, and immigration. But when you talk about the two places where this issue really fits, you see that Trump women and Clinton women can be talked to about this issue.

Let's look again at the ideas that people had. In our polling, we asked "which of the following do you think would be most helpful to families who are supporting someone who is ill, elderly, or disabled?" Twenty percent said financial help for the family caregivers, 20% said easier access to care workers and in-home services, 11% said housing suitable for people with disabilities, and 41% said all of it.

This shows a very undefined agenda, in part because people think the need is so great, not because people cannot think of solutions—they can—but because the need is so great. That is not a very good thing, because the problems that are getting solved right now are the problems where you can pick off a bite-sized piece and go make some progress on it. People really are confused about how you can afford and how you can implement something that is this large.

This survey is very interesting because we really tried—about half-way through we noticed how many people were saying, "all of the above" and we went back in and said to the interviewers, "Don't let people pick 'all of the above', really push them; 'Okay, if you had to choose, which would you choose?' and repeat the question". Even when we did that, we got no decline in "all of the above." People think this is a huge problem and we are not making very much progress on it.

Notice also that the people at the core of this agenda are the ones who really think the best answer is "all of the above". So, women: 47% say, "all of the above". People of color, African-Americans: 60% say "all of the above"; Latinos: 42% say "all of the above". People who actually are experiencing this tend to think it is bigger and bigger. The more you have direct experience, the more you think this is a huge problem.

In lots of areas, direct experience is actually mobilizing. Here, it is a combination of mobilizing and demobilizing. One of the problems that we have is that caregivers are themselves so overwhelmed that they are often not very activated on an issue.

On other issues, the minute you have experience you tend to really want to do something about it. On this issue, the minute you have the experience you are so overwhelmed you do not have time to do anything about it, and then when the problem gets better, if it does, or passes away, you are so exhausted you do not want to do anything about it. You want to catch up with all of that life that you were putting aside, and all that financial obligation. So, this is a funny kind of issue where direct experience is both mobilizing but demobilizing, which is not what we usually see.

So, looking at the paid care workers: a paid care worker is extremely respected by people, thought to be very under-paid, but also thought to need a variety of services and help. One of the things that is really interesting here is that people think they do not know anything about this issue, but actually have instincts about it that are much, much better than what we might think.

The number one thing that people think about for paid care workers is opportunities for skills training and career advancement, better benefits and retirement, and increasing wages to \$15.00 an hour. By the way, on the increasing wages to \$15.00 an hour, you will note that, in the four states that had this on the ballot, increasing minimum wage passed, even though Donald Trump took some of those states. Secondly, the \$15.00 per hour issue increased steadily in support over the course of the campaign. Now, if you were running an initiative, it was still hard to pass in certain states, but this agenda is really on the rise and people are very aware that care workers do not make decent wages.

You will see here that almost every demographic group has skills training and career advancement at the top, and then has the benefits, then the wages. The biggest difference here is Trump voters, who think you should have skills, training, and career advancement, and they are overwhelmingly in favor of it. This was one of the biggest partisan differences we saw in the survey, and there really ought to be a conversation early on with the Trump Administration about this agenda.

Clinton voters, who tend to be women and Democrats, wanted to do it all. But it's very interesting that the saliency of the skills and opportunity issue resonated among Trump voters, who, remember, are overwhelmingly white, blue-collar voters--for whom training and skills development is very salient for them personally, as well as for others.

So, that is a very quick appetizer portion here on a lot of different issues. Let me turn it over to my colleague, Brian, to talk some more in-depth, and particularly bear down on the Republican side of this and then we are glad to take your questions.

Brian Nienaber

Celinda did such a good job on the slides. I did not bring my own, but I do just want to highlight a couple of points. First, I want to thank all of you so much for hosting this. I know probably not a lot of you voted Republican in November. I appreciate having the opportunity to be here, and it is always fun to work together on these issues that are so universal. Certainly, as someone on my own dealing with aging parents, and this year running around getting wills notarized and finding a safety deposit box for my parents' funeral plan that they bought and all these other things, my wife and I now joke about which one of us is going to get the most responsible of our four children to take care of us when we get older.

I do think this is certainly an issue that hits close to home, both on a personal and a professional level, and I would say I think at some levels I am sort of the best and worst Republican pollster you could have. Through the magic of firewalls and campaign finance dealings, we had four different presidential efforts at the Tarrance Group this year, none of which were Trump, and one of which was actually the biggest single "Never Trump Group" out there. So I never looked at Pete Ricketts the same again when I saw him during the Cubs World Series Games, but we did not do any pro-Trump stuff, even in the campaign. I do not want to bore you with too much inside baseball, but normally that is not the case. We did stuff for Bush both times and McCain and Romney, but they were not eager to share and so that was an issue.

I certainly have an enormous amount of respect for Reince Preibus but I will tell you I think what was really interesting about the outcome was that we had a lot of legislative candidates, we had a lot of Senate candidates, we had a lot of gubernatorial candidates that were kind of on the fence; Trump winning provided a big margin for them getting over the top, getting those last few votes they needed.

What I would emphasize is a lot of those guys are now coming in and they are ambitious. When I look at this data what it says is people are really frustrated with the dysfunction in Washington, people are really frustrated with their pocketbooks. [For a politician, this translates to "I want to find solutions I can give that both ease people's anxiety and look like Washington can get things done on things that matter," and I do think this is one of those issues.

I can certainly tell you that I know we talked about how daunting the caring issue can be. When you get people volunteering "all of the above," that is huge. I do not want to get too much into the inside on polling, but when people volunteer an answer, that is an extraordinary step for somebody on the phone.

Normally, even if it is something that they are not real familiar with, they will pick one of the options just because that is what your sociological impulse is. When people volunteer "all," that is one indicator that they grasp the depth of the problem, and I think too an indicator that they are not fully versed in what the most appropriate or easiest bite-sized solution is.

I would emphasize that if you have a bite-sized piece of this, you can come forward in your state, community, or at the federal level and say, "here is what we can get." I can certainly tell you my personal experience with Medicare Part D. We were working for PhRMA at the time, and they were obviously very anxious about

Medicare Part D going down the drain, or Bush having issues with it. What was shocking to me was when we did two sets of focus groups: one with pre-seniors, people 45-60— in the pre-Medicare range—and then we did groups of people who were actually enrolled in the program. This must have been 2005-2006, and when you talked to the people who were not yet in the program, it was so overwhelming to them. They said, “there are so many choices. I don’t understand what I’m going to do. How does this work, where do I enroll, what is really covered, what about this donut hole I’m hearing about, how does this gap work, what should I pick?”

But when we got to the group of the seniors who were in the program and in receipt of benefits, they were so happy--and most of them had enrollment through some sort of automatic means. Their employer had them in Medicare, or their employer had them in Blue Cross Blue Shield or Aetna, and just rolled them into the Part D program. They couldn’t be more pleased, couldn’t be more happy. So even if it is a minor solution, even if it is a piecemeal solution, or a little bit of a solution, that help really carried over for them. They had such fondness for this [Part D] program because before it had been daunting to them, and then suddenly it was not.

They went from, “now when I do get my medicine?” to “I know how to get it” and “when I do need it,” to “I can work with my doctor to get my pills in a less expensive way, or a larger dosage that I can break into smaller portions,” or other things. It was just so much easier for them now that they at least had some part of this anxiety about health care when they get older solved.

I think the big takeaway I would have from this data for you is this [caring issue] is a problem that is really daunting for people, and there is really kind of a two-level [response to this] issue, at least from what I see. Unless you are *in* it, this is a problem that is hard to contemplate.

Maybe you know somebody who has [caregiving responsibilities] or does not. But most of us do not really realize the scope of how daunting it can be to have a parent or a grandparent, or another relative, that you are now making extraordinarily important life health care decisions with them. A part of it is that [many don’t] understand the scope of the problem, but then also I think people do not sort of fully understand the scope of what are good *solutions*.

I think somebody said Trump voters have a greater preference for making sure there is upward mobility for care workers. I think that a large part of his appeal overall was this thought of [possible] upward mobility, particularly for people who feel sort of trapped. [Regarding caring], I think that is a real important issue: Can you offer something that even someone who is not in the system, even someone who is not having this problem—if you are a millennial or in your 20’s or 30’s and you are not dealing with [an aging] parent that is staring down the barrel of having health issues—[can you make them] understand this is a long-term problem?

I certainly would say, to roll back to the Part D philosophy, it was quite rewarding for me as somebody who at the time had much younger parents, to now look at this and realize whatever other problems I have when my parents get older, I know they will have this prescription drug benefit, and should they need some sort of long-term pharmaceutical care, I will know that is out there and I will know how to navigate this process for them.

So many people offered dysfunction in government as their top issue. I think you cannot underestimate that for a lot of people that are economically disadvantaged, or think there is other unfairness in our society, what really stood out to them was that nothing ever gets done in Washington, or nothing ever gets done in my state capital. To the extent you can come forward and say “hey, this is something we can get done and this is something we can get done that really matters to a lot of people who are really in need,” I think that is going to make a substantial difference in the mind of a lot of legislators.

Josephine Kalipeni

Thank you both for sharing that. If we have questions in the room please walk up to the mic and offer your questions. I am sure Celinda and Brian would more than welcome them and offer their insights. You guys did such an excellent job. Gail?

Gail Hunt – President & CEO – National Alliance for Caregiving

I am Gail Hunt, President and CEO of the National Alliance for Caregiving. I know that Trump talked a great deal in his campaign about being anti-establishment, but it does seem that people that he is bringing back are establishment in spades, but also we do not have a lot of new people necessarily in Congress. These are people that have been approached before around the issues of caregiving and maybe we approach some from the story angle rather than the economic angle. Could you comment on the fact that we would be talking to the same, essentially, a lot of the same people that we have already talked with?

Brian Nienaber

Sure, I think that is an excellent question, thank you. I would tell you--and again, we do not have close ties with the Trump campaign at this point--but certainly seeing him on "60 Minutes" last night when the health care issue came up, what he seemed to be mostly leaning on was, "I want to keep things that are popular"; coverage until you are 26 and not being screened out for pre-existing conditions. So, I think to the extent you can drive providing assistance for people who are trapped in this sort of circular pattern, with having *both* children and caregiving for elderly parents, and [agree that] this is a crucial issue that hits at people's pocketbooks, it is an incredibly valuable theme.

The other I would say is, I think this is going to be a Congress... [Rep.] Paul Ryan is really a policy person, I think, at heart. [Senator Mitch] McConnell has seen the success of Ryan, and I think is wanting to delve more into being a policy person. I would not underestimate—even if you are going back to the same people, they are now [more aware that they are] looking at an electorate that... [has] a real economic anxiety and a real feeling of, "I'm trapped in my station at life and there aren't [enough] people in my elected officials who care about this."

So if you are an ambitious Member of Congress you [may] want to go back to people and say, "Listen I've gotten things in government, the government is not so dysfunctional, and I've gotten things done that really matter to people. When your parents get sick, or if your parents are sick, here are some substantial ways in which you are going to be able to lean on the assistance of the federal government through these types of policy solutions." I think that is going to hold a lot more appeal now than maybe it did when it was sort of a theoretical concept of "well, you could work with Obama and we could expand this or do that, or so and so."

I think [Members of Congress] are going to be looking for wins, and wins that matter to people's lives, and I think I would not underestimate the value of going out there and saying "Hey, here is where I think you can get a policy win that will really matter to people's lives."

Josephine Kalipeni

Anything to add to that Celinda?

Celinda Lake

The only thing I would add to it is that initiatives...the progressive issues did not lose on Election Day. In fact, except for the death penalty, progressive initiatives did quite well, and it is hard to do proactive policy by initiative, frankly. It is often too comprehensive, but if there are some bite-sized pieces that can be done I think they might also be very interesting initiatives to put forward.

The second thing I would say is even following normal turnout patterns—and there was some drop off among millennials this presidential election—the off-year electorate is going to be much, much older in many places. In most mayoral elections, two-thirds of the voters are senior citizens or 50-plus, and in the gubernatorial races it will probably be the same. So, think about how this issue appeals particularly to women 50-plus. Again, you are going to hear some more about that data in a moment.

Neil Wasserman – Timewave Analytics

Good morning, my name is Neil Wasserman. My company is Timewave Analytics and one of the things they are working on is transgenerational models for care, and in particular we have looked at implementing this in China where you have a huge older population but a tighter family unit that can perhaps provide the resources.

And one of the things we know is the conflict between demographic growth in the care population, the professional care population, versus the population in need. So, that crisis is going to emerge.

I wanted to raise the question of embedding the care issue in the larger context. There are two threats to the fiscal health of the federal government. I mean, one we do not need to discuss that here, is the unrealistic tax cut proposals on the part of the Republican candidate. But the other is the cost of health care for the older population, which is growing at a rapid rate both in terms of per-patient cost and the population itself; [so that] 80% or so of the health care budget will be consumed by the older population.

Providing care in home to the population prior to when they need continuous care in, say, a nursing home has been shown to reduce the cost of health care in a very substantial way by preventing falls, by helping older patients adhere to medical regimens, preventing hospital visits. That quantifies [as a] very large benefit, [since it], limits the growth in health care spending for that population. It's one of the critical benefits of providing adequate care in the home. And that seems to be an area where the economics can produce perhaps bipartisan support from a fiscal standpoint, and from a human caring standpoint. I just wanted to know if that makes sense as a focus for advocacy.

Celinda Lake

Yes, I think the in-home health care is a huge issue right now that is really soaring on the agenda [and] the economics make it work for [itself]. It is kind of like the mass incarceration issue; the public has concluded that mass incarceration does not work for a lot of reasons. Some of the more conservative legislatures have been brought to the table because of the fiscal argument. So, I think the same thing [is true] here—that some of the more conservative legislatures might think of this as a private issue but the fiscal numbers bring them to the table.

That said, you do not have to have an economic argument to bring the public to the table. The public is adamant about [wanting] in-home health care. They want to keep Mom in their home and they want to be in their home and the latter is particularly true.

Our problem is the reason this issue is not mobilizing more [policy] is that frankly, it seems like a huge concern that people already think is a good deal when you do not have to personally worry about it. [But] they do not want to put another big intractable problem on the table, so it is the lack of solution in people's minds that is inhibiting this issue from being on the agenda. It is not a lack of awareness. It is not like you have to emotionally engage people, they are emotionally engaged. It is not like you have to educate them, this is a problem they know. That is why they are trying to avoid it unless you [show you] are going to provide a solution.

