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The Long-Term Care Crisis—Why Few Can Afford to Grow Old in America

Event Host: Welcome to today's web event, The Long-Term Care Crisis - Why Few Can Afford to Grow Old in America. Today's event is being recorded, and later today an email will be sent to all registrants with a link to the recording. A transcript will also be available. Automated live captions can be turned on at the bottom of your Zoom screen. You are welcome to submit questions for the panel discussion at any time during the conversation, access the Q&A function at the bottom of the screen. And now it's my pleasure to introduce Rani Snyder, vice president for program at the John A. Hartford Foundation for introductory remarks.

Rani Snyder: Thank you so much, Robyn. The reporting from Jordan Rau and Reed Ableson and your colleagues has been nothing short of remarkable. I've had so much outreach from friends and family who know that I work in this field, but don't know about the relationship that we have together way beyond the norm. That speaks volumes about the impact and the reach that you've got. Big, big thanks to you, KFF Health News and to The New York Times for collaborating on this incredibly powerful and important Dying Broke Series.

I am Rani Snyder, vice president for program at the John A. Hartford Foundation, and we're really proud to support today's event and KFF Health News in its coverage of aging and health issues broadly. Just a couple of words about our foundation. We are a non-partisan national philanthropy, and our mission is to improve the care of older adults. We do that by working in three main areas, creating age-friendly health systems, supporting family caregivers, and improving serious illness and end-of-life care. So, you can see how important this topic is to us, and I want to welcome and thank our audience for joining today's discussion about the financial and the emotional toll that millions of older people, people with disabilities and their family caregivers in the United States face when it comes to providing and paying for long-term care.

In statements from both Reed and Jordan, they've noted how woefully unaware people are of how much long-term care can cost, and also how the no win choices that are facing people and their families can happen to anyone and they really do. So, this series aims to help to change that by elevating long-term care issues as social and not personal. We're seeking win-win solutions. This is about

all of us as we age, and it's also about our policymakers, our providers and communities working to find ways to ensure access to affordable age-friendly, long-term services and supports.

One resource that I want to point you to is the recently released Long-Term Services and Supports State Scorecard developed by AARP and co-funded by us at the John A. Hartford Foundation. That scorecard includes indicators of how states are performing along a number of different dimensions, including affordability and access. Some states are doing better than others, that's not a shock. And some states are innovating when it comes to long-term care financing. Check out Washington and Hawaii as two examples of that and take a look and see how your state is performing and advocate for the changes that you see in other places. A little friendly co-opetition is not a bad thing. At the federal level, we've been deeply engaged with the administration for community living on the national strategy to support family caregivers through which over 15 federal agencies now have committed to actions in support of caregivers.

One of the five goals of that national strategy specifically calls for ensuring financial security for caregivers with recommendations on a whole host of actions that should be taken. Beyond federal agencies, the national strategy also has actions for employers, for philanthropies, and for all sectors that we should take to help support caregivers financially and in a variety of other ways as well. But let's be honest, the scale of the change that we need is going to be hugely challenging. We need changes related to long-term care insurance. We need changes related to regulations on assisted living. We need a lot of changes around ownership and financing transparency, and that's just to name a few of them. A key step is to help the public understand these issues so that they, we, can better advocate for policy changes, which is really what the series and today's conversation is all about.

Many thanks to our fantastic panelists, some of whom are bringing their really very personal stories to share with us. They're going to help us understand and learn from their experiences. And thank you to all of the people in the audience for joining the conversation. We hope that you'll continue to follow the incredible aging and health journalism of KFF Health News and use our resources at the John A. Hartford Foundation. With that, I will gratefully turn it back to Jordan.

Jordan Rau:

Great. Thank you, Rani. Appreciate it. I'm Jordan Rau. I'm a senior correspondent with KFF Health News. I'm one of the reporters along with Reed Ableson at The Times, of the series, Dying Broke, which is a joint project of our

two organizations. Hopefully, most of you have read it, but if you haven't, you can find it on The New York Times website and on our website, kffnews.org. It is just briefly a series that we did that was looking at long-term care, which is a very sprawling subject. We looked at long-term care for the elderly and we looked at it in particular in how the middle class is faring with it because as we wrote into series, the United States really doesn't have a system like it does for Medicare and health. It doesn't have the same system for long-term care. By that we're talking about things like personal aids for people who need help with basic activities of daily living, like eating or walking, and people who have dementia.

There were a lot of components to the series. Hopefully, you will read them all because we worked very hard on them. Some of them looked at the assisted living industry and how that works and costs. Some of them looked at the long-term care insurance industry and how that works and costs. We took a little international tour into what other countries do and how they handle this and how much resources they put into it. Spoiler alert, they tend to do a little bit more than the United States does, but the heart of the series was really the people that Reed and I interviewed and that we portrayed in the project. We have a great panel here today. Reed Abelson is on the panel with us. She's been a reporter at the time since 1995. If you're a journalist, we are a profession where you read bylines, which means that you'll look for who wrote the story.

There's certain people, you'll always read what they wrote no matter if you're interested in the topic or not, just because of how good they are, and Reed is one of those people. So, she's here with us. We have two of the people who were profiled in the project I'm really excited to have here. One is Robert Ingenito. He is from the suburbs of New York, and he was in a section of the project we called Vignettes or Voices. We had seven people telling their particular experiences in first person. These really resonated with a lot of people. They really resonated with me. They were very powerful. So, I'm thrilled that he is here to join us.