Brian Nienaber

Just to close out the question—I do think you raise a valuable point that the door to a lot of Republican legislators is not that this is a warm and fuzzy thing that will make you feel better about yourself at the end of the day. It is more like, “the state has a finite amount of resources, or the government has a finite amount of resources, and this is something that will provide a substantial cost savings.” I think that is a very compelling message to a lot of Republican Members of Congress, a lot of Republican state legislators who do wring their hands about the budget and are hawkish about the budget... Ryan was a former Chairman of the Budget Committee.

If you can go and say to these people, “this is great policy that will make people happy but also it is a substantial cost savings for almost every case,” I think that is a good one/two punch for both getting a broad coalition of people who are going to be more moved by the emotional part of it, and also people who are going to be more moved by the ledger part of it.

Josephine Kalipeni

All right, thank you for that.

Barbara Gay - LeadingAge

Barbara Gay from LeadingAge, trying not to pontificate. We represent not-for-profit aging service providers, nursing homes, home care providers, affordable housing. And I, like many people in the room, am trying to connect the dots on platform issues.

One of our most severe challenges is the workforce and retaining and recruiting people to work in long-term care, and one of the obstacles is the lack of benefits and wages. Many of our workers first got health care coverage through Medicaid expansion through the exchanges. We see those going away probably next year, and during the last recession, we worked very hard with the Department of Labor to try to provide jobs to people—long-term unemployed people. [But] our jobs were not attractive to them because we were paying \$7.00, \$8.00, \$9.00, \$10.00 an hour and that was not enough to support a family.

Our ability to pay attractive wages and benefits is very much tied to the way long-term care is financed, which is primarily through the Medicaid program, which we see as being threatened under the current agenda, so I am just curious as to other solutions we might be able to develop in the current environment.

Josephine Kalipeni

We will take your question too and then answer them both.

Mary Anne Sterling – Connected Health Resources

Mine is actually more a comment and that is, this is an “all of the above” problem as our speakers have pointed out and the problem is we have waited way too long to start addressing it, so it has now become an “all of the above” problem.

I would like to point out--I am Mary Anne Sterling by the way --a frustrated former family caregiver of multiple parents with dementia, and [concerning] the results of the election Tuesday: For the average family caregiver, their lives did not change Wednesday morning, they had to get up and take care of somebody, right? Nursing home care did not improve [overnight]. Resources in the community did not become easier to acquire or fund out of their own pockets.

So, again, not to pontificate, but the average caregiver does not want to step up and become involved in these issues. To your point, they are exhausted, and nothing that happened Tuesday is changing that. If anything it is going to become worse, but just know from the family caregiver perspective that there really is not much hope on the horizon for answers to the problems that we experience on a daily basis.

Brian Nienaber

The answer to both your questions [is that] this will be a fascinating time, because certainly on this issue there were not a lot of specifics from Trump about health care policy. He does not seem to hold... he does not have a 10-point plan he is going to implement, [i.e.]” this is what I want to do,”-in the way President Obama had a much larger vision of having a wider health care system.

I think that is a crisis and an opportunity, where there will be a lot of openness to [calls of] “let’s put all the ideas on the table” and “what do we think is going to work?” and “what has a lot of advocacy behind it?” and “what would really help people?” I think they are going to go to the drawing board. One of the questioners brought up Newt Gingrich. Gingrich was notorious on health care, where he would have three ideas a day, sometimes contradictory ones, and whatever sort of seemed to hold appeal he was willing to give it a look. I think Ryan has a similar sort of flexibility about looking for policy solutions, and certainly Preibus was not a huge policy maker. Even when he was at the [Republican National Committee] he was much more [focused] on the mechanics side. I think there are going to be a lot of people out there listening for “what are ideas?” [and] “what are things we can get done?” [and] “what are solutions that would work and really make a difference in the lives of people?”

The other part of that is I do not think the [Trump team was] sort of fully ready to run in with “I’ve got a giant health care agenda that I am going to get passed on January 21st”. You do really have an opportunity to get in with these people and say “I think I’ve got some real ideas and solutions” and they are going to have an open ear for you.

Celinda Lake

I really agree with what Brian said. I would just add one quick note, which is I know what statements have been made about Medicaid, but I think one of the things that is getting missed here is how really, really popular Medicaid is. Medicaid is significantly more popular than every single politician who wants to do away with it thinks and many of the politicians do want to keep it.

Also, this is an area where state and local dialogue really makes a difference. I mean, Missouri—and I do not know if they are represented here—but the Missouri Healthcare Foundation engaged in a 10-year conversation with their voters about Medicaid, and Missouri voters really know what Medicaid is and really like it. Missouri voters liked Medicaid at 65% on Election Day, when they went 65% not just for Trump but for every single Republican down the ticket.

So, I think there is an ability to really organize about Medicaid and I do not think we should accept as a fait accompli that—and I do not really know the policy end of it, but I do know the politics of it - Medicaid is the Rodney Dangerfield here. It is a very underappreciated issue politically, very, very popular with voters. I do not think we should assume that the die is cast in terms of Medicaid.

Josephine Kalipeni

Well, thank you both. I just wanted to add that one of the really fascinating things to me that came out of the research is the “all of the above” phenomenon, and I actually think that creates an umbrella for all advocates to be able to say, “we need a system that works for all, and the expertise I am bringing to the table is on workforce, or is on family caregivers, but not in a way where those things are pitted against each other,” [and it is possible], as we have seen in the exit polling information, [that] the solutions people want are the “all of the above” solutions.

It creates an excellent opportunity for us to both to have a unified message while also bringing the expertise and things that we are advocating for to the table.

Celinda Lake

Josie, if I could just add to that, what you said is so smart and I just want to put an exclamation point on it. We are in a period of extraordinarily polarized politics, [and yet] this is not a polarizing issue. This is a uniting issue. So, I really think you are right.

Josephine Kalipeni

Well, thank you to Celinda and Brian, and we will keep the program going.

Anne Montgomery

That was a splendid panel. We have so much to do and a lot of material to work with, and now we are going to hear from Rhonda Richards of AARP. She is going to tell us about the survey that Celinda referenced, which is one of the best surveys of women over 50 that has been done in a long time. Thanks so much.

Rhonda Richards – Senior Legislative Representative – AARP

Thank you, Anne and thank you to the Altarum Institute Center for Elder Care and Advanced Illness for the invitation to participate in this forum co-sponsored by Caring Across Generations.

Supporting family caregivers is a priority for AARP, whether it is providing information and resources, conducting research on family caregiving or advocating for family caregivers at the local, state, and national levels. There are over 40 million family caregivers in the U.S. caring for Veterans, older adults, and people with disabilities of all ages.

Family caregivers caring for adults provide an estimated \$470 billion annually in unpaid care, larger than the entire Medicaid system in 2013 and the sales of the four largest U.S. technology companies combined in 2013 and 2014.

As you know, family caregivers help their loved ones live independently in their homes and communities delaying and preventing more costly care and unnecessary hospitalizations, saving taxpayer dollars. They provide assistance with tasks such as bathing; dressing; eating; transportation; handling financial, health care, and legal matters; and often complex medical nursing tasks. Many, as you have heard, are working outside the home and raising families.

AARP often surveys the 50-plus population on issues important to them. Prior to the election AARP worked with Lake Research Partners and American Viewpoint to survey women voters 50-plus likely voters on several issues, one of which was family caregiving. I am sharing some of the findings with you today, which complement the survey findings you just heard.

The survey found that women ages 50-plus see themselves staying in their home at retirement age --83% among all women ages 50-plus, as well as among boomers, and 82% for women ages 70-plus. We have seen this consistently over the years, and the vast majority of people want to live in their homes and communities, so this finding is really no surprise.

Also in the survey, among a majority of women age 50-plus, 54% are currently or have been a family caregiver providing unpaid care to an adult loved one—someone who is ill, frail, elderly, or who has a disability. This underscores what most of you know from personal experience; that almost everyone has been, is, or will be, a family caregiver, or will need one.

Women ages 50-plus overwhelmingly—85%—believed it was important that the presidential candidates talk about how they would support family caregivers. Caregiving moves women 50-plus. Again, this is an issue that touches just about everyone so this finding is not surprising.

Today, as you may have heard, AARP released a new report on the out-of-pocket costs of family caregivers. The report shows that family caregivers spend nearly 20% of their income, on average, providing care for a family member or other loved one. This translates to about \$6,954.00 paid out-of-pocket on average annually.

Family caregivers face physical, emotional, and financial challenges. In the new Congress and Administration, just as now, bipartisan solutions are needed to support family caregivers. This is not a Democratic or a Republican issue, it is a family issue. I encourage you to look for bipartisan opportunities and champions in both private and public sector solutions.

In addition, family caregivers will only face greater strains in the future as the caregiver support ratio, the number of potential family caregivers who are ages 45 to 64, for each person aged 80-plus shrinks. In 2010, the ratio was more than seven potential caregivers for every person in the high-risk years of ages 80-plus. By 2030, this ratio is projected to decline sharply to 4:1, and to less than 3:1 in 2050.

Family caregivers provide the bulk of services to their loved ones, but as the U.S. population ages and family caregivers face greater demands, the need for a stable, quality, paid workforce will increase. This workforce can provide respite and support when needed or peace of mind for those who rely on the workforce.

Commonsense bipartisan solutions are vital, and AARP looks forward to continued efforts working with others to achieve those common sense bipartisan solutions. Thank you.

Anne Montgomery

Thank you, Rhonda. In the break that we will have coming up I know I am going to want to ask you about that 20% out of total income figure—that is kind of shocking. Now we are going to move to a panel, our first panel that will really look at the results that all of you provided us in the survey that you took. It tried to drill down on specifics of policy, and so we have prepared a presentation that Joanne Lynn and Josie Kalipeni will be presenting. Thanks so much.

Joanne Lynn, MD – Director – Altarum Institute Center for Elder Care and Advanced Illness

Josie and I are so riled up we cannot stand to sit. So, here we are. This is about what you all said and it is really time to convene around what kinds of things we really want to get done. We have tremendous opportunity and

if we do not capitalize on that opportunity we are going to face really grim circumstances in 20 or 30 years. So, being an old person in training I am looking for a better set of solutions.

At the present time in my immediate family of about 15 people, four rely on Obamacare exchanges for their insurance, and we are solidly middle-class. So the kinds of things we face [in our old age are not good]. There are 800 people waiting for Meals-On-Wheels in Detroit alone today. The kinds of things that we are allowing to just sort of slide by are already outrageous.

Here is what you all said in response to our survey. 128 people responded, there are 130 or so here today and there are another 100 online so it is probably about half of the people who did respond. There you can see the rate of people who responded, 62% said they had participated in policy work. We gave you 20 possible things that caregivers could unite behind and they were organized in those four arenas. The respondents used a five-point scale and everything, as Celinda Lake was saying, was well supported. So, there was nothing that was easy to move off the policy agenda.

Josephine Kalipeni

As Celinda noted, even this room had an “all of the above” approach to solutions. When we asked folks to rank the most supported policies, these were the ones that came up the most. It is not to say that the other ones did not get quite a bit of attention, these are the ones that came up the most. So, it ranged from housing to resource referral, identifying and assessing caregivers, flexible workplace...you will hear that come up quite a bit throughout our presentation.

The last one, which I think is really interesting, is the idea of expanding [the Program of All-Inclusive Care for the Elderly] PACE and other community-based services. It is a really interesting way to get at the immediate impact to families that are feeling it on the ground, understanding the matriculation of policies at impact that happens at the federal level, and how to get the most immediate impact on the ground at the state level.

Joanne Lynn, MD

We asked people a forced choice question of, “given that you have to make choices, what are your top-ranked?” And these were the two policies that were most often ranked at the federal level: one was policy calling for more flexible workplaces, and the other was on better care worker pay. Those were the ones that most often rose to the top when you had to make choices.

The next one was when we looked at the top three--when people picked just three--then what came out as highest was more money for family caregivers: improved Social Security benefits, respite care, something that makes it more plausible for families to carry this burden.

The second most highly ranked priority was the flexible workplace. There are so many people who get fired if they come in two hours late because they had to cover for their family member. So modest flexibility in the workplace makes so much difference.

Josephine Kalipeni

The most often-selected priorities at the state level were things that I think we should be mindful to include in whatever work we are doing. So, they are not standalone but [remind us] to really think about how do we incorporate these things in an overall plan. Those two things were first, better resource referral. I think we often hear about the complicated systems that family caregivers and individuals have to navigate, and folks are looking for a lot of help in finding solutions that work best for them. Second, care worker pay really resonated quite highly as a solution at the state level.

At the federal level, it is really interesting to look at the solutions that folks elevated: long-term care, public financing, the idea of how do we make care more affordable and accessible for folks that need it with an identified pay-for--an identified revenue source and making sure that it is robust enough to meet the needs of folks that need it, as well as the idea of using public programs to focus and support caregivers. Medicare came up as one of those solutions when we surveyed this audience.

Joanne Lynne, MD

The state policy priorities [of] people who worked in policy, and people who did not, were all together on the flexible workplace and care worker pay.

Josephine Kalipeni

There were also other policy options that were less frequently selected. And there were some open-ended questions asking you all what are some other ideas that are out there that we should consider when really talking about this issue. These are a list of them but I thought I would raise at least four: First, I think the need to educate the public about long-term care needs and costs was huge on all of our radars and we all know that there is [a major] discrepancy between what people should [be able to] expect and what is the potential reality. So continuing education I think is huge.

Second, eliminating waiting lists for Medicaid waiver programs also is something that I wanted to list as [having] a potential immediate impact for folks on the ground. Third is this idea of Medicare expansion: how much more can we get out of public programs, and how can we reinvent them and reimagine them to really meet the needs that folks are prioritizing in their everyday lives? Lastly, having caregivers involved in MediCaring Communities was another thing that I really wanted to highlight.

Joanne Lynn, MD

Here is our short overall summary: First off, everybody supports everything, as Celinda has said, but making caregiving more possible was one area of convergence, and another was support for paying for the work --we have to really get around to paying for what it is that we need.

In summary, we all feel like it is a big problem. I often tell our audiences, imagine that Medicare was set up by a group of 88-year-old women living in second-floor walk-ups, and living on Social Security. What services would they have put first? My guess is that they would have put first housing, food, socialization, hearing aids, eye glasses, podiatry...all things that are excluded from Medicare.

Medicare was established by 55-year-old men in suits who had been Blue Cross Administrators, and they were used to dealing with paying for surgery. We have never built the care system for 88-year-olds, and now is our chance to do so. When you look around at who it is who could carry the water it is really only caregivers.

It is really unlikely that PhRMA will suddenly jump up and say “yes, pay us less.” It is really unlikely that insurers are going to jump up and say “yes, change the ground rules.” It is really unlikely that medical providers are going to jump up and say “yes, there’s a lot of fat in Medicare and we really want you to be able to use that.” Instead we are going to have to shift the locus of choice and power somehow, and we contend that it should be to localities, at least initially, so that we can get some examples [of reliable population health systems] that really work and we can get them soon-- before we are utterly swamped.

Josephine Kalipeni

That is right, and just in addition to that, I think the idea—you will hear more from our state partners in Maine—of really galvanizing power at the local level is important, and really using states as experiment labs for what could be learned and what is fully possible, are key ideas that we can use to really impact and mobilize people.

The other thing that I found fascinating in looking at this information from folks in this room [and online], and lining it up with the information that Celinda and Brian shared, is that there is not a wide span between what the policy experts and the advocacy community think are solutions and what folks on the ground are asking for. This does not always happen in issues-based organizing and issues-based advocacy; sometimes the solutions are far removed from what people are identifying as the things that they want, and in this space we are actually really well positioned to form bridges between DC, maybe, and folks directly impacted by these issues [living around the country] and come up with really meaningful solutions that impact people’s everyday lives.

Joanne Lynn, MD

We have time for a couple of comments or questions and still get the break that we need.

Mark Dann – Compassion & Choices

Hi, good morning, my name is Mark Dann I am with Compassion & Choices. In terms of health care policy and

what we are seeing, obviously we had a really big win in Colorado with 65% of the population supporting aid in dying, over 1.5 million people coming out and supporting that initiative. So, in terms of how people are engaged on health care and how people are looking at their care, it is certainly something we are thinking about, and as an organization now that we have all these people mobilized and ready to go, we are taking a look at the big picture of care and coordination, and what is the system that people want to see. We want to advance that in a way that has meaningful impact on real peoples' lives.

So, my big question is, where do you see that bridge in policy coming forward between what people want to see? What is their ideal picture, and where do care ideals and policy solutions line up?

Joanne Lynn, MD

I hope that as we liberalize aid-in-dying laws, as you were saying, that people have honest choices that they truly can continue to live without bankrupting their families, without their families being driven to distraction. I was just talking with a person in New Hampshire who has lost everything in the care of her husband with early onset dementia, [who is] thereby bankrupting their two teenage sons, all care just fell to her.

All of the people who have responded on the online chat, we should mention, are talking about financing; they're talking about things about payment. I have a special call-out for Angela Hult from the Cambia Health Foundation—the Cambia Health Foundation helped support this meeting—so we are especially grateful, but the first five comments on the chat were all “we've got to figure out the financing, we've got to make it possible.”

So, when you look around for where the financing can come from in the short run, my contention is that it is the fat in Medicare; that Medicare could be so much more efficiently run that the savings could come back, at least, for a while, to help support the supportive services.

In the long run we are going to need a much more intelligent long-term care financing system, which means resurrecting some kind of a marketplace for private financing, and also probably some kind of a federal backstop other than just spending down to Medicaid. Right now, spending down to Medicaid is our backstop.

Josephine Kalipeni

Let me just add to that as well. I think one of the alignments is this idea of real choices, but also quality and affordable choices that are done in a way where the workforce is not pitted against consumers and that... is integrative of all of these really important solutions, and backbones, of our care system.

The other thing that I think is really important is that when we are inside the “D.C. Beltway” and we think about financing, it is a very different conversation than when you are mobilizing people and talking about affordability, right? I think it is important to keep that in mind that we cannot talk financing in these big billion-dollar programs, and how to pay for them, to folks who are thinking about the \$6,000 that they have to pay to remodel their home in the next two months. Those tend to be conversations that do not easily line up when we are thinking about how to mobilize people in a way that care can really impact their lives. We have to really think [carefully] about the conversations we need to have in this room, and then the conversations we need to have with people who are feeling the impact and the squeeze of caregiving.

John Schall – Caregiver Action Network (CAN)

I am John Schall from Caregiver Action Network. Joanne, I will not take personally your comment about 55-year-old white men in suits.

Joanne Lynn, MD

Who had been running Blue Cross plans.

John Schall

Oh, okay. Well, actually yesterday I turned 56 anyway so I knew you were not talking about me. But I do want to pick up on your very important point that came out in the survey about flexibility in the workplace, and I think we all need to remember as we are putting that message out there, that it is not a message that we should just give to federal policymakers, but one we give to those big private sector employers as well. That is why at [Caregiver Action Network], as a nonprofit, we put together an off-the-shelf kind of thing that big employers

can use to give that flexibility and support to their employees who happen to be caregivers [in order to] to remain productive on the job. It's called ACE, Assisting Caregiving Employees. We all need to remember that this is a two-fold conversation—one for federal policymakers in terms of the [Family Medical Leave Act and its] expansion, and one also that is directed to employers themselves.

Josephine Kalipeni

That is right, absolutely.

Joanne Lynn, MD

Okay, let's take a short break and come back soon.

Elizabeth Blair

Next up is going to be an excerpt from the film CARE. That film is directed by Deirdre Fishel and produced by Tony Heriza. It is about care workers, caregivers, and their families, and it is called CARE. This will be showing on PBS in June of 2017. It is also meant to be used as an organizing tool so you can go to the website, www.caredocumentary.com to learn more about it. We are going to be showing a few clips right now.

Playing video – Excerpt from CARE Documentary

Anne Montgomery

That was an excerpt from a really outstanding documentary called CARE. It is available for community organizing as of January 2017, and we very much hope you will contact us and we will send you right to the filmmaker so that you can get a copy and proceed to use it to its best effect.

We are now going to move to a panel with Judy Feder, Sarita Gupta, and David Rolf; Daniel Wilson will be moderating. We are going to talk about where opportunities are moving forward at the national level. After that we will have a state panel. So, panelists come on up. Thank you.

Daniel Wilson – PHI National

Good morning. Now we will begin the conversation on where it happens here in DC and where those opportunities lie, particularly as we are looking on a national level and on the federal level. My name is Daniel Wilson. I am with PHI. We focus on quality care through quality jobs. The panelists here have extensive backgrounds in national health care, and I have forewarned each of them that I am only going to steal about two to three sentences from their bios as many of you are fully aware of who they are. To my immediate left, Judy Feder is a Professor at Public Policy now at Georgetown University. From 1999 to 2008 she served as the Dean of what is now the McCourt School of Public Policy. A nationally recognized leader in health policy, Judy has made her mark on the nation's health insurance through both scholarship and public service.

To her left is Sarita, and as she have talked earlier, she really needs no formal introduction, but she is the executive director of Jobs with Justice and co-director of Caring Across Generations. She is a nationally recognized expert on economic, labor, and political issues affecting working people across all industries, particularly women and those employed in low wage sectors.

Immediately to the left of Sarita is David Rolf. He is a nationally known innovative labor leader and currently is the president of SEIU 775, the fastest growing union in the northwest representing home care and nursing home workers in Washington State and Montana. We will start with Judy.

Judy Feder – Professor - Georgetown University

Good morning, everybody. I would say that it is really good to be together in this challenging time. I wanted to talk about the care recipients as well as the caregivers as we think about a future for the nation. When I spoke to Anne by e-mail over the weekend I figured, well, given the circumstances, there is no need to hold back this morning.

I want to start by observing what is the obvious--but not often enough said--that protection against the unpredictable catastrophic risk to individuals and families of a need for extensive long-term services and

supports is a missing piece of our social insurance system. It is not good enough, and [we do not have] an adequate social safety net.

I want to remind us that it is an unpredictable catastrophic risk for many of us. It is clearly an unpredictable risk for younger people, [some of whom] become impaired, and even for those of us who are now 65 and just turning 65. Many of us are going to die without needing any long-term care. I do not know whether you are lucky in this proposition but some people are going to die [suddenly] of a heart attack, or something that will require no care. But 14% of us are going to need more than 5 years of care.

That unpredictability and variability is true for family caregivers as well. In some families, some will be people who will have parents who are in that [suddenly] dying group, and not deliver any care. Some people, as we heard this morning, will have their parents, and their in-laws, and potentially many other relatives, and be caregivers for years, and years, and years.

That is why we need insurance for individuals and families. Without insurance, we know that families do all they can—in fact more than they can reasonably do—to take care of their family members with disabilities, and when they cannot, they turn to a public system that systematically underpays and poorly treats the direct care workers, who are mostly women, mostly women of color, many foreign born. They are the ones who provide care [professionally], but they are not recognized in a way that supports their quality of life.

What we need to recognize is that the nation's long-term care system is caregiving on the cheap. It is relying on unpaid family members who exhaust their own resources and underpaid workers who are struggling as a result.

So, what to do? I am going to just state categorically that we do need a public long-term care insurance system. There is a teeny ray of hope in this system. This system will never replace family caregiving, it will not even replace a need for private long-term care insurance. It might even create a situation in which that could become a piece of the solution. It cannot happen on its own.

But the slight ray of hope is that in the past year we have seen some explicitly self-defined bipartisan groups recognize that this is what is needed and so start a conversation. It is going to be a long conversation but the start of that conversation is really important, the recognition. We need to take advantage of it.

I secondly would turn in a much narrower realm to some things that we can do today. I am holding—actually an advance copy—of a report from the National Academy of Medicine panel that I sat on, looking at what we can do to support family caregivers of older Americans. The challenge, or the question, that we asked on the panel was: Given the enormous value and the critical role of family caregiving in health care as well as in long-term care, how do we enable caregivers to most effectively contribute to better care, while at the same time assuring that caregivers themselves are able to sustain their quality of life?

Now I will state the obvious about this report: it is hardly a silver bullet. It is a list of recommendations. What we ended up doing was creating a call for action to the Administration that will take office in a couple of weeks—some of us might have thought it would be a different Administration, but it is a bipartisan issue and applies to both—a call to develop a strategy to address the health, economic and social challenges facing family caregivers, especially the 8.5 million who are providing help to the people with the greatest impairments and consequently, the evidence shows, exhausting themselves and their resources in the process. We define that action—that strategy to be developed—as identifying, with stakeholders, both administrative and legislative action that could be taken to better support family caregivers. One of the issues that came up, after a better long-term care system in terms of our policy priorities, was using Medicare to engage family caregivers.

We focused on, in general terms, making recommendations for steps that [Department of Health and Human Services] and [the Center for Medicare and Medicaid Services] ought to take in Medicare, specifically in development of mechanisms that identify family caregivers: both in the record of the care recipient and the medical record of the caregiver; and to screen those identified caregivers to determine what they can and cannot reasonably do, and to find the ones who are most at risk; and then assess those caregivers to see what they can and cannot most reasonably do. [We recommended that] Medicare assist in finding them-- if not paying for--the kinds of supports and connections that caregivers need in the community.

Doing this would also require, as we identified and noted, a change in the payment mechanisms Medicare uses, so that particularly in the new payment mechanisms that are ostensibly paying doctors and others to coordinate care, [to reflect the fact] that coordination ought to not simply be about acute care needs, but also be about connecting caregivers to resources in the community--of which we know there are not enough--but [nevertheless] to connect them to what is available, and better enable them to provide care.

Now that is an agenda that can be a bipartisan agenda for this Administration, just as it could have been for an alternative president, and so I would urge us to get to work on that.

But now let me close by saying that that's all positive and great, but a little bit contrary to what seemed to be in the prior discussion. I do believe we need to be not simply on the offensive in pushing forward our caregiver agenda. We have got to mobilize on defense, too, because I do believe that the Republicans in Congress know exactly what they want to do: they cannot do it all, but they know they want to repeal the Affordable Care Act. Replacing it is going to be a challenge for them, so how they handle this remains to be seen, but they have been waiting and trying decade after decade to undermine the Medicaid program and the valuable protection it provides.

[An agenda] to undermine services, create waiting lists, undermine worker pay... this is not tough to see coming. We have prevented this before, and we have stood up for what Medicaid does for our families and our communities, and I was delighted to hear Celinda say that Medicaid is a very popular program. I would urge us, as we are thinking about the future, to remember that we have to hold onto what we have, even as we try to advance the system for everybody. So, I did not hold back anything!

Sarita Gupta

Great, thank you, Judy. It is always good to follow Judy because I echo a lot of her sentiment and agree very much that we have to play defense and we also need to continue to push the line forward and play offense in this moment.

So, I just want to ground us again: nearly 90% of people desire to age at home and heal at home, connected to the people and the places they love—really hold onto that. Because of this, we believe that all people should have increased access to quality, dignified affordable care choices--particularly home and community-based services. Caring Across Generations has a set of ideas where we see opportunities and ideas that we would present or suggest to a new Administration to take on and address the needs of older adult family caregivers in the workforce.

One bucket of recommendations and opportunities we see is increased access to quality care choices. We need a new national system that works for all and we have been hearing this all morning. We know Medicaid and Medicare have not kept up with the changing demographics and economics, and the systems are really difficult to navigate. They have gaps in services. They do not address some of the key workforce needs, and have not kept up with increasing health care costs and declining wages. Given this, we need to be innovative right now, and be thinking about what will really make a difference for families.

Families need a new flexible social benefit that provides support for the range of care needs from childcare and paid leave to elder care, and accounts for loss of income when an individual has to leave the workforce in order to care for a loved one.

We have talked a little bit--you heard Kevin talk about it this morning--about universal family care. We really believe we need to be thinking expansively in an integrated way around care needs.

The second is that we need to expand access to home and community-based services: expanding Medicaid, long-term services and supports, by financing innovation and allowing for flexible waivers; re-authorize programs like the Balancing Incentive Program, and Money Follows the Person; extend the timeframe that states can expand Medicaid as outlined in the ACA, and maximize the federal match.

We also need a publically financed long-term care benefit for those that need it, and this can come in the form of adding a long-term care benefit to Medicare.

A second arena that we think about is support for families--increasing financial and programmatic support for family caregivers. So we advocate for policies that will provide paid family medical leave for a father and a mother, including care for parents and grandparents; adjusting the rates and caps of Earned Income Tax Credits to make care more affordable; income credits towards Social Security for individuals who reduce their work hours or leave the workforce [to provide caregiving]; increased funding for Lifespan Respite Care programs, and a refundable tax credit for costs incurred as a result of elder care.

We also believe we need to lift Medicaid asset limits used to determine eligibility for long-term services and supports, and to index asset limits to inflation. We need to address gaps in national data—there is a lot that we still actually do not know and we have an opportunity right now to do some real research at the national level. One is really assessing the need for long-term supports and services and the impact of family caregiving for those in the age range of 50-64. There is a lot of research being done on those who are 65 and above, but in other age ranges we need more data to really understand the needs. We should study the impact of increased worker wages and training on the quality outcome of consumer care. We need to model different ways states can provide a meaningful and sustainable universal family care benefit. We need to update the national study on caregiving youth. So, I think there is a lot of opportunity right now at the national level to be doing that kind of research to inform our work.