We also have Angela Jemmott and she's in the Sacramento area. Another fantastic person that I was just so thrilled to get to know during this process. She was actually the lead of our long-term care insurance story. And I'm very excited to have her here too, because one of the things about these stories is you just take, for the actual article, you just take a sliver of people, but everyone we interviewed. Their stories are so much broader. So, this is really an opportunity to sort of play that out. Finally, we have Anne Tumlinson on the panel. Anne, she has her own research and consulting group in D.C., ATI Advisory. And she's one of the first people that I turned to when we started this

off because she really has a lot of knowledge on the ins and outs and the details of long-term care. She really knows it really well. But she also has a separate organization called Daughterhood. And this is a, I guess I'd call it a support group of caregivers, adult children mostly, of people who are going through what the people in our series went through.

They have an elderly parent who needs assistance, who can't live independent anymore, and she's organized these, I think they're in 20 cities or so. I talked to a bunch of the people in the groups in the course of recording this story, and they were really wonderful. Anne was just a natural to want to bring on with her double hats that share her brim. That's a very bad metaphor, but you get the idea. In any case, that is our panel, and I'm going to start. Welcome Reed. Good to see you. I haven't talked to you in like 35 minutes.

Reed Abelson: Exactly.

Jordan Rau: Reed, we knew that this story would be read, but I was really surprised really how much it resonated. We've got thousands of comments on the New York Times website. The reader metrics were really off the charts. Why do you think it resonated so much? What nerve did it hit?

Reed Abelson: I think what we found is that this is a really universal experience. I literally didn't talk to anyone who either didn't have this as a personal experience or didn't know someone very closely who was going through it. I think the fact that this resonated so much just shows you how universal this experience is that people are struggling to figure out long-term care.

Jordan Rau: Yeah, I think that's right. It was amazing how many people in our own lives, in fact, we knew and we're going through this and the editors and your colleagues and my colleagues. So, it really does hit a lot of different topics. One of the things that you and I talked to when we were doing these interviews, we interviewed people over the course of well over a year, was we were both surprised at the fact that we would contact people and they would open up very quickly about their personal situations with their parents. They would open very... Sometimes share incredibly intimate details of what was going on with their families. They were really great about that. But a lot of people, the thing that they were most uncomfortable talking about was their finances. What have you come to think is behind that?

Reed Abelson: I think it's a couple of things. I think one is that the finances are just so difficult for people. I think many people really didn't have a grasp, even as they were going through it, how they were going to pay for it or what this would mean to

them. So, I think there was some denial. And I think culturally, people don't like to talk about money, but I agree with you. I was really surprised at how much people did want to talk about their situation generally. They really were very generous about what it meant to them and the emotional toll.

Jordan Rau:

I've thought about this series a bit about it's in a way, an affirming series in the sense. There are some stories that just tell you something that you had no idea about. And then this one, I think, a lot... It certainly had elements that people weren't familiar with, and we certainly, I think, we pieced together a very complicated universe that most people don't have that experience with. But it really was also something that said, your experience, you're not alone. In fact, you're not an outlier. You are the norm. And I think that's one of the things that certainly resonated with it. One of the things that you've said that you've noticed multiple times that I really thought is true is you were surprised at how resilient people are. Can you talk about what you meant by that?

Reed Abelson:

Sure. I think we approached this because there's a problem in terms of long-term care, but I was amazed at how people were able to find solutions. They really worked hard and they were very creative and sometimes really self-sacrificing. They moved into their old childhood bedroom, they had their mother sharing a bedroom with their child. They figured out how to get a network of people to watch over someone. I was impressed by how personally people really rose to the occasion. And really, I was really impressed by what people did to try and make sure that their loved ones were not neglected, had the care that they needed.

Jordan Rau:

Yeah. I want to quickly, I forgot to mention earlier that as a reminder, you can submit questions for the panel at any time during the event using the Q&A button at the bottom of your Zoom control panel. Yeah, I agree, Reed. One of the things that really struck me in the conversations with people was how different it was from, if you scroll through Twitter, just the conversations about everything really, or any of the social media is so brittle and angry and blaming. And I was really amazed at how little sense of entitlement people had. No one was like, hey, the government should step in. People obviously understand and have opinions that in some cases government should do more, but everyone really shouldered this as their responsibility, even when they were... We talked to people who were alienated from their parents, had barely spoken to them and got together and they made, as you said, tremendous sacrifices.

That really amazed me, and I think that that comes through in this series. I just found that very heartening. It would be great if there was more of that out there as opposed to the icky mush that just makes you feel bad about people.

But I felt it was a very... You and I even talked about at one point about doing just almost a hero's story of what people had done and the selflessness of it for the relatives. I know some people will say, well, that's what they do in other countries, so they could get their own story, I guess. But it really was because I think that the image a lot of people have in the United States is we just dump everyone. We just throw them in a nursing facility and wash our hands. That was not really what our, I think, reporting experience was.

Reed Abelson: No, I completely agree. People were incredibly committed to trying to make life better for someone. People agonized over decisions. I think that that's one of the things that also really struck me. People were very thoughtful about, should I think about a facility? Is mom getting enough care? Am I neglecting my kids? Whatever it was.

Jordan Rau: Yeah, I think that's right. Actually, I want to pull in Robert now because Robert so epitomizes this experience. Robert, your situation was very, in my eyes, traumatic because your mother had you make a wish or she made you promise on her dying bed not to put your father into a facility. And then you had a whole experience during the time that we were talking as well as before of really going all out for your father and ultimately having to grapple with that wish versus what was best for him and best for you. So, Robert, can you just give us that story and your journey on that?