We also need to continue the work that AARP has led in doing through the CARE Act to better document and train family caregivers. We think that is really important to continue at the national level.

Then a third bucket of opportunity we see is around jobs--creating better care jobs. Our nation has to improve existing care jobs, as we have heard all morning, and create new jobs and recruit and retain a robust care workforce. Some things we think about here include increasing the national wage floor for all care jobs. We heard this in the exit polling; people generally agree with this, that the people we hire to care for our families should really earn enough to care for their own is the principle here. So, it is exciting to see all the momentum that is building, and I am sure David will talk some about this as well, so I will keep it short.

A second important area is improving workforce training and career mobility. Although some states have training requirements, there is currently no federal standard for training or assessment of personal care aides.

A third is developing a path to citizenship for undocumented caregivers--a path to citizenship for undocumented caregivers who have already provided caregiving services helps fill the worker gap, and provides security for families who are already receiving quality care from an undocumented caregiver. Fourth, creating a national initiative to incentivize and recruit family caregivers into the paid workforce as we have also heard some comments this morning is key.

Then there is a broader general recommendations that we would make to the new Administration: Pass a fair and sensible budget that prioritizes the needs and programs of people over the narrative of scarcity and debt.

Finally, we [need] to improve the Older Americans Act. I know all of this is hard politically—there is so much uncertainty—but we have to continue to keep these [priorities in the public eye.]

Judy Feder

We have to be for it.

Sarita Gupta

We have to be for it. We have to be strongly for [a proactive policy agenda], and I would add that we need to be in there making recommendations around key personnel appointments. An appointment for an Assistant Secretary of Aging, expansion of the Administration for Community Living, appointments to the Council of Economic Advisors and the Domestic Policy Council. We need people who have expertise [in aging], so those are some of the things we think we need to move at the national level.

I do want to just shift for a second--pivot--I do think we continue to see tremendous opportunities in the states. Understanding that federal improvements cannot and will not happen overnight, we believe that states can and must take intermediate steps to expand access to affordable and accessible long-term care until federal improvements are made.

Today marks the release of Caring Across Generations' new long-term care white paper, where our recommendation is for a new universal state-based long-term services and supports benefit, which directly responds to the extra financial support being named as the number one benefit sought by family caregiver voters in the results we heard earlier this morning.

Caring Across Generations recommends the creation of a state-level public long-term services and supports benefit that is accessible to all who need it, and it must be accessible to all individuals and families regardless of income, and be administered by the state government.

Why states? States are the nation's laboratories of democracy and innovation and within their full legal authority states can provide the solutions people need and implement models that the federal government can learn from. State-based programs can address the unique care problems faced within each individual state and these programs can yield invaluable insights into what works and what does not and build momentum for an eventual federal solution.

Our paper outlines a set of minimum recommendations for what universal state-based long-term services and supports benefit could and should encompass; so, one is universal, as I said. Two, it is secondary to Medicaid and Medicare, and applied to anyone needing care for more than one ADL (Activity of Daily Living). There is flexibility in whether the benefit goes directly to the family or a provider, and there is the option of consumer directed care.

In the development of this new benefit, states have to build in consumer protections, like Medicaid asset protections, and states who take this on also have to create a workforce development plan. Some states have programs they can build upon to establish this type of program that we are recommending, and in some cases it is about developing a whole new program with a separate dedicated revenue stream or the development of a new Medicaid buy-in program.

The cost for a program like this will vary state-by-state, and we also set out options for how states can pay for it. We include some basic principles that we think work at the state level, and which groups and advocates should take into consideration around financing such a benefit.

To close, I am not pivoting to the state level because I am trying to let the federal government off the hook by any stretch of the imagination--but this is an effort to use states as learning labs for what the federal government should and must do, and as states make progress on our recommendations and the issues we all care about, the federal government can and should offer technical assistance and financial support in the form of pilots and initiative grants. With Senator Hirono [of Hawaii] we introduced legislation last session that would offer exactly this level of support to states, and we must continue to push for support to states who are on the frontlines trying to figure this out. Our thinking around a state-based benefit as well as our federal recommendations can be found on our website at caringacrossgenerations.org. Thanks.

David Rolf – President – SEIU 775

Good morning, I want to embrace and sort of incorporate by reference, I think just about everything that Judy and Sarita said in their remarks I think it was really quite right.

I think I want to approach this really by thinking through three big themes of the work that needs to be done. First of all, the specific challenges and opportunities with the nation's long-term service and support system such as it exists. Secondly, the moment we find ourselves in the federal sector right now; and thirdly, like Sarita, I want to pivot and shine a light on a couple of really encouraging and innovative things that are happening in states, particularly the state where I come from, the other Washington.

I suspect that because you all are here, and because the program today has been what it is, I do not need to take a lot of time explaining some of the core challenges facing both caregivers and care recipients in the United States today. I lead a caregivers union. I helped organize the Los Angeles Caregivers in the 1990's and then helped build the model that grew SEIU from representing about 50,000 caregivers 20 years ago to 500,000 today.

I have spent the vast part of the last 20 years of my life working every day with people who have to take a vow of poverty in order to provide life sustaining services and supports to those who are at the point in their life when they are most in need, and that is the principal reality for caregivers in the United States is every day. They have to make incredibly difficult choices. Whether you are an unpaid family caregiver or a paid caregiver, between which needs of your own and which needs of your client or consumer you meet, and which ones you do not--because that is your economic reality, it is your time reality, it is your space reality and those are the folks who elect me and send me to conferences like this. I always like to begin by remembering that those, mainly women and some men, but mainly women, who do literally backbreaking work are in most places invisible and powerless; and that is a choice, that did not happen by accident, it happened in some ways by design and I want to talk about that momentarily.

But backing up and thinking big picture, regardless of which party holds political power or who has which jobs in this Washington, we have a caregiving system in the United States that has some incredibly significant challenges as we reach the 30 or so years during which the baby boom generation will be at their peak level of needing services.

One is still the structure of how we provide long-term services and supports. In places like Washington State, for every one person in a nursing home, there are four or five people receiving home and community-based services. So my state is "rebalanced," and, we are a beacon to a lot of the states where there are still nursing home owner caucuses in their state legislatures preventing anything but small pilots and waiver programs from growing. But I think the reason we work so hard on [the Balancing Incentive Program, or] BIP for example, and the Community First Choice [Medicaid state option] was precisely because there are so many states where legacy institutionalized care systems were really created when Congress accidentally photocopied a Blue Cross Blue Shield benefit plan into the Medicaid Act in 1965. That is still the [federal] default for how people receive paid care as opposed to unpaid family care, and that continues to be a huge challenge through a lot of what I frankly call "Red State America."

But there is an additional structural challenge, in that when I speak to physician groups I often say "when you are treating a Medicare patient, how many of you know whether Medicaid is paying a caregiver to sit in your waiting room doing the crossword puzzle while your patient lies to you about falls, diet, prescriptions, memory, depression, etcetera, et cetera, et cetera," and they inevitably laugh because no one knows--they do not, because we have siloed systems where even in--especially perhaps--highly rebalanced states there is not a link between Medicaid fee-for-service and HCBS, and whichever Medicare or especially [Medicare Advantage] programs that people access. So the actual person who knows whether Mrs. Jones stopped taking the green pill because it gave her diarrhea, but which will therefore result in her having a stroke six weeks later--the one person who knows that is not in the conversation about interventions that could happen in a lighter-touch upstream way to prevent a downstream high-cost major medical event.

Even for those of us in highly rebalanced environments, we still have the *next* structural challenge in front of us, which is really how to integrate the work that caregivers, paid and unpaid, do with the team that is thinking about the health of the whole person. That is I think is the structural challenge.

Secondly, we have a [major] workforce challenge [in long-term care.] There are simply not enough workers doing this work to provide care for the number of people who are going to need it. This is a more acute problem at the personal assistance service level than it is at the primary care physician level or the nurse level, because the way that our medical system adapts to higher-level health professionals being in shortage is to expand scope of practice one level down, right? Historically, the guardians of scope of practice almost always lose, because the result of their turf-conscious, rent-seeking behavior is that they eliminate their own supply, and therefore we have to expand scope of practice downward within the system; but this is not possible for a minimum-wage unpaid caregiver with no training.

There is no lower scope of practice to go to; so for that reason we can imagine what to do with distance, health, and technology, and say in a rural area where you lack access to a sufficient number of primary care physicians much more easily than we can imagine what to do where the caregiver supply is simply inadequate to meet the needs of the people who need care.

People often talk about training and workforce together. They belong together, but it is also not true that simply by training more caregivers you will *get* more caregivers, because unless you address wages, benefits, job quality, and also the work environment, and the need for example peer mentorship and day-to-day support with what is really an emotionally taxing job, then simply training more people to do the work does not result in more people staying in the jobs. It actually just results in spending more money on training for people who do *not* stay in the jobs. This is not an argument against training. I will talk a little bit more about that momentarily. It is an argument about pairing the professionalization of the paid workforce with actual increases in pay and benefits to result in incentives to both enter and to stay. Those are our workforce problems which I will come back to momentarily when I talk about Washington State.

Then finally, the financing problem: We did a number of things in this country. First of all, we built a nursing home system kind of by accident after the Medicaid Act was passed. Then seven years later in the next recession, with states starting to realize these were really expensive entitlements Congress had just helped lure them into, we began creating home care programs on the cheap, because this is what was, first of all, designed in many ways to escape the cost of more expensive institutional care; Secondly, that is what they could kind of afford at the time. So, that obviously contributed to building a minimum-wage workforce in Medicaid.

But meanwhile, our country made a number of other choices, and we never had a national conversation about care, even while women doubled their formal workforce participation, [rising from] 37 to 77% between 1977 and 2012, for example.

We also, during that same generation, shifted more and more risk for retirement planning and savings, and investment, onto individuals and away from institutions, resulting in a world in which the average person in America has enough money for \$55 a month in post-retirement income, and the average person nearing retirement has enough money for private investment for \$120 a month in post-retirement income. This is obviously not enough to pay even the basics for what you need to live, much less pay a caregiver, which then exposes Medicaid programs to be essentially the payers of almost first resort--almost first resort for half of the population that needs care.

The combination of creating an on-the-cheap, low-wage workforce while simultaneously having a 40-year wage freeze for American workers generally and transferring most risk for retirement onto individuals rather than institutions, has created the perfect storm, where now our state Medicaid programs--and therefore state general fund budgets--end up being the primary, for lack of a better word, insurer of long-term services and supports. That puts them in direct competition with everything from education to transportation and infrastructure and public safety. That barely works during periods of growing economies and robust state budgets. It will not work at all as the demand continues to grow, and during inevitable business cycle downturns that result in states--counterintuitively from a fiscal policy perspective--but nevertheless needing to cut their budgets.

We have this perfect storm of an imperfect structure, an imperfect situation on the workforce, and a highly imperfect financing mechanism--all of which have to be addressed. They will ultimately need to be addressed federally, but they cannot be addressed federally unless they are first addressed in states. The federal government does not do anything new and big, and good in the United States, it just does not happen. Name me a domestic policy area and I will tell you the state that did it way before the federal government, from child labor to marriage equality, to health care reform, you name it.

Judy Feder

Not Medicare or Social Security.

David Rolf

California was beginning to experiment with Social Security in the 1930s before the Social Security Act.

Judy Feder

I will take you on there.

David Rolf

Okay. So on the federal level we clearly have some defensive fights ahead. There is going to be a debate about Medicaid--whether the right answer is to block grant it, or simply to cap it, right, and that is going to be the majority opinion inside Paul Ryan's House. So, we will have incredibly important defensive fights to fight there. There is obviously going to be a debate about the Affordable Care Act that so many of us worked so, so long and so, so hard to get passed.

Particularly for this group, even as other things we value perhaps end up on the chopping block, we have to really keep our eye on the long-term services and supports pieces of this, such as Community First Choice and BIP, for example.

Then finally, I just want to mention some good news, and I know there is a whole panel on states later; I am not going to try to talk about everything happening in every state. But I do want to share some things happening in my state, just because I did not see anyone else from Washington State on the list later on.

We have, under our union contract, wages that will rise over the next years. So the pay scale for home care workers starts at \$15.00 and ends at \$18.15. If you are a home care worker in my state, and you work more than 70 hours a month, you get a comprehensive individual medical, dental, vision, pharmacy benefit for the cost of \$25 out-of-pocket. You get paid time off, you get reimbursed for the use of your car for mileage, you have a pension plan. This was not always true.

Fifteen years ago it was minimum wage, no benefits, no workers' comp, no unemployment insurance, no federal tax withholding, no paid time off, no mileage reimbursement—all adding up to invisible powerless poverty-stricken work. Because of the power of workers coming together, we were able to fundamentally change the economics of caregiving in Washington State.

Today if you are a caregiver in Washington State you no longer have to take a vow of poverty if you are willing to work and able to work full-time. People are not wealthy, they are not necessarily even incredibly comfortable, they do not live with a lot of luxury, but the caregivers have gone from the most abject poverty imaginable among wage earners in the United States to being lower middle-class.

In addition, we have the most comprehensive caregiver training program that we designed and we implemented; we ran a piece of legislation and two ballot measures to make it happen. If you are a caregiver in Washington State you have—if you are a caregiver for anyone other than an immediate family member—a training system that matches the federal minimum for certified nurse assistant with 75 hours of required basic training, 12 hours of required continuing education, and a competency-based tested certified profession, all of which is geared towards adult learners provided in 14 languages in 200 locations. Workers get paid their regular hourly rate while they sit in class to learn.

I mention some of these innovations--and this all in a state where we serve four times more people in homes and communities than we do in institutions--to remind us all that incredibly progressive and positive change is really possible. This was not something God did for us, this was not the reality Washington State was somehow born into; founders in 1860 did not write it into the state constitution. It was actually something we have done in real-time over this last generation, and so even when things seem the darkest in this Washington, I think there is lots and lots of room for us all to work really hard to improve the systems here and wherever we are.

Daniel Wilson

I have a question before we take questions from the audience and any Web questions. I think that this panel focused on the hope aspect of what we are looking for; but I have a specific question for Judy: As we look at public policy opportunities that may be there, in particular for this workforce, what is that one overarching venue that you would see where there would be an opportunity that would be open?

Judy Feder

On the workforce I actually think it is on the paid workforce. I am with David here on the activities in the states supported by the people in this room, and the ones I am sitting next to, that the move for a living wage is huge for this population. I would add to that, especially based on some of the polling information that we got this morning, the support for building on Washington's excellent example in terms of training direct care workers so they can not only give good care but have the capacity to advance in their careers.

Sarita Gupta

I would say at the end of the day we have to be thinking about both what is necessary for the paid workforce, and again what is necessary for the unpaid family caregivers. When I spoke this morning I talked about how I am part of the panini generation, and the reality is, thank God I have paid leave. I work somewhere where I have really good benefits, and that gives me the flexibility and the time I need to be able to really care for my loved ones.

Beginning to think about the care infrastructure that we need to be building that weaves together the elder care supports we need, with the paid leave and the childcare supports we need: We think this is really important, and that is not just theoretical for us. You will hear from our partners in Michigan in the next panel, but when we talk to people on the ground they are like, "terrific, you want to figure out a solution around elder care--that is awesome. However, here are the other things I need in order to actually survive this." We need 21st century workplace policies that speak to this. We need childcare, affordable, accessible childcare...so I just think this is a moment when we need to be really holding the whole...care infrastructure [in mind.] It is a huge opportunity right now.

Daniel Wilson

Any questions from the audience?

Carol Redfield

Hi, I am Carol Redfield I am a grad student in Nursing. Quick question for David. I am from Washington as well. I am really glad that we are doing very progressive things, but I would like to hear some things on elder abuse. An ombudsman can go to institutions, adult family homes—caregiving happens in a lot of homes. Who is keeping an eye on them? Because there are still abuses happening, thefts and so forth.

Number two is, how do you know what the outcome is to your training? You can talk about training, it is great, but how do you measure how effective they are?

David Rolf

I am going to speak primarily about the Medicaid home care system in Washington State that provides the vast majority of paid care, because that is the part of the system I work in. In our state, there are a number of categories of both health and social service professionals who are mandatory reporters for elder abuse, and those include the case managers and social workers who do at a minimum twice yearly visits with every Medicaid home care beneficiary.

The way the system works in Washington is that when you first begin to imagine you might qualify for Medicaid home care, often it is—you all understand what the general system is, it is a hospital discharge, a life event or even as often happens, just a holiday where the family gathers and realizes that Mom cannot really do things by herself anymore, and then there is planning and there are conversations, ultimately people meet with the social worker and spend three hours with them going through a uniform algorithmic-based assessment tool that measures ADLs and IADLs. That includes things like family and home environment, and challenges in the home environment, and then it provides a benefit level that is calibrated based on the level of need for ADLs and IADLs.

The case managers are mandatory reporters; health professionals are mandatory reporters; and as you can imagine it is mainly a dually eligible population. Many of us, looking at our ages in the room, are probably likely to see a doctor once or twice a year. This is a population that sees a doctor once or twice a month very often, sometimes even more frequently. So, everyone in that system is a mandatory reporter of elder abuse.

We also have criminal background checks, and there is a long list of disqualifying crimes. To become a caregiver you go through an FBI fingerprint background check and if you have ever committed check fraud, if you have ever committed anything that touches on victimization of a frail individual, this results in disqualification. So, those are some of the safeguards we have.

We actually think from an anti-fraud perspective we are one of the better states. A number of years ago SEIU put together a model set of state policies by talking to a bunch of state Medicaid directors and figuring out who was doing what well and who was not. I think the Northwestern states, in part because they invested so much in home early on, have managed to figure out how to do a really good job at anti-fraud stuff. That was the elder abuse part. The second part of your question was?

Carol Redfield

Outcomes.

David Rolf

Yes, outcomes. So, we run a competency-based training system. It is geared towards adult learners, it is very hands-on, and the goal of it is to make people competent to provide the plan of care that their client has. There is not yet a ton of robust academic data on the link between training and cost, but there is some emerging both in Washington and California. There are now a couple of studies that show the impact of a trained workforce on controlling for 9-1-1 calls, emergency room visits and hospital re-admissions, and although I would say it is a research field that is in its most nascent stage, the two or three studies that exist so far are really encouraging. They show that with good training, even a relatively small amount of training, of caregivers can dramatically improve [care] or decrease the number of significant occasions that people need to access higher levels of medical care.

Judy Feder

I just wanted to say that in responding to both comments and to questions that I only touched on the surface of, there are recommendations in here [the National Academy of Medicine report on family caregivers] in terms of the kinds of issues that you are raising about research, innovation, evaluation, data that we are collecting, and oversight. There is a lot. My colleagues were very serious academics with very serious credentials and so it is there for us to use.

Daniel Wilson

I will just chime in, I think Anne would agree we, at PHI, work a lot with training, retention and recruitment, and one of the things that we are looking at is the advanced training and the advanced aide role--which really does lead to improved health outcomes--and you can make the case for the cost savings, but you cannot really actualize it [yet] in a way that individuals really see savings. But we, as an organization, are working along with other organizations in that effort as well [to produce more data]. I think we have time for two more questions.

Sarita Gupta

I have a comment.

Daniel Wilson

Absolutely.

Sarita Gupta

Just in response to the elder abuse, which is brought up very frequently, I would like to point out the unpaid caregiver abuse that is perpetrated against family members by the system, a system in which there is the ultimately exploited group, together with paid caregivers; and I think that connection is really important and my most important point is just the abuse of the family members.

Judy Feder

When we think about opportunities right now for better engaging family caregivers and direct care workers in terms of the health care of care recipients, I think we have to be very mindful that there will be organizations that will want to do this in very positive ways, this engagement, in order to support the care recipient and the

caregiver to reduce the use of unnecessary health care services. But there will also be cases where organizations, insurers, and providers will be wanting to shift burdens onto caregivers, and so we have to be very mindful and evaluate and assess, and not make assumptions.

David Rolf

Let me just add onto that. It wouldn't be a panel with Judy if she did not warn about the potential downfalls of a managed care migration.

Judy Feder

Well, David at least you have heard me.

David Rolf

Yes. I would say on the opportunities front: one of our signature employers is a Medicare Special Needs Plan that came up with a very innovative idea, which is to hire the pre-existing Medicaid home care workers for its SNF [skilled nursing facility] clients, adding more hours of care for workers in addition to the hours they are getting paid by Medicaid for their Medicaid work. So now they are also getting paid for Medicare work on the bet that if they go through a little bit of extra training and learn to coordinate with the primary care physician, that they can really make a transformative difference in the health outcome for the most frail and most high need Medicare recipients that there are.

Daniel Wilson

I think we have time for one more question.

Elizabeth Blair

Hi, I have a comment and a question from online. The comment is, from April Koontz, Founder of Doctors Unite: I am a daughter and clinical social worker who has been a caregiver for years, but never was aware of the term caregiver until I came across it in the medical versus mental health arena. From my perspective, the label "caregiver" is a temporary identity, versus the permanent identity of daughter or son. The majority of people are not introduced to being a caregiver until adulthood when they find themselves in a caregiving situation. Do any of you have reflections on that?

Sarita Gupta

Yes, absolutely. I will just share a story. A few weeks ago we held a summit called "We Won't Wait" where we gathered 1,500 women of color from communities across America to come together and talk about the issues that really matter to us. Not surprisingly care was a big one, and when I got up and shared my personal story with a little more detail than I did this morning I had numerous women come up to me and say "oh, my God it was not until I heard your story that I realized I am a caregiver." This one woman literally told me that her husband is a wounded warrior, a soldier, and that she cares for him. She has a son with a disability and she has a father who has had a stroke and she cares for all of them while working full-time, and it never occurred to her that she was a caregiver.

I share that because that is so very real, and I appreciate that comment, and this is where I think language matters. Stories matter -- stories that would not have actually surfaced without storytelling work, which brings me to a component of Caring Across Generations. It is work which is about culture change, and how we are creating our own stories about what it really means to be a caregiver, and somebody who needs care in this country, and the values that come with that along with how we are actually finding ways within existing culture and pop culture. Using existing story tellers in our society, we are actually lifting up the positive and opportunities around how we think of ourselves, and placing ourselves in [larger] conversations.

There is tons of work that we have been doing at Caring Across on this, but I think that is absolutely right, that it is a temporary identity and people really do respond to "I'm a working daughter who cares for my parents" and "I'm a working mother who cares for my daughter" and how do you manage that? So, very appreciative of that comment, it totally resonates.

Daniel Wilson

Thank you and please join me in thanking our panelists today.

Anne Montgomery

You can see there is a lot of conversation going on which is very exciting, and we hope that is true online, I am sure it is. I am just going to say it is with deep pleasure that I introduce Edwin Walker and Gail Hunt. Edwin Walker is Acting Assistant Secretary for Aging and Acting Administrator of the Administration for Community Living that was created in 2012. I think Edwin is one of the most knowledgeable, trusted, and forward-looking senior government officials that there is and he will be talking about the role of diversity in the changing demographics of older adults as well as younger generations, and Gail Hunt is one of the best and most well-informed people on family caregiver issues in the country -- so we are looking forward to a robust discussion. Thanks so much.

Gail Hunt

I thought of this more like a fireside chat because there are just the two of us up here and I have known Edwin for a really long time. I will not ask the question that is sort of top of mind.

Edwin Walker - Acting Assistant Secretary for Aging and Acting Administrator - Administration for Community Living

Ask.

Gail Hunt

Well, okay, maybe I will ask it.

Edwin Walker

You know me, I am frank.

Gail Hunt

Yes, well, Judy just barged right in there and said what she was really thinking. So, Edwin, you have seen over the years, it has actually been relatively stable at ACL [Administration for Community Living], even though it used to be AOA [Administration on Aging]. Then it was broadened to—well, then you thought you were going to have the CLASS [Community Living Assistance Services and Supports] Act; and that went away. Then you got disability added, and so [ACL's mission is] really much broader now. So, how is it looking now since last week?

Edwin Walker

Well, a few things changed last week and good morning, good afternoon. It is my pleasure to be here. Thank you all for the invitation, certainly Anne, thank you for the invitation and it is great to be here with you, Gail.

I will talk about last week, the day after. After staying up all night, I walked into the agency knowing that I needed to be positive and I came across a number of staff, particularly young staff, who had never been through transitions before who were crying, who had tears in their eyes; and we had both groups, we had people who were very concerned and fearful, we had people who were rather pleased.

The important thing for me was to really get a sense of how many young people we had and to encourage them that we have always had changes in administrations and it is important for us to simply continue to move forward.

What I think is also important for us all to know is that these young people are the very young people that we have always wanted to attract in the field of aging. They are incredibly bright. They are dedicated. They have captured what we have always been about. They believe in the mission and the value of what we do, and for them to wonder whether or not they should continue in this field, in public service, was a heartbreaking thing to witness coupled with, you mentioned that we also have -- we are the Administration for Community Living -- we have a high number of people who have disabilities, some with very severe disabilities; and one in particular was really just weeping. She was weeping because while I tried to encourage all of the staff she said, "You don't understand because you're an able-bodied person. The person that represents this administration that I've seen to date is a person who mocks me, a person who doesn't value my life and I can't imagine values the work that I do."

So, what are we to do? Just saying to these people, “well, we have to continue on” really is not enough. The next day I participated in a discussion broadly across the Department of Health and Human Services where we had a lot of people from the Centers from Medicare & Medicaid Services who had dedicated their lives to implementing the Affordable Care Act, and were wondering, “what do I do now, do I continue for the next two months, do we change course, what do we do?” In addition, some of those staff indicated that they are fearing for their personal safety, because people know that they were responsible for implementing Obamacare.

Within the Department of Health and Human Services we have a huge challenge before us. As leaders within the department, we are continuing to encourage them to move forward, not to change course, to continue to implement. We are going to continue to implement the Affordable Care Act to the best of our ability until it no longer exists.

We also would say that it is important for people to understand why this is significant, and we are ready for the Trump transition team. We are going back with the expectation that I will be meeting with them. We have been told to expect them as early as this week, and we are looking forward to them. We are looking forward to attempting to figure out who they are, what they know about us, what they know about the people we care for each and every day, the people that our aging and disability networks interact with on a daily basis and positively impact their lives and we are going to do our job, which is to educate and to inform them. And just as the title of this session say today--this forum--we are going to try to get them to understand that America does care. America cares, and we want them to care.

I will also say this: it was not that long ago that I went on a field trip with a renowned Democratic Congressional Member in the House, and this was during the time we were trying to get reauthorization of the Older Americans Act passed. We were strategizing, because he talked about his struggle just trying to get folks to understand [why the law is important], and he said to me, “all your stories are great, but I can’t sell compassion, they’re not buying it. What you’ve got to give me is hard data, cost savings arguments and couple that with the compassionate stories, but the compassionate stories alone are not going to be enough.”

So, we are going to continue down this track. We are totally ready and I am looking forward to interfacing and doing my best to influence the incoming administration.

Gail Hunt

Very inspiring I have to say. I am hopeful that you will be successful in that.

Edwin Walker

Thank you.

Gail Hunt

Let me ask you a little bit about of some stuff that came out this morning. One thing that I have not heard much about is really the fact that long-term services and supports is something that the private sector, for example--health insurance companies--are beginning to be interested in. But I do not really see a lot of movement in ACL about this. We have the Older Americans Act, yes, that is true, but where is the outreach from you guys to say to the private sector, let’s move that agenda forward?

Edwin Walker

We believe that a part of our core is advocating on behalf of long-term services and supports. As you mentioned, the CLASS Act was part of our agenda for a period of time until we determined that as written in the statute it would not be sustainable. We are very committed to the issues of long-term care, long-term supports and services. We have worked in various iterations on long-term care insurance, and home and community-based services is what we are all about. We know that the huge challenge in this country is addressing long-term care.

I loved the [documentary, “Caring”] because it is absolutely correct. The country is not prepared for elder care; it is not ready for long-term care, period. That is what the film is really talking about. That is what we are talking about when we talk about the caregiving challenge in this country, and I believe I am going to go back

to your question earlier this morning, where you were discussing the fact that some of these folks in Congress are people we have dealt with in the past. So [the question is] how do we get them to be different than they have been in the past?

I want to hope—I am an eternal optimist—I want to hope that the issues of aging, the issues of long-term services and supports, the issues of caregiving, are issues that now [policymakers] have discovered them because they are older, their family members are older, their parents are older, and they have experienced in their personal lives the challenges that we always talk about. So, I am hoping that we have new avenues to approach those individuals, and to make an appeal to them for a new model in this country.

Gail Hunt

Well, I hope so too. Could you talk a little bit about the issue of diversity? It has come up several times in people's presentations, for example in the fact that in the paid workforce, direct care workers typically are women who are of color, and a large percentage of them are from other countries as well. So I would really be interested in hearing about that, but also I know that when we look at family caregivers, they are paying out-of-pocket a great deal for long-term services and supports for their loved ones or their neighbors, and they also tend to be people of diversity, people of color. So could you talk a little bit about that too?