Robert Ingenito: Yeah. Thanks for having me on the panel, Jordan and Reed. When I was about 18, 19 years old, my mother passed away from cancer. And I vividly recall when she was on her deathbed, she said to me, "Do not put your father in a facility." And that stuck with me. It stuck with me. I'm now 44 years old. It's still something I think about. In the past couple of years, my father, who's now 93 years old, when he was 85, he had a heart attack. At that point, I made the decision to go from working full-time to working part-time so that I could become his caregiver. For the past five years, he's been living in our home with me and my wife and our six-year-old daughter. But most recently, this past August, he got very sick. And in September we made the really incredibly difficult decision to move him into an assisted living facility. It was the most difficult decision that I ever had to make. Sorry.

Jordan Rau: That's okay.

Robert Ingenito: I really wanted to keep the promise that I made to my mom. But I remember on the day that we signed the lease, I remember telling my wife that I just feel awful and that I felt like I was throwing in the towel. But to be perfectly honest, his level of care was becoming unsustainable for me. I wasn't getting any sleep. I

couldn't leave him home alone. We had a home health aide coming in during that month or so, but that was only during the day, and it was only during weekdays. I couldn't go on outings with my wife and my daughter. I was tied to the house. And if I did go out, it would only be for just a very short amount of time maybe to run and do groceries so that I could get back home and know he hasn't fallen, he hasn't fractured himself. So, it was just really hard.

When this was all happening, as I said, it was in August, my family and I were supposed to go on vacation, and we were planning for my dad to go into what's called respite care. It was just like a two-week stay at an assisted living facility for just a brief amount of time so that people like me, people who are caregivers could take a respite from that care. But he got sick, and the conditions that we agreed to the respite care with this facility had changed. So, it was just a very difficult decision. And what ended up happening was that my wife and our daughter went on vacation and I stayed home and it was stressful, but that was the decision that we came. It was one of those points where I just remember thinking, I don't know if I can... It's a tilting balancing act that you have to make, and it was so hard. That was the most recent example, I think, that resulted in us having to finally make that decision and move him into an assisted living facility.

Jordan Rau: How is he doing now and how are you doing now?

Robert Ingenito: I'm doing okay. And the place that he's at, it's great. He's doing well there. I try to visit him at least three times a week. I always express my thanks to the staff who are there. They're doing incredible work. Having had my dad at home for five years and helped him with things like bathing and things like transferring from the bed to the commode and back again, I know what that's like. These workers who do this day in and day out for a good number of residents at these facilities, they deserve our thanks. And I always make a point to say thank you to them whenever I'm there.

Jordan Rau: And your dad, how is he adjusting or handling it?

Robert Ingenito: He is handling it okay, given the situation. When I said this to him at the onset, he said he understood. He totally realized that this was getting unsustainable for me. And I said to him, "You're not doing this for your sake, dad. You're doing this for my sake." And he was okay with it. There are times when I visit him and he will ask me, oh, I really miss your spaghetti, Robert, or I really miss your home cooking. And I tell him, well, I'm going to bring you some food or I'll arrange for a day where you can come out and I'll bring you home and you can

hang out with me, my wife and our daughter. So, he has those opportunities to look forward to, but it's still hard. It's still very difficult.

Jordan Rau:

Yeah. It's very lucky that you are in an area of the country that has a lot of assisted living options because there are a lot that don't, and that causes a whole separate thing. The other thing I wanted to mention, and then I'm going to move on to Angela. The data showed that the vast majority of caregivers are spouses and daughters. And that I'm not taking anything away from them, but they're also, and we interviewed people like you. There are a lot of sons who are also stepping up. And the fact that you had to make some compromises with your work and your career is notable. I can see that this is difficult on many levels, so thank you and thank you for sharing that.

Angela, your mom, maybe you can talk a little bit about you and your mom, and you've got a bunch of siblings who are all helping out with your mom to take care of her. Your story and the part that we had in the story was about long-term care insurance was that your mom had bought a policy a long time ago, and it only covered, as those policies often did back then, nursing home care. But when it came to the point that your mom needed help, she was very adamant that she wanted to stay in her house, which is very common. So, can you talk just about how you and your siblings have divided up your responsibilities and how you're taking care of her now and what type of help you're giving her both personally and professionally?

Angela Jemmott:

Yes. Also, too, I want to begin by saying thank you Jordan and Reed for elevating our voice, our message, our story. It has been a long journey and we are very grateful for those who come alongside us to help us share our story, so thank you for that. Robert, you struck emotions inside of me that I didn't know was... I thought I had it all in check, and so I will try to share as eloquently as you have. But yes, we had come together as family to put together a plan in our mind to safeguard our mom when she gets old. My father died young, at 56, with a heart attack. And so, we the siblings... She has six children, and mom was there for us all the way as kids and we were like, "We're going to take care of our mother." Knowing that, oh, if you ever get stuck with not having funds to take care of her when she gets old to go into a facility, if need be, we just thought that's only if.

Like insurance. You only want it if you have to. You don't want to use it, but if you have to, you have it and you're not in a situation where you're scrambling. So, we thought we were being very proactive. We felt very good about the level of support of siblings putting our funds together on a quarterly basis and paying for this insurance, again, thinking at the worst option that if it had to come. My mother was as strong as an ox. She was a farm girl from Alabama. And

physically, I remember arm wrestling her up until she was... I was 40 and like, "My God, this woman's still stronger than me." There was never in our mind that anything like this was going to happen to her. And this thing that has come upon her is this battle of dementia. I never say she has dementia, I say she's battling it because in my mind, no, she's going to fight this as long as she can because there's no one thing that happens to people with this disease, so it's she's going to fight it through.