Edwin Walker

Sure. I think, as was stated in the earlier panel, the pollsters [and many others] got it wrong; everyone thought that because of the degree of diversity that already exists and that we know will continue to do nothing but increase in this country, that there would be a different [election] outcome—and that did not happen.

What we need to do is to legitimize the diversity and the people in our direct care workforce, our paid and unpaid workforces in order to get others to see that they are a part of a system. They are part of the fabric of this country and they do work that most people do not want to do; and there needs to be greater acceptance and a greater sense of the fact that this is going to do nothing but increase. So, we want to work with each of you to find ways to support, enhance, and legitimize those individuals.

There was an issue that was raised earlier as well, about whether or not caregiving is a bipartisan issue. When we look at family caregiving historically, it has been a bipartisan issue and that sounds great and gives us hope for the future. However, I think that it is often misunderstood because it is viewed very much like volunteerism, it is viewed as something that is free—and it is not free, it comes at a huge cost. It is a huge cost to the caregivers and to the family, and to employers. It is a huge cost and we need to get policy makers to understand that and we need more support for caregivers.

The second thing is, as it relates to the paid direct care workforce, I do not think that has ever been a bipartisan issue, because it involves issues of wages, it involves issues of benefits, it involves issues of labor, and therefore I believe that we do need to take an offensive effort in order to address those issues moving forward.

Gail Hunt

Very good. Before we turn to the audience for questions are there any other particular remarks you want to make?

Edwin Walker

Sure, there were a couple. I would love to take questions from the audience, but I heard a couple of questions earlier that I want to comment on.

Gail Hunt

Good.

Edwin Walker

One was what are we doing in terms of trying to make this a better system and what we are doing in the Aging Services Network and the Disabilities Services Network: we are trying to bridge health and social services in order to truly provide a holistic approach to health care in this country.

We know, and have known for decades, the value that the home and community-based services network provides to people in terms of helping them follow through on discharge planning orders, providing falls prevention and chronic disease self-management, and an array of programs and services that are related to achieving better health outcomes.

We are working with our networks to give them an acquired sense of business acumen, so that they can better partner with the health care sector in order to create a complete picture, and so that the health care world sees us as a valuable asset and contracts with us. That contract [must be] something that [the Aging and Disability Networks] benefit from and are not taken advantage of. So, I want folks to know that we are doing that.

The second thing I want to address is the question on elder abuse. It is important for you to know that many people make the false assumption that we have a national elder abuse system in this country because we have had a child abuse neglect system since the mid 1970's. But it is also important for you to know that what we are now doing in the area of elder abuse is by virtue of the Elder Justice Act, which was a part of the Affordable Care Act, and we certainly will be making a pitch that as they talk about repeal that they do not repeal that.

What we have in this country [allows] individual states to develop systems in order to respond to abuse, neglect, and exploitation within their given jurisdictions. What we have as a result of that is a hodge-podge. We do not have any consistency. No uniformity, and on a national level we cannot tell you who is abused, what their characteristics are, who are the perpetrators, what their characteristics are, or the best interventions to prevent abuse or the best ways to remediate the issues or to provide services in response.

What we have been able to do—and we are appreciative, because first President [Obama] put it in his budget, and Congress did not respond for two years; but the President then funded it out of the [ACA] prevention fund on his own, and then Congress [later] responded and gave us a little bit of money. So for the first time in history, we now have appropriated money dedicated to elder abuse, neglect, and exploitation.

What we have done is we have developed a number of key things. We have developed the Elder Justice Coordinating Council, which coordinates activities across the federal government in this area. Tremendous accomplishments have occurred because of this coordination. Twelve different federal agencies are involved in talking about these issues and dedicating their time and resources to making what we have work better.

The second thing we have done is within the Administration for Community Living, we have created the Office of Elder Justice and Adult Protective Services. That office is focused on these issues, and out of that what we have done is we have developed a national data collection system, and while we know that we do not have the authority to mandate a system, we have worked in a consensus way with every state; and I am pleased to say we have 49 states who are voluntarily saying they would give us their data because they know the benefit of doing so. We will then be able to solve issues [of data gaps] and respond.

The second thing we have done is to develop a set of national guidelines, voluntary again, for states to adopt. We sort of took the old Institute of Medicine model of highlighting the best of the best, and raising it up as the gold standard, which others then try to achieve as an incentive for better performance.

The third thing we have done is really focus on the provision of training, technical assistance, and research so that we have taken the best there is--the best knowledge throughout the country--and we are holding that back up and giving it to states so that they can improve their systems.

Gail Hunt

Great, I am appreciative that you decided to respond to some of the questions that people raised earlier. I just wanted to mention the RAISE Act because that is something at the federal level that everybody here should know about. I don't know how it is going to go through. It went through the Senate, and it was voted on unanimously; now it goes to the House and we do not know what is going happen, but it is really an excellent bill that begins to raise the visibility [of family caregivers. If it is enacted we] will have a panel of people, both federal agency people and advocates on the outside, who are going to be looking at how do we support family caregivers similar to the Alzheimer's group [created by National Alzheimer's Project Act]. I think it would be great if you could talk a little bit about that and what you see as the opportunity there.

Edwin Walker

Well, I think the key opportunity [in the bill] is the fact that it raises awareness. It will be a vehicle by which we can then create more conversations, and have conversations with Members on the Hill, about the broader issues that are being discussed here at this forum today. That is what I see as the real value.

Gail Hunt

Yes, it does not have a deliverable exactly, but it is a camel's nose under the tent.

Edwin Walker

Yes.

Gail Hunt

Okay, so you are up.

Elizabeth Blair

Question from our Web audience: How can we shift the funding trends in LTSS and community-based services, particularly through a shift in health care investments for the entire aging population? You can handle that in a minute, right?

Edwin Walker

I look to you. We have done a lot of talking about it. We have tried a number of things. Part of our transition materials was to review—and I am going to slice this with what might be achievable in the next four years or so—one of the things we had to do was to look through the campaign promises of the two candidates to predict what the impact would be. We could not find very much, but one thing that we did find was a response from the Trump campaign to a survey done by the—I am going to get the names wrong—the National Association of People with Disabilities and another group called Rev Up. They asked a series of questions [about long-term care, and] the Trump campaign's response was focused on the [Medicaid] institutional bias. Certainly, the Administration for Community Living is focused on community living and enhancing the array of options that would allow people, older people and people with disabilities, to continue living in the community.

Mary Anne Sterling

Mary Anne Sterling from Connected Health Resources, a long-time family caregiver, and my quick comment here is after all these years don't we finally need a caregiving czar to be appointed? While we are appointing people over the next few weeks wouldn't that be great?

Edwin Walker

Yes, but I could list a whole host of czars, and I think what really is important is a better basic understanding of what we know to be the real issues and what we will do is encourage the incoming [Trump] Administration to listen to people. They claim that they listened during the campaign, and so we are going to encourage them to listen to the issues we will present to them—issues that I [also] want you to present to them—but we are going to encourage them to go and talk to real people who are faced with challenges each and every day in the area of long-term services and supports, caregiving. We hope that out of that they will develop a heart toward older people, and that they will care and will respond.

Gail Hunt

I had another question. I had great hopes that the NASEM National Academies of Sciences, Engineering, and Medicine study on caregiving would address the idea that the family caregiver and the patient should be looked at as a unit--the family unit--and that this would be a way that, for example, CMS could [use] to [develop protocols to] provide services to family caregivers; especially because, and I know the [Centers for Disease Control] is interested in this, the health of the caregiver is becoming a public health issue.

Edwin Walker

Yes.

Gail Hunt

So how do you see ways that we or ACL can work towards that?

Edwin Walker

Well, I had an answer that I want to hope that it is still applicable, which is we have been on track for some time of pushing forward science-based, evidence-based solutions. Certainly the fact that it was an [National Academy of Sciences] study gave us leverage to say, “hey, policymaker, this is real, this is proven--this is what you should do, it’s already validated.” I am hopeful. I have to be hopeful.

Gail Hunt

Yes, well thank you so much.

Edwin Walker

Thank you.

Gail Hunt

I really appreciate your comments.

Anne Montgomery

All right! If we were not pumped up before, we certainly are now. That was just an amazing and wonderfully emotional, for me anyway, series of remarks. Thank you, Edwin and Gail. Now we are going to turn to Maggie Ornstein, if she would come up, and she is going to share a story.

Maggie Ornstein

I am really glad to be here. Gail, I have so much to say just about the last, the caregiver dyad/triad, I could talk for days. Given that it felt difficult to squeeze 20 years’ worth of caregiving into 10 minutes, I decided to focus more broadly on caregiving.

Over the past two decades, I have primarily cared for my mother and grandmother—more than half of my life at this point—but I also cared for my grandmother’s cousin, who required dialysis, and his wife who had Alzheimer’s disease, as well as foster children, and I recently invited an 80-plus year old woman into our home who had no family and needed some help. So, I have been a caregiver for a very long time, home-based and institutions, both for acute care and long-term care.

Throughout my years as a caregiver, and particularly when I was a very young caregiver in my teens and early 20’s, the messages I got were either that I was such a good daughter, or that I should go live my life and put my mother in an institution. While I always felt good about the choices I was making in living my principles by taking care of my family, I also resented these sentiments because I *was* living my life. It just so happened that my life included people with various degrees of disability who were in need of assistance. I did not think that they should have to be institutionalized in order for us to all get the help that we needed.

Very early on in my mother’s medical crisis, I became an advocate for families of people with brain injuries and got involved in various efforts to bring awareness to the fact there were caregiving youth, kids under 18, who provide significant care to their families in the United States who were and remain unrecognized for the work that they do.

When I started reading the literature, I was struck by the near complete focus on the negative aspects of caregiving. I resented the messages that caregiving is bad for one’s health, the individually based rhetoric that caregivers must take care of themselves and especially that there was little mention in the caregiver burden literature on the impact of caregivers’ interactions with the system in terms of the burden they face.

There was a popular discourse that focused on supporting caregivers through the development of services, but few are looking at whether these services were actually helpful given the way they were provided. I did a lot to keep my family protected and shielded from a long-term care system that did not have our best interest in mind, took away our personal agency and power with the delivery of services, and often made things more difficult rather than easier.

Over the years I often found myself saying, “This doesn’t need to be this difficult.” I could not fathom how, in dealing with the extremely sad and devastating loss of my mother as I had known her, I also had to continually fight with a system which was supposed to help us.

The long-term care system is one that each of us will be enmeshed in likely at several different points in our lives. No one is exempt from the all-consuming nature of it when we or a loved one gets hurt, becomes ill, or ages. My situation, while extreme, is not unique. Mine is the plight of family members who love someone who has been hurt, gotten sick, or old. We are there day and night. We are the vessels for grief, loss, pain, and anger. It is difficult, humbling, rewarding, and heartbreaking and we are often alone as we navigate this purgatory between illness and ultimately death.

Many years ago I wrote a journal entry after being part of a support team for friends who were participating in a 100-kilometer fundraiser walk. Being on this team was a big deal. We were at each check point prior to the arrival of our walkers, we had good healthy food they liked, changes of clothes, medical supplies, and good cheer to keep their bodies and minds cared for and spirits up as they were on the walk of a lifetime and needed support to make it to the end. Of course it was their effort and perseverance that got them through, but they would not have been able to finish without major assistance with basic requirements of daily life, food, shelter, and emotional care.

As the walk progressed, I remember seeing their bodies and minds change, they became emotionally exhausted and their bodies started to object to the long distance they were walking. Towards the end, sleep deprived and suffering with blisters, I wondered how they would finish and was determined to assist in any way I could, given the extreme circumstances they were faced with. I wanted to help minimize the suffering that was inevitable from this long trek that required endurance to complete.

In the end they walked over 60 miles in 36 hours, and at the end we were all exhausted but filled with elation that they had completed. We did it together. We were there for them because of our dedication to our friends and the bigger issue they were walking for. They finished in part due to our care and support. The following journal entry was written just after the walk. I share it as a metaphor for caregiving in the support the caregivers so desperately need.

[In my journal entry I wrote] “The team did their 100-kilometer hike this weekend, my friend and I were their support team, and I could not help but feel a similarity between this hike, the length, and the uphill struggle that is caregiving in today’s world-- and thinking about how the medical system treats family members—it is the equivalent of having someone punch the hikers in the face as they were approaching the check points.

Caregivers need a really good support team if they are to endure the lengthy and arduous struggle of caring for their ill loved ones. This means listening to the caregivers about what their needs are and meeting them, but also providing financial and tangible supports that caregivers can use for whatever it is they need to keep going.

As much as the hike was similar to caregiving, there was also nothing like it in that the hikers could see an end in sight, even if it was very far off at times. In caregiving there is often no end in sight, and that end means the death of someone very close to us. Is there anything so awful to experience the feeling that someone must die for the struggle to end?”

When I first wrote this, I envisioned the hikers as the caregivers and the support team as the system which, instead of being supportive, was just the opposite. As I reflect upon it and think about it now I realized there are multiple metaphors in this story that give it meaning. The hikers could also be the people with care needs and the support team the informal family caregivers. Had the hike gone on any longer the support team would have needed support.

Here is where the metaphor ends. Caregiving is not a 36-hour sport but more appropriately often feels like 36-hour days much like that hike, but for longer periods of time; often years and even decades. The long-term care system must be a caring and dedicated support team for family caregivers who are in the trenches or, continuing with this metaphor, in a long and arduous hike with their loved ones.

When I was 17 and thrust head first into a complicated life-and-death medical situation with my mother, I was naïve. I believed the medical system was a place to get help, to provide support, information, and comfort to me and people like me who are experiencing what would become a continuous battle with myriad systems with one traumatizing experience after another. Little did I know these same traumas would actually be inflicted by the inescapable system to which my family was now linked. Now I know better. I am equipped with life and professional experiences and academic research tools needed to better understand, analyze, and critique what I and countless others experience and suffer at the hands of a poorly run medical and long-term care bureaucracy.

Now more than ever the personal must be political. Arthur Kleinman speaks of caregiving in the genre of tragedy, but it need not remain there—not entirely anyway—if policy can provide for the caregivers so diligently providing care to their families.

Two months ago the National Academies released “Families Caring for an Aging America” and called for the incoming Administration to develop and execute a national family caregiver strategy. I hope we are already on our way towards transforming the long-term care system, but we must remember that we make the road by walking in the same way the hikers finished their walk—one step at a time and with significant support.