With her fighting through, she wants to live and we want her to live as normal as possible. We want her to enjoy her community. She's called Grandma Jewel in the community. She was a part of the community. All the kids knew her. My kids went to the school by her, so all the kids around knew her. The families knew her. She's just beloved. Last year we had a drive-by birthday party, and it was hundreds of people that drove by. I was shocked. People thanked us for having such a celebration for her, and it was wonderful and light years difference of what we're in now. But the thing about it for us is as the years start going by, 80 years old, she was again sharp moving forward. And it's amazing, she's 91 years old, and it was like night and day for where she's at now. At 85 we we're starting to see, man, mom's slowing down and she's not remembering. And we started trying to get help in, and then we came together as a family and said, let's get some in-home care because she's needing support like that.

Well, that's when we discovered that, oh, you can't add a rider onto your plan now, it's too late. We're like, wait a minute, we... We said we'll just cancel and buy another one. If you cancel and buy another one, she's too old. We won't insure her. So, we were either stuck because they said at 75... If you changed it before 75, you could make changes. But after 75, you can't. Well, who has a crystal ball? Who knows beforehand? My mother had no signs of it at 75, so why would we know to add on? All these little things. Does anyone tell you about it? No. Does anyone send you information, hey, 75 is coming up, do you want to change your plan? No, we just lived through a journey of finding out the hard way.

Here we are at 91. My mother not only is battling with dementia, she's physically... With the brain challenges, she's not even walking. The world has changed. People ask me, "How's grandma Jewel doing?" And I said, "We're in a new norm." To have her in her bed and have to physically lift her up, watching out for bedsores and changing her adult diapers, bathing her, feeding her. It is a daily journey. Again, I'm glad Jordan brought out about men because my brothers have been amazing, all of them. I have five of them, and they love her differently, but equally. I tell them all like, he's got this, you got this. And not to

feel bad that you don't have what the other one has because some just have more strength in certain ways than others. Two of them actually live with her, but that's not enough. Both of them work, so we bring in caregivers and we are paying this out of pocket.

This is something we're struggling with. We need more help. And yet we're finally trying to physically, financially do it on our own, it's a challenge. And I'm just always looking for strategies. My brothers and I always, it's a constant strategy of what to do today. How do we handle today and what's new? What's different going to happen tomorrow? Those are the things we're living with.

Jordan Rau: The amount that you guys are paying for home care is substantial, is that impacting all of your retirements?

Angela Jemmott: Our family, the insurance plan, we just said we just going to keep it going because we thought if we cancel this, then something else will happen. Even though we have no intentions, really probably using it, in our minds it's just like, this is something that we're not going to cancel in spite of the fact that it was raised 75% in the last two years. That's another story I hope you guys have covered. But the reality is we have that. The financial burden is supported through all of us. My mother has my father's pension and my father's a wartime veteran. And still, we can't get any of those things. We've been trying to figure that out. Why is that such a maze? My father was in the Korean conflict. We can't get any benefits of that. Somehow we can't figure it out and can't get through the maze, basically. But she has a pension from his job because he was civil service and social security.

We have that, and that's her basic living. That would've sustained her, honestly, she wasn't sick battling with this, but the added cost that no one would know without a crystal ball into the future and what your life is going to be compared to another. So, we financially pull in and do what we can along with her finances.

Jordan Rau: Yeah, that's great. Thank you. Anne, can you start by just talking a bit about what you've noticed about what are the big challenges from your diverse group of people in your Daughtershood group and what echoes what Robert and Angela have talked about and what other things you think are common struggles for people who are caregiving for their elderly parents?

Anne Tumlinson: Thank you, Jordan. Thanks for having me, and I really appreciate this series so much. I just want to echo what Rani said that it's, I've just heard from so many people about the work that you've done here. I want to say Robert and Angela's

stories are so similar to the stories that we have been hearing in our Daughterhood community for five, six years. This is email after email, comment after comment within the communities. It ranges from many, many people who are not, and this is going to sound very strange when I say it, not even as fortunate as Angela and Robert to have the siblings or the resources and the ability to pay for assisted living, even the ability to pay for long-term care insurance policy, however inadequate it is to the task. Really, the majority of the people that I hear from have nothing available to finance care.

So, they are doing what Robert did before he had the ability to share that burden with an assisted living community. Robert, you're feeling that emotion that was so touching, I think to all of us. I hear that all the time. What I just want to say to you and anybody who is feeling that way right now is that you have to do what's best for the family as a whole. I think a lot of times when it's our parents, we feel like we have to do the most heroic thing for this person that we treasure and love. And I think most of the time, what our parents would've said if they could have is you have to do what's good for the whole family. And you did that, and I really applaud that decision and just appreciate you sharing that because I know we just hear that all the time.

There are these core emotions, I'll just touch on for a minute in family caregiving. So, each individual's situation is really different. Angela's situation is different from yours, Robert, but underneath it all family caregivers are feeling overwhelmed. They're feeling guilty and they're feeling alone. Those are the three things that are the same. On the financing side, you're dealing with this really difficult financial situation no matter what. Also, you have to get along with your siblings. You have to convince your parents that they do... There's all of these family dynamics. Whatever's going on in your family, whatever that system is, we're going to just inject steroids into that and make it even more stressful. You're dealing with the navigation of the care delivery on a day-to-day basis. So, it's not just the home care, it's not just the bathing and the diapers, it's the medical appointments, it's the medications. It's getting this doctor to talk to this doctor, this home health company to... There's just an endless series of navigational and management tasks.