So, that is where I had ended, but after this morning I just felt like I wanted to make a couple of other points: that for many, many years I personally saved the government several hundred thousands of dollars doing the work in my home that I was doing, and did not get anything back for it, right-- no support, no tangible support that we really needed; and so for a very long time I have advocated for Social Security credits, fully subsidized health care for caregivers and also housing subsidies. It is taken for granted that there is a household where my mother can receive care and that is because I provide it. If we do not do this we are basically effectively creating our next generation of impoverished elders. Thank you.

Anne Montgomery

I think Maggie just lengthened our list a little bit of things that we can work on, and thank you so much Maggie. That was an incredible narrative, thank you for everything you have done.

Now we are going to move to a panel, it is our “Careforce II Panel: Where the Opportunities are Moving Forward in States and Municipalities.” We have already talked a little bit about this, but we have one of the best panels I can think of to tell you about what is going on everywhere from Mississippi to Washington, DC, to Maine; so looking forward to that. John Schall will be the moderator. John, if you want to introduce people or have people introduce themselves either way will work. Thanks so much.

John Schall

Thank you, Anne, and welcome everybody to this panel, which I think is going to be very exciting. I am John Schall. I am the Chief Executive Officer of Caregiver Action Network. I also wear another hat, which is the President of something called Caregiver Voices United which is a 501(c)(4) organization so that we can advocate both at the federal and the state levels on the issues we have been doing today, and that is why I am particularly happy to be moderating the state panel.

Before we get into the state panel there are two things I want to show you, which nobody mentioned yet today but actually one of the reasons this is happening now is not just because of the election: November is National Family Caregivers Month. This is the month dedicated to the issue in those tens and millions across the country who are talking about it.

So, this is the theme—and my organization chooses the theme every year, we have been doing this since 1997. This year, the theme is “Take Care to Give Care,” which is really a reminder to those tens of millions of family caregivers that you have to remember to take care of yourself first so that you can be strong enough to take care of your loved one. I just really love how Altarum and Caring Across Generations, and Maggie and her wonderful story, has reminded everybody today that caregiving is not an elder issue, it is a lifespan issue. Only half of it is those of us over 50 caring for someone who is over 50. The other half, is if you are a parent of a child with special needs, you are a family caregiver. If you are a married couple and the wife got [multiple sclerosis] MS in her 30’s, you are a family caregiver. If you are a 30-year-old spouse of a double amputee wounded warrior you are a family caregiver, so I am glad that question came up online.

One other thing I want to show you for family caregiver's month: USA Today just distributed this weekend nationally, in print form, an edition supporting our caregivers: That is Montel Williams on the cover, we are bringing him into town tomorrow. This is also available online at futureofpersonalhealth.com. Five million eyeballs will see this this month, with resources for family caregivers, so please those of you who are watching, streaming, and everybody here make sure you are one of those pairs of five million eyeballs.

We are going to talk about states, and I have a terrific panel here with us. Immediately next to me is Ben Chin from Maine People's Alliance, next to him is Spencer Blalock from Mississippi, Jennifer Dexter from Easterseals, and then my friend Carol Regan from Community Catalyst, and actually I am glad they did this because I was actually going to for the first time ever going to do men first instead of women first.

We are always doing ladies first—this gives me an opportunity to remind people one of the big changes in the last four or five years; how many more men coming into the family caregiving role. Not that we are replacing you women, you are still doing it—but the demand has become so great that you have kind of dragged us into it, sometimes kicking and screaming, sometimes we are a little bit more willing to do it, but now men are almost as likely to identify as family caregivers as women are.

We are going to talk about the states, and actually I am going to ask Spencer first, but I just want to say one thing about the states—and it was mentioned very briefly this morning: the CARE Act, which AARP has been pushing in the states is a phenomenal success; some 35 states and Puerto Rico have put in place the Caregiver Advise, Record and Enable Act. So there's a real sense that things can happen at the state level, because as we were reminded in the previous panel, nothing good comes out of Washington, DC, so it has to be up to the states.

Also one thing I think is worth keeping in mind, this is a bipartisan issue: This is not a red state/blue state issue. It is interesting when you look at states that have tried to do something, or are doing something in the family caregiving realm, you are not necessarily talking about big liberal Democratic states; Oklahoma was the very first state to pass the CARE Act, interestingly enough.

I just came back from Arkansas, the University of Arkansas Schmieding Center, the only state I know of that actually has a training program for both paid and family caregivers, and they train family caregivers for free in eight centers throughout the State of Arkansas. That should be true everywhere in the country. You look at states like New Mexico, when Congresswoman Michelle Lujan Grisham was still the Aging Director, and they[made progress], so it is interesting, the types of states that we are looking at. That is why I think it would be great if we start off with Spencer with the Mississippi experience. So, I will give it to you.

Spencer Blalock – Mississippi Family Caregiver Advocate

Thank you, so much. I am Spencer Blalock, it is good to meet all of you have and a great opportunity to share some of this time with you. At my day job I am a clinical social worker and health administrator in a private health system. Just to kind of give you an idea of where we have come from in a short period of time, the Mississippi Family Caregiver Coalition was started initially around the year 2000, but fizzled out when the people in positions of authority had to become caregivers, and we have recently come back into formation in 2015 where we were able to re-charter as a coalition.

Leading up to that, in 2014 Senator Terry Burton created a bill, the Mississippi Family Caregivers Task Force, and Governor Bryant wanted me as chair of that Task Force working with several state agencies that provide social services and supports for families as well as advocacy groups--several that are represented here but on a state level. We had a very short period of time to create a blueprint and study the issue from the point of caregivers' perspectives, and we provided that December of 2014 to the legislature—a blueprint with several action steps that we would like to see in the next five years.

One of those first steps was the CARE Act and we were able to enact that in 2015. We did not want to die with the completion of this, because our Caregivers Task Force [that worked on the bill] was an ad hoc committee. [We decided that] we did not want to be done. We said we cannot just let this [task force] die, so we have to

stay together and most of the people on the task force folded into a coalition, and now I am one of the co-chairs of that coalition.

Earlier in the year we received some information from Anne Montgomery regarding the Family Caregiver Platform Project, and because of the relationship we have with several of the legislators, we were able to share this information with them and keep the momentum going by creating a family caregiver resolution.

The resolution expresses the need to understand the impact of caregiving in Mississippi. We have a state of about 3 million residents and it is estimated, by AARP, that about 500,000 are caregivers for their loved ones. That is to me a large group of individuals who are not well represented to their legislators, and so for us it was important to be that voice for them and we continue to do this.

This resolution passed without any problem. Now the next step is to use the resolution piece of it. I have a copy of it here that my representative gave to me. I just want to speak briefly on it, but basically the resolution piece says that we work on evidence-based practices. If you look at John Kingdon, who is one of these political science gurus, he said there are three things you have to do: first you have to define the system well, define the problem well. Second, you have to provide evidence-based solutions, and third, which is probably the hardest part, you have to engage the political will of those in power based on whatever the feeling of the nation or the state is at the time. Gratefully, we have seen some of that happen for three years in a row, and we are hoping for some [more] progress in the next few months as our legislative session opens up in January.

John Schall

That is perfect, thank you, Spencer. I want to remind people that for National Family Caregiver's Month the President released his proclamation on October 31, and a lot of states do state proclamations and this resolution, which is substantive from Mississippi, and some of those state proclamations you can find at caregiveraction.org, and it is still not too late for your states, counties, and cities to do proclamations and we actually have draft proclamations there for you to do it if you want. So, from the south to the north: Ben, shall we go to you in Maine? Ben Chin.

Ben Chin – Maine People's Alliance

Yes, Maine is sort of the Mississippi of the northeast. My name is Ben Chin. I am the political director of Maine People's Alliance, and we have the unfortunate distinction of living in a state that has a Governor, Paul LePage, who probably most closely resembles Donald Trump. I want to mostly talk about good news and hope that we can pass, eventually through ballot, a universal family care proposal that would provide universal access to home health care, to paid family leave, and to childcare for everyone in the state.

And I want to actually center the good news and hopefulness of this message around taxes, because we have talked a little bit about financing today. I think that one of the big obstacles to doing all these good things, maybe one of the weaker spots, is less about *how* we would actually implement all these programs-- , but where does the money come to actually pay for this? Really focusing on taxes is perhaps counter to how a lot of us would traditionally approach policies like this.

This was not a planned remark, certainly not before last week--but I just want to say living in a state that has been through this nightmare for the past six years of having a right-wing, racist, misogynist, populist as governor, that there are certain political rules; yes, I am a political director, so half my job is elections, the other half is policy in the statehouse. In the same way that many, many political rules were violated during this election cycle, upsetting conventional wisdom--that is just shock one. What we should all expect as advocates is that shock two comes when legislative processes, traditions, and courtesies--things that we have normally expected are effective--fail to be effective in a new environment.

So, in the same way that the Clinton campaign and many people are re-thinking how to do elections right now, we should take this seriously--this moment--and start re-thinking how we approach our policy advocacy in a brand new environment.

Just one quick story that is an example of how taxes play into this, and why we are so committed to approaching it from this framework. The very first budget deal that our governor pushed through—this probably sounds

familiar—started with a very large tax cut. He essentially pitted education against health and human services, and Democrats decided to accept a budget deal that made massive cuts to education and to retirement security for state workers who had no access to Social Security, and it was an exchange for protecting things on the health and human services side; and it actually included reimbursement rate cuts for all sorts of care workers.

The very next year before the ink was even dry on that so-called “deal,” a manufactured crisis from this tax cut,[together with]incompetence in administration of health and human services, forced a shortfall that brought the legislature back into emergency session. Then another 50,000 people lost Medicaid, and Maine since has not accepted federal funds for Medicaid expansion. That feeling, being in the room and watching that vote go down, was one of the worst feelings of my entire life, and it was far worse than the feeling of when Governor LePage was elected. I think we need to get into this mindset that however bad we might have felt after the election, there is a great likelihood that far worse feelings are at stake.

Let me just say hopeful things on taxes. One is that the public is *with* us on tax fairness right now. We just actually did a ballot measure that called for a 3% surcharge on income over \$200,000 to fund education--partially to make up for the tax cut and education cut that were the legacy of our Governor. This passed last Tuesday. That undoes one of the major accomplishments that he had, and that passed, outperforming Democrats in many, many districts. At a time when the second congressional district and many working-class people voted for a right-wing populist, they also voted for this.

Our issues, as has been said, were not rejected on Election Day. Certain candidates who often distance themselves from our issues were rejected, and I firmly believe that the public is actually with us.

The second thing I want to say about taxes is that the knee jerk reaction that most of us have when we think about financing these systems are payroll taxes, and usually flat payroll taxes—maybe a 0.6% payroll tax applied to all wage income. Payroll taxes are regressive. I have a bunch of slides that I am actually not going to show you with very exciting charts about the regressivity of payroll taxes, but Social Security is perhaps the best example, where income over \$118,000.00 is not subject to taxes and in point of fact non-wage income. Income from stocks and bonds, and treasury yields is subject to no social insurance taxes of any kind. If you are in the top 1%, the top 1/10 of 1%, that is where most of your income is coming from--that sort of income, business income, things like that.

Our 20th century social insurance system was built on a false sense of who is actually really responsible for taking care of everyone, and the current payroll tax regime basically says that people who are wealthy do not share in the responsibility of making sure everybody has the care that we need--and so as long as we put forward payroll tax regimes that *reinforce* that, not only are we reinforcing just bad policy and a bad moral argument, we are missing a political opportunity, one of the fundamental political opportunities we have in America right now. People of all political persuasions believe that the wealthy need to pay their fair share in order to provide people everything that they need, including care.

We just did polling on Medicaid in Maine, Medicaid expansion, and found that taxing the wealthy was not only—I mean, Medicaid is popular, health care is popular—[but] taxing the wealthy is *more* popular. You would think that health care would be popular with Independents and raising taxes would be popular with Democrats, and it is actually the reverse. Independents gravitate towards this [tax fairness] message and this policy for very good reasons. So I will close with that. I am happy to talk more about this sort of aspirational universal family care policy, and how it is administered, but really the cornerstone is figuring out an equitable financing mechanism and seizing this political opportunity. Thank you.

John Schall

Thank you, Ben, you really do have a crazy chief executive up there in Maine. Before World War II, political scientists used to say “as Maine goes so goes the nation.” I guess you guys brought that rule back. I am not sure everyone will thank you for that, but why don’t we move to the end and go to Carol Regan first and then we will finish up with Jennifer.

Carol Regan – Community Catalyst

Thank you all for hanging in for so long. My name is Carol Regan, I work at Community Catalyst and we work with about 40-45 state and local partners around a whole variety of health care issues, and I would say I would echo what everybody said earlier but I will also echo what Judy said, which is, [we need to focus on] Medicaid, Medicaid, Medicaid.

Many folks have fought so long and hard to make Medicaid a program with good benefits and able to cover more people. Even in states where we have a number of “close the [coverage] gap” campaigns going on now, where we are trying to bring Medicaid into states that did not take it under the Affordable Care Act, I think defending Medicaid is going to be front and center of our agenda.

I think everything is shook up, and we will be talking to our state partners to find out what they are going to be doing around this—but Medicaid is also obviously a really important long-term care program. So I am going to talk about a couple of things that we have going in some states that I think will continue forward, and what twists and turns appear along the way I don’t know yet.

Before I talk about three state examples, I wanted to say we just finished some focus groups that Celinda Lake and her partners at Lake Research did for us, looking at focus groups on people who were getting long-term services and supports in the duals demonstration in two states, and that report will be coming out soon. I want to share a couple of things that they said about what is really important to consumers, and which ground us in terms of what kinds of data we need to be collecting and what kinds of stories we need to be telling.

Without some prompting, people really *do* care about what we all talk about here--coordinated, integrated care. It means a lot to them. They want their long-term services supports [providers] talking to the people who provide their medical care. That was very, very clear.

Secondly, they really want people who listen to them, and they really talked about two people: their doctor—they want a doctor who is going to listen, and they want a [frontline long-term care] caregiver who is going to listen to them. So it was both ends of the spectrum. Why aren’t we putting those people in the room together when we talk about care planning? Because often it is the long-term care, the personal care attendant, who sees [what’s going on at home,] and who could actually translate things to the care coordinators and to the doctors.

The last thing that came out in these focus groups concerned the consistency of caregivers. In the state of Ohio, when they moved into managed long-term care, 6,000 personal care attendants lost their jobs, and it was not clear how to integrate a self-directed independent care worker into a managed care plan. That is sort of being fixed now, but people are still really feeling that disruption. To have a consistent set of caregivers that come to your house that know you and know your lives, your preferences, and your goals is really, really important.