So, all told it's a lot. And Jordan, if I can, as I was listening to everyone, I did want to just take a minute and just, I'm going to switch hats for a second out of Daughterhood and into ATI advisory and just share a little bit of data because I think what your stories and what the stories of Jordan and Angela and Reed, a beautiful summary of what you heard, tell us is what we also see in the data, which is that the vast majority of older, I'll just say older adults right now, there's certainly a lot of under age 65 individuals living with physical disabilities

and developmental disabilities. But just talking about older adults for a moment, if you take the entire set of people right now who have really high levels of need, they're at that point, Angela's mother, Robert's father are at the vast majority of them are actually living in the community right now.

They're not living in assisted living or nursing homes because of the cost and because we do not have a financing system in this country to pay for it. Of those people, the vast majority, I would say 50% are living in the community right now. Only a third of those people are getting financial support or assistance from the Medicaid program to pay for the home and community-based services. The remainder are doing it all either out of pocket or exclusively by family caregivers. I say that because of that remaining two thirds, half of them live under 200% of poverty. So, we have a lot of older adults living in the community today without any kind of Medicaid assistance, who cannot afford home care assisted living, who do not have long-term care insurance policies [inaudible 00:38:56].

Those people are reliant on family caregivers if they even % have them. If they don't, it's a very dire situation. Those are often the people most at risk of spending down into a Medicaid nursing home. I just want to lay out the numbers because sometimes we talk about how expensive all of this is, and it is so expensive, but the fact of the matter is that our system is actually underfunded. We don't have enough money sort of flowing into the system to attach to all of the people who have these needs. As a result, people who are in Angela's situation or Robert's situation who maybe do have some means to pay for care, are dealing with not great choices. I have a colleague who's going through this right now, their family has the resources to pay for nursing home care out of pocket, they cannot find good quality care.

I think, in part, that's because we've just starved our system. If it's a system where every single family is developing their own solution, one family at a time, one household at a time, of course, we don't have an infrastructure. Of course, we don't have a system. Of course, assisted living is kind of... So, I do think that it is that huge starvation of funding in the system that is the reason why the choices that we have, even when we have money, are so inadequate to what we need.

Jordan Rau:

That's helpful. I want to get back to that issue of solutions, but first I want Robert to hop in and Reed and Angela, you too. If you guys want to hop in at any point, please feel free to do so. Hop, walk, skip, whichever mode of transportation is best for you.

Robert Ingenito: To Anne's point about the incredible costs that are going into assisted living or to home healthcare, there's no question about it. That's a huge, huge piece that's missing. But I feel I can say this, as a 44-year-old person, there's also lost income that's going on here. Lost income among the adult children, the spouses, whoever's the caregiver who's taking care of the loved one instead of pursuing full-time work. I feel very fortunate that I have found a part-time job that pays a reasonable amount money that also has given me the flexibility to do all this caregiving for my father. But I'm in this group of people called the sandwich generation. I'm 44 and I'm not working full time, and this is a big group of people who are trying to care for their loved ones, but what's the safety net that's going to exist for me when I get to be my father's age? I just don't know. That's a huge question as well.

Jordan Rau: Reed.

Reed Abelson: Yeah, I do want to emphasize, one of the things that I also saw were people who had no one, basically, who just sort of did without. That meant they didn't leave their house, they didn't really get good care. Maybe they didn't have dinner or what have you. I just think it's such a stunning... I think that context is really important that it's so hard for even the people who are cobbling it together, because very few people really had 24/7 help, so they're already sacrificing a lot. But for the folks who had really, not a lot of family, not a lot of friends, I think it's just a very isolating and difficult situation, especially if they didn't qualify for Medicaid, and so there really was no support.

Jordan Rau: No, it is a great point. I remembered a lot of the comments to the stories. There were a couple of those. In hindsight, you can't do everything, but it would've been great if we'd also sort of profiled people like that, because I think that, and I'm not an expert on this at all, but some people have to form their own families if you're on your own to do it. But the other problem of course, is that if you don't have kids, even if you're in a couple, someone's at the end of it, not in the couple, unless it's like a Shakespearean situation. You're going to have a lot of people that are on their own. Our series, one of the things that we did consciously so, was we took representative stories. We didn't take the really dramatic outlying stories, but there are people that have nobody at all, and it could be very, very devastating/ Angela?

Angela Jemmott: And the reality is sometimes a nobody just comes at living long enough. My girlfriend just buried her mom. She was the last of all the siblings. All her siblings died first, and she and her mother was the last, and it was almost like, thank God the mother went first because her mother was blind and battling dementia, and she was the last of... She had no one else except her daughter who worked

full-time and came in every so often to check on her. You both have seen, the stories are so endless and so similar all over and over again. But I think the biggest thing... My mother is 91, she came from a generation that had lots of children. I have three children. I'm thinking like, okay, let me... We think about that. The reality is that it's not necessarily... We're in a crisis as the story is saying because our society has changed and we are not going to have the underground economy like we used to all the time in general.

We just have changed the dynamics on our own, and we must. I do have to say that we have depleted the resources in a lot of ways, as Anne has mentioned, but also the fact that we don't pay them enough. The salary for someone who wants to take care of my mom or Robert's dad should be at a living wage, so that way they can feel honored because they may love to do the work, but they just can't afford it. So, they move on to do something different to take care of their own family. We have a lot of dynamics of how to change this. I know, Jordan, you're about to head on that direction, but I just know we have to start coming up with better solutions in different pockets of the space that we're in. [inaudible 00:46:49].