Taking those as sort of foundational to our work, I want to talk about three things we are doing in the consumer advocacy movement in several states, as they are moving towards managed long-term services supports, because that is going to continue to happen and accelerate.

What is important to consumers in [this process]? Protections--consumer protections, grievances, and being able to have someone to talk to if there is a problem and it is important. The ombudsman programs that have been built up under the Affordable Care Act and through the Medicare/Medicaid Coordination Office are critical. Choice of caregiver is also very important to consumers for all folks needing personal care attendants, but particularly for people under age 65 really want to be able to choose their own caregiver and not go through an agency.

[Another important factor to consumers is having] a voice in determining their own goals and needs, being part of those care plans. I think pushing back on some of these health plans to make sure that they are getting that seat at the table is really important.

Then I think I would also say having a voice at the plan and system levels. Plans are supposed to have consumer advisory committees where we work really hard to make sure they listen to the needs of the people in their community, as well as at the policy level. Of course that is going to vary across states, but it will be part of our consumer agenda.

Then importantly, there is the question of accountability of health plans, as we heard a little bit earlier--making sure that we have decent contracts with the states and the health plans, and [provisions for] those health plans to uphold contract standards. We are monitoring those all the time.

The last piece is the role of community-based organizations in contracts with managed care plans, because it is those community-based organizations—the triple A's, the other services providers, the Centers for Independent Living, the folks who really have been serving folks in these communities—they really need to be part of those contracts.

There are three places where we are doing this work and I can give you some ideas of where I think there are positive things happening. In Massachusetts, the disability advocates—there is a group called Disability Advocates that is working on advancing health care rights, and they are working in collaboration with Health Care For All. They really pushed back the state when they wanted to cut overtime for personal care attendants, and were able to win that back in the budget. They just got, last week, an 1115 [Medicaid waiver] approved to move to manage long-term services and supports for everybody who is not in the duals demonstration. They are working really hard on that—on that implementation—and that will continue to make sure that they get the best standards from these health plans as they possibly can.

In Rhode Island, in their duals demonstration, we have partnerships with policy and organizing groups. [There is the] Rhode Island [RI] Organizing Project, which has the Senior Agenda Coalition of Rhode Island, and the Economic Policy Institute, which pairs policy and advocacy. They just are beginning to enroll people in the duals demonstration, and I will say Rhode Island is one of those places where there are many, many more people in nursing homes than are getting home and community-based services, so the big push there will be shifting some of that budget into home and community-based services. There is a very friendly administration in Rhode Island, including the Secretary of Health, to help move that, as well as one health plan. It's different than places like New York where there are 25 health plans. There is just one health plan called the Neighborhood Health Plan of Rhode Island that is very, very open to having consumer and community involvement.

The last place I want to mention where we are giving a new grant to is Pennsylvania, where that state is also moving towards managed long-term services and supports. They are starting in Pittsburgh, and they are going to roll it out over the next year to Philadelphia, so it will be at two ends of the state. Our partner there is the Philadelphia Health Action Network, and they are working really hard to mobilize consumers; they have been having community and town hall meetings to bring consumers together to meet with the health plans. Many of these are big commercial health plans, not necessarily some of the mission-driven plans like we have in some other places. To push them [for consumer protections] is important to us. So, I was really delighted to hear what somebody said earlier about the exit polling, which is that there is really support for advancing and skilled training.

I just wanted to give you [an overview] of what we are working on and what I think we will continue to work on: There may be some shifts along the way, but I think all of us have to begin to make sure that, as people move to managed care, that this is something that works well for low-income consumers. Thanks.

John Schall

Thank you Carol and now last, Jennifer Dexter from Easterseals. Jennifer?

Jennifer Dexter – Easterseals

Thank you, I am really happy to be here. Easterseals is unique in that we are a service provider that is geographically throughout the country. We serve people with all disabilities and people of all ages, so we serve a very unique role. I describe my job a lot of times as translating between populations and between providers.

While I agree with a lot of what has been said today about the public interest, the public support, and the public engagement in issues affecting caregivers, I think the long road has to move that into actual action, both programmatically and politically. Where that action needs to take place, and the only place it really can take place right now, is at the state and local level, and those are two areas where there is the most need and the most

opportunity right now. The first [opportunity is] Medicaid--I am going to agree with what everybody has said--and the second is in transportation.

In the Medicaid world, there is such a lack of understanding. As popular as Medicaid is, there is such a gap of understanding about what it actually means on the long-term services and support side. Particularly among state legislatures and federal legislatures, there is an incredible gap of understanding of how Medicaid actually supports [long-term care] programs.

I have sat in Congressional offices and called Medicaid a frugal program, and have had them laugh at me, and I have replied: "You go tell that to my affiliate in Kentucky who is getting paid \$19 a day to do adult day services," and then they go, "oh, okay." That is a really, really significant gap in knowledge that we need to close and we need to overcome, and this is an area where both the paid caregiver world and the family caregiver world come together.

The issues we have had over overtime rules and over reimbursement rates and all of that really ties back to the fact that the sole payer outside of individuals' pockets that is available to pay for those services right now is Medicaid. We are going to keep fighting as hard as we can at the federal level to expand Medicare to cover more long-term services and supports to create alternative financing mechanisms. That is a long road. Right now what we have is Medicaid, and we have people's pockets. We need to improve that.

The Medicaid block grant or [per capita] cap movement that is coming--whichever way they choose to go--in some ways will be a mobilizing event for both people with disabilities and older adults at the state level. It is really important that this be a uniting thing among those populations, and not a dividing thing.

Block grants eliminate optional services, which is 99.9% of what we are talking about today. Per capita caps also limit that, but what they also do is transfer a lot of costs to the states. I think there is actually a real opportunity here for advocates at the state level to engage governors, state Medicaid directors, state legislators—they are going to be the push back when that block grant proposal comes up at the federal level, and so how can we all work together to combine?

The other thing that is most effective, and we have found to be most effective—is, as you heard earlier, combining real stories with the economic impact. And frankly, it is not a really good environment, because what happens is that investing a small amount now saves Medicaid a whole heck of a lot down the road at your state level; yet investing in caregiver supports, and investing in home and community-based services does not translate into [immediate savings under] budget rules. We need to hope that [policymakers] will take that leap and know that savings are coming, even though that is a really hard thing to convince people to do.

What we have found convinces [policymakers] is the real stories; it is people, it is Moms and daughters, and sons and fathers of people with disabilities and older adults showing up at those hearings, telling their story with their child, with their Mom beside them. This is really critical, and empowering those voices at the state level is what is going to move the dial.

The other thing I want to talk a little bit about is managed care. It is a really fraught situation, but one that we, as advocates, all need to get better at navigating. There are a couple of points [that can make a difference]: getting in earlier, developing those relationships with [managed care organizations] MCOs, that are going to be coming into your state. Too often we are talking to them *after* the [Request for Proposal] RFP has been responded to and the contract has been awarded to them to figure out what piece of the pie we had. We need to force our way to that table to be talking about the formation of the RFP, the response to the RFP. We have had at Easterseals some luck in getting access to some innovative solutions and good services when we have done that. It is really hard, it takes a lot of attention away from day-to-day operations, but it can pay off.

I have also found is that one of the side effects of people moving different populations and long-term services and supports into managed care in their state Medicaid systems has been that we are starting to be able to have some [productive] conversations with the managed care organizations--not about the core long-term services and supports, but some softer caregiver support programs, including some small respite care programs, some caregiver training, some transportation supports..

Another thing I wanted to talk about very quickly is transportation access. That is something that I think is too often overlooked, and these are decisions that are all made at the state and local level. Easterseals works really closely with a lot of communities to help them implement transportation planning in their communities to assist people with disabilities and older adults. That is so often the reason for a loss of independence, and too often what falls on the caregiver. I think of my own family: so much of my mother's lost time at work was not to do direct care for my grandmother, it was to get her to doctor's appointments, it was to get her out once a month to get her hair cut and those kinds of things, whereas if she had transportation services to support her somebody else could have helped with that.

Looking at how we engage communities, because so many communities have all sorts of both public and private transportation programs: usually they are small, they are disparate, and they are not communicating with each other. How do we come together as a community, and look at everything from our broad transportation system to our sidewalks, to where the bus stops are, to where the church volunteer program is, and how those can all come together in a way that creates a comprehensive system that gets people what they want and has an easy entry point for people?

There are federal and state resources to help support some of that planning--not enough--but there are some. So how do we convince our transit system to actually put somebody in place who will look at our services and look at our community, and how are [well-designed services can help] older adults and people with disabilities [and save money over time]?

Finally, one of the things we are very focused on right now for older adults, which holds both opportunity and risk, is the movement of transportation network companies like Uber and Lyft into paratransit services. For people who can navigate that it holds great opportunity. Too often, though, for people who use mobility devices, they need a wheelchair-accessible vehicle. For folks that might need more assistance door-to-door, and those who might have cognitive issues—they may need even more assistance. [Moving contracts too quickly] holds real risk, because what many communities are choosing to do at the local level is move those folks that can use Uber and Lyft type services onto that, but leaving behind those that cannot the older chunkier system, which is going to slowly fall away. Getting involved in transportation planning is something that takes a lot of hard work and energy, but it is really important to the people we serve and their caregivers.

John Schall

Wow, terrific. Well, what a shame our panel had nothing to say about things at the state level. We are going to squeeze a couple of questions in here though, I know we are already a few minutes behind time but we have to get some questions in here. Please come and those of you online too, but I want to start it off really for the whole panel.

Trying to get a sense on all these things we talked about, the one or two top things that we should try to do in the states, you saw this morning from the online survey of this brilliant group and those we surveyed, that for states worker pay for paid care workers came to the top as well as resource referral, we spent a lot of time today already talking about the worker pay issue.

What about resource referral? Is that one of the most important or actually I am hearing you guys really bring out more issues and actually reaching even further, which I think is terrific and you are making an argument for transportation which is awfully compelling. So, which one or two kind of bubble up to the top for you as we make a difference at the state level here?

Spencer Blalock

From the state level in Mississippi, I know one of the aims of our coalition is to help create a resource network for those individuals as they are trying to find those resources. Of course Mississippi is—I do not like to tout this—but we are the poorest state in the country, and we are very rural, and so when [Jennifer] talked about transportation, for example, that is an [important] issue [that calls for more more] people in the workforce who can get to them.

We do want to create a better resource network, but bringing all the players to the table is a good part of the challenge. I think we are getting closer. We did have some help through the division of Medicaid in Mississippi. They are responsible for our Mississippi Access to Care program, and they are trying to beef up their resource integration in that system.

John Schall

Carol?

Carol Regan

I think it is defending the Medicaid program, and I think particularly around caring issues. That means getting a number of the Republican legislators and governors who have expanded Medicaid, who want to protect it and talking with them. I think there will be some budget cuts within Medicaid, so I think there is going to be a defensive mode. To the extent we want long-term services and supports, we have we have to protect that.

Jennifer Dexter

I would echo what Carol said. I think it is about protecting Medicaid, and improving where we can. It is continuing the discussion about alternative financing-- that is more at the federal level, although there is some work happening at the states.

In terms of the resource management issue, I think it is really important, because this is a sector where there is a lot of duplication happening. How many caregiver training modules are out there now? There are millions of them, and doing some coordination at the state level around services and around training, and around supports would go a long way in setting the table for those other two high priorities [highlighted in the exit polling], because that is how people start finding each other and get to know each other and advocate together.

John Schall

Go ahead, Ben.

Ben Chin

Yes. Just maybe one more cautionary tale from Maine. The only thing that gives me pause around the framework of picking one thing to prioritize or go after is that we were very proud of ourselves last year that we won a 50% reimbursement rate increase for about half the agencies that are providing care for seniors. [But] that money came from TANF [Temporary Assistance for Needy Families]. There is about \$100 million dollars sitting in a TANF account while our childhood poverty rate has doubled. Before our Governor came in, one in four children were on free and reduced lunch in Maine schools. Now half are on free and reduced lunch in schools.

So I guess I would just say it is good to find the tactical short-term wins, but in this new environment expect the next move to be to pit you against somebody else and to be constantly dividing between the deserving and the undeserving. It does speak a little bit to the need to have these broader alliances where we address the fundamental budget structure that will provide opportunity for everyone.

John Schall

Absolutely, and on the [call for] broader alliances, [we have] a terrific reminder from Carol that Medicaid is again not a blue state/red state easily divided issue: the Republican Governor of Ohio, John Kasich, is probably the biggest supporter of Medicaid expansion.

Jennifer Dexter

The Medicaid block grant is being sold [as a way] to preserve Medicaid for the future. They [say] are “helping” us.

John Schall

Interesting way to write talking points in Washington, DC.

Josie Kalipeni

My name is Josie Kalipeni. I am director of policy and partnerships with Caring Across Generations, and on behalf of Caring Across Generations, I just wanted to really thank everyone for being here. We had a great wrap-up and [we haven't decided about the] next conversation, but what I will do is ping you in a follow-up e-mail asking for information to help us coordinate the next steps; and also for some of the resources that you all are gathering and thinking through at the state level and at the federal level in order to better coordinate and to build our power together and really move the care agenda forward.

Joanne Lynn, MD

So, this is our time. We have an enormous number of ideas that have been put forward, lots of strings that are not quite fully wrapped up and brought together but that is the work of the future. It seems that now what is really important is that all the different organizations and different interests and so forth really converge on making a difference.

This is the time to get angry. This is the time to support one another in outrageous claims, because then the more moderate ones will look more acceptable. This is the time to help other people get angry. I keep telling practitioners, once you see a person through a really tough situation, encourage them to write that letter back to the CEO, encourage them to write the letter to the newspaper. This is the time to really elevate these issues because it is fundamentally a shift in power.

It is fundamentally a shift from doctors, hospitals, and insurers to caregivers and consumers, and the only way we can engineer that shift is to demand it. It is not going to come because somebody has big money. It is not going to come because someone is somehow wonderfully benevolent. It is only going to come because we demand it and that means that we are going to have to learn to support one another, to divide up the field for some parties to take over one thing and another party to take over another. We are not strong enough to just sort of all throw it into one advocacy group.

This is our chance. This is our time. Let's make sure that it happens, because otherwise in our old age we'll face really grim circumstances, otherwise we'll face bankrupting large numbers of families. We face having large numbers of young people having thwarted careers. We face having large numbers of very old people without transportation, without food, without the medical care they need.

We can do so much better--and all it takes is changing those fundamentals, and changing what it counted as being salient. Let's get on the road to doing that, and thanks for coming today. It is a remarkable group that is assembled here and online, and we hope that this is a couple of bricks in the road that lead toward a much better future.