Jordan Rau:

No, no, no, those are great points. Thank you. The pay levels is not just home health, but it's everywhere in the long-term care area. I sometimes call it the backwater of healthcare. Nursing homes have the problem where they'll be paying, and we can debate it on a different time, whether they can pay more or not, but where they'll be paying their nurses and their certified assistants at a level where they're constantly losing them to the hospital that's nearby, if not to the McDonald's and the Target because they pay better. That's just a huge issue, especially... These jobs are so hard. My job is super easy compared to having to lift someone and bring them to the bathroom and deal with all that and deal with all the emotional issues, deal with the family and then-

Anne Tumlinson:

The family.

Jordan Rau:

Yeah, exactly. But Anne, I want to get back to you, and or everybody. The big question. Sometimes when we do a story as journalists, the answer is there. It's like, oh, this should be regulated tighter, or that person should be in jail right now, something like that. But this wasn't one of those type of stories. So, I want you to talk a little bit about... Realistically, I'm going to go out on a limb here, and I'm going to say that the United States is not about to turn into Denmark. We're not going to suddenly have a national social health insurance program and a zillion other types of support. Given within the realm of the somewhat reasonable, what type of solutions are there out there?

Anne Tumlinson:

Yeah. Okay. First of all, I'm not going to challenge what you just said, but I do think we should start there just to say that the... I've been working on this for a long time. I started my career a long time ago researching and studying and modeling out how could we create insurance products that work the way we want them to work it in a manner that would scale to the point where everybody would have this and we would have this funding stream that I was talking about earlier. After many years of working on this, the conclusion that I finally came to was that certainly the private market cannot solve this by themselves. This is just not an insurable risk that is possible to address through a private market. This is not car insurance. This is not even health insurance where you have events that are happening.

You buy your health insurance, you get sick, right? This, you buy long-term care insurance and then 30 years go by and then something happens. And that thing that happens is so unpredictable, you don't know, to Angela's point. Her mother's 91 years old. I thought my dad would live to be 91, and he died fairly quickly of a serious disease when he was 82, having been zip lining two years before in Costa Rica. It is that unpredictability that makes this appropriate for insurance, but not for a private market where some people buy it and some people don't because that creates a very big risk cooling problem. So, we do need government solutions and ideally the federal government would be the one that's solving this. And the reason why, Jordan, you say we're not Denmark. The only way to pull risk through a government program is taxes or premiums. And let me just say that is actually simple.

It is a simple thing to put a program like that in place. We are not reforming a program that is existing. We are putting a new program in place. And for everybody who is listening, I just want to be super, super clear about something, Medicare does not cover this. Medicare doesn't cover it. We'd be starting from scratch creating a new public program that would pay for this, and we'd have to raise money for it through taxes. It is politically incredibly difficult, but as a matter of policy, it's actually pretty simple. We have done so much work, papers and papers and papers and papers have been written about this. So, we know what to do. We just haven't had the political will. And I think it's because something Reed that you hit on really early that I thought was so perfect was, people look at this very much as an individual problem.

They think they should have saved more or they should have bought long-term insurance, or they should stay home and take care of their parents, or this is about my family. In America, we're all about, we're going to solve this in our family, but really it is a collective problem that requires a collective solution. So, I would love to see more caregivers and families rise up and make their voices

heard on this issue, because I do think politicians would respond if it became a political priority. It's not an impossible thing to do. In the absence of that or as we're waiting for that to happen, then Jordan, to finally answer your question, I'm actually pretty optimistic and hopeful and excited about some of the things that I'm seeing at the state level right now. Less than ideal, because we'd like for everyone in the country to have access to the same level of support, but Washington State actually funds public insurance for its residents.

State residents are all paying taxes into an insurance pool so that when they need care, they actually get funding to pay for care. There's some qualifiers, it's \$36,500 total, which won't go that far. But when you think about every single person in that state having entitlement to that funding pool, that will infuse the system with a lot of funding that it will raise all of the boats. And other states are looking at this too. Minnesota is looking at it. I believe California is looking at it. We've seen states and state legislatures really sitting up and realizing the federal government is not going to solve this problem. Medicaid is a liability on their books, and they need to start looking at other options for paying for it. The other thing I would just say at the state level, one of the things that we're seeing at ATI that we're doing a lot of work on is work to expand Medicaid.

The way this program works is that you have to be very, very, very functionally limited and very poor before it will pay for anything. What this means is there are a lot of people who are near poor, as I mentioned earlier, or near functional decline who are getting nothing. That doesn't make any sense. We're paying for a lot of care at the very end, which is a really expensive way to manage risk. So, innovative states like Vermont, Wyoming, Washington state, again, always Washington state, are working to address this through Medicaid demonstration programs, which are like pilots that test new ideas. The final thing I just want to say, and then I'll pause I promise, is that I don't want to lose the fact that the population of people who need long-term care. People like Angela's mother, Robert's father often also use a lot of medical care.

Our data shows that people who have long-term care need are sometimes costing the Medicare program two or three times what you would see from somebody who doesn't have that level of need. There's a lot of exciting work happening in Medicare Advantage plans, happening by the federal government, happening in health systems to try to address some of the long-term care needs. We have something called the Program for All-Inclusive Care for the Elderly, which combines funding from Medicare and Medicaid to create something really all-inclusive that will provide a more seamless experience. We have a new model out of CMS called the GUIDE Model, which is Guiding an Improved Dementia Experience model. This is Medicare now basically focusing

on dementia care management and improving the quality of life for people living with dementia and their family caregivers. There's a lot of things that we can do, and every health system, honestly, I think is starting to feel this pain because there are a growing number of people who have, whether it's severe dementia or functional impairment who are sitting in hospital beds because they have no place to go and no one to take care of them.

I think the message is, as families, we cannot solve this problem by ourselves. We are going to have to collectively solve it, and states are going to be part of the solution. Hospitals and health systems are going to be part of the solution. And CMS is going to be, I think, behind the scenes helping to make... The centers for Medicare and Medicaid services helping to facilitate all of those solutions while we wait for Congress, hopefully, to act on something more universal and national.

Jordan Rau:

Thank you for your incredible optimism. I want to quickly ask both Robert and Angela, from your experiences, are there a couple of things that you think, or from your broader knowledge that you've gained during all this, a couple of things that you think would help you or help people like you or people who have, I know that you've both gotten a lot of feedback since you've been in The Times that just sort of pop up to your head that are things that would've made this a little bit better. Angela, why don't I start with you?

Angela Jemmott:

Yes. As you said, I've been contacted by so many people, folks I haven't talked to in years since the story came out. One was that while we talked and gave them a little bit of tips of that or what contracts I use or whatever, but it was the emotional support that helped them readily just by talking. I definitely know that being a part of a group, a small group, a support group, you got to get it. The isolation is so emotionally hard. I had a situation where I just felt so alone and so drained. I remember driving saying I got to get gas, and I drove, and I don't remember how I ended up at the gas station. I was sitting at a gas station with money in my hand and I was sitting there for... I fell asleep. I was just there for who knows how long.

We need help. Everyone needs to get help. So. I'm part of a volunteer group called Hand-in-Hand. Just find a group that you can be a part of. To me, in terms of bigger picture, I look at long-term, short-term opportunities, and Anne mentioned a number of things. I think it should be a federal... The 2024 campaign should be all over this. We should see everybody every time they get up and talk on their debates. If they don't talk about it in their debates, scratch them off from your mind. In my mind, it should be that high priority for each candidate, but that's the long term, get the federal. Each state's doing great

things or trying to, but if the federal government, then that's how we move it down from a holistic standpoint of the nation.

But personally, I'm part of a faith-based community, and I just feel like that's the short-term. We can mobilize right now as believers and those who follow God, who knows that... We have a network of folks that we can mobilize ourselves to help each other. These things that we do naturally as a church, we need to be more strategic about. I have some many ideas that I just know that the faith community needs to step up and be a part of the solution. I know we can do it. We do it small scale, but we need to do it at a bigger scale and then bring the government in and let them see us prove to them that we can come together. That's in my mind that the faith-based community should be more so helping each other, driving people to doctors.

And the respites, we don't have to hire somebody for respite. Respite should be a part of the church. They should be coming in and bringing people together and helping each other, training and foster care. I have a lot of ideas and I'd love to talk to Anne as at whoever else wants to get engaged in this because it can be done immediately. This is a fire. In California we have fires. We know as soon as a fire hits the forest, we get hoses and put it out. That's what we should be doing right now, putting the fire out, not waiting for government totally, because government should, I believe that, but we can take this and put the fire out right now and small groups and then a larger group. We can be looking at other countries and tell them, look at what United States is doing. We can do it.

We have the ability to come together. We did it in 9/11. We can do it now. That's what we should be feeling in our hearts. You said the story's been hitting across the nation never before. That's because it's hitting everybody. Everybody is feeling it. You are going run into this door. Believe it or not, if you keep living, you're going to run into this door and hopefully you'll run into this door healthy and go out like Elijah and just take off. But bottom line is some of us are going to take off and need somebody to push in a chair and push us along the way. We need to come together and that's my-

Jordan Rau:

That's fantastic. Thank you. Robert, do you have some thoughts? And then I'm going to go to Anne, and then I'm going to go to the questions that we've been getting.

Robert Ingenito:

Well, I want to talk about Angela's point about the church and faith-based groups, but I want to embed it in the conversation of... Those of us who are caregivers, I really recommend seeking communities of intergenerational people, whether it's through Anne's Daughterhood website or through your

local library or through your house of worship. As I said, I'm a father. I'm a son for my 93-year-old dad, but my network of friends are mostly other parents with young kids. And fortunately, I have found an incredible church across the street from our home that's progressive. It's in line with my own political beliefs. It's open, it's affirming. It's just a place where I have connected with so many people who are going through this experience.

They have just such a wealth of information that we all share with each other. I talk to other parishioners about stair chairs, or I'll talk to other parishioners about home health aides or things like this, and it builds friendships and it builds empathy that I really want to... If there's one thing that I could recommend, it's just find a community of people, one that spans multiple generations through a house of worship, through a library, even if it's an online discussion group, where you're able to bounce ideas off of other people and get some of that help that you need help. At the very least, it's going to remind you that you're not alone. You don't have to do this by yourself, that you can find the help.

Anne Tumlinson:

Robert, that is literally what we say. That is the message I feel like I'm delivering over and over and over again to our community at Daughterhood and Angela, just yes, yes, yes, yes, yes. It is hard sometimes for caregivers to find... It's like there's a big bridge they have to walk across to get from that day-to-day oh, you're in it to, I'm going to set aside a time to connect with other people who are in a similar situation, who can make me feel more normal, who can normalize so many of these weird experiences that you're having and help you feel less alone. That is huge piece of it. I always like to say to encourage caregivers especially, we have this big culture in the United States of self-care. It's better take care of yourself.

I'm like, how about other care? Let's take care of each other through this experience trying to do it by yourself. If you have Tom and you can do yoga or take a walk, should do it. Meditate. All of those things are important tools. But being in community with other people, there is no substitute for that. And then I think, this is my theory to Angela's point about this is a fire we got to get on it, is that when we are in community together, that creates the opportunity then for us to elevate our voices as a community. So, it's not left to each individual family or individual caregiver, once again, to sort of advocate or elevate to their policymakers or to their representatives what is going on the ground level, this fire that nobody seems to see except for those of us who are in it.

We have to elevate that fire and we can do it as in community with each other. And these lived experiences are critically important for policymakers to hear because it informs everything. Just echoing everything that you said and putting

a little plug in here for Daughterhood because we do have online circles now. Thank you COVID and Zoom, giving them an advertisement. We do make an effort to bring people together that way it seems to make it easier for them.

Jordan Rau: That is terrific. We're going to go for questions now. Start with an interesting one. I'm going to see, Reed, how you handled this one. Carolyn wrote in and wrote, "Jordan, Reed, have your personal long-term healthcare plans changed as a result of your investigation?"

Reed Abelson: Oh boy, that's a good question. I think one of the things that I learned is that denial is not the way to go here. I think the one thing that has truly changed is that I feel it's important to discuss this with my family and talk about what options there are before the crisis occurs. Jordan, you had this experience too where so many families are suddenly dealing with this for the first time, talking about finances and preferences at a crisis rather than before.

Jordan Rau: As part of our project, KFF did a poll for the project and one of their main findings was that I think fewer than half of people had had any discussions whatsoever. And I agree with you, I think what this taught me was that you have to recognize that this can take many different courses and that you have to have a plan that is flexible. You can't just have a plan for nursing homes or plan I'm going to just stay in my house and put in an extra rubber mat and a bar in the bathroom because then you get dementia and how do you plan for dementia two years down the line? I think what makes it so difficult to figure out. I think that when I think about it, that's what's really affected me from the reporting experience that you just can't be like, I'm going to do...

And then the other thing is people's needs change. The number of people who said they're going to off themselves before needing long-term care needs in our comments on the stories took us a little bit by surprise, and I think some of that is hyperbolic, I would hope. The data is not there that at least for money reasons that people do that. But I think that people's opinions do change and you're like, "Well, I'm never going to go into a nursing home." Sometimes you have to or sometimes as in Robert's case, that's the best thing for your parents. That's the main thing, I think, is that it's so unknown, you need to have some flexibility to that. I'm going to pass this on to the other three of you and see what your experiences have affected you. And I'm also going to ask you another question that was in the chat that I think Reed and I are not going to answer because we're journalists is have you taken out long-term care insurance? If so, why? If not, why? Who wants... Angela, go ahead.

Angela Jemmott:

I'll start because what it has done for our family, my medical insurance gave us this chart of things to talk about and I thought it was really helpful. It talked about last suggested things you want done. Do you have things prepared? It was a nice checklist. My brothers and I were still working on certain things, some areas because I have three brothers who are single and no children. Three of them are single, no children. And it's like, "Dude, I may want to move to Sacramento." I said, "You live too far." He had something happen to him. And I said, "You live in Oakland and shoot, you can buy a house in Sacramento cheaper. So, move here, we can take..." So, we started thinking differently about aging and he moved and bought himself a house closer in Sacramento.

But we also want to know each other's finances. If you die tomorrow, I need to be able to get into your account. Somebody has to be able to open up your check account and pay for your burial. Let's talk real. So, we did those things with each other and we said, let's put it all in one location or at least one of where are the other person's financials. We made those requirements of each other to help in aging. We also even said, "How do you want to be buried?" We wanted all those things answered because those things, we don't want to have to add the stress. We see the stress. Now, my mother and father... My father was a veteran, so he's at a veteran... He had the benefits of that, although he had already bought the plot. The plots already paid for. All those things we talk about. We just put it out there and talk about.

We have clearly changed in how we know we need to prepare for each other. As Jordan, you said, we only can guess. We realize you're not going to know, not really. My mother's, one of her best friends was 90 years old, picked her up to go shopping. I'm watching her 90 years old driving. My girlfriend, her mother's 95 and she hangs out with her sisters who are 92 and they're hanging out drinking tea and [inaudible 01:11:13]. You don't know how you're going to age. There's others who are in their 80s and are sick or 70s are very sick. You just don't know. So, we have done that as a family and I think it's been very helpful and we talk very, very candidly with each other.

Jordan Rau:

That point is so great and it actually goes back to what Reed and I were talking about with people's reluctance to talk to us about finances, that people are... I think about it just in terms of two factor authentication. I can barely get into my own bank account. That's such a good point. Robert, what about you? What are your thoughts?

Robert Ingenito:

When it comes to the long-term care insurance question, I'll just say it's on my to-do list. The thing that I think I've come away from and yeah, lots of folks have been coming up to me and saying, "Hey, I saw you in The New York Times." Just

this past weekend, I was chatting with another friend of the family, we were on this discussion about long-term care insurance. I was thinking about Angela's experience with the policy that they bought versus what the reality of the situation is. And I was saying to this friend, "Take a close look at that policy."

For myself, I really think about when I am with my dad and all of the things and all of the tasks that are on my plate. And then I maybe say goodbye to him at his assisted living facility to go pick up my six-year-old daughter from school. I think about what are the tasks and what are the questions and what are the challenges that she's going to have to face when I am at my dad's stage. That's a big question and I know my wife is watching this video. We're going to have to figure that out dear.

Jordan Rau: Anne, long-term care insurance. What's your personal view?

Anne Tumlinson: I don't have a policy and it's on my to-do list, but I don't love the options. I don't feel like it really... If I could buy a lifetime policy meeting, something that would cover the most catastrophic scenario, like early onset Alzheimer's where I am needing care for a very long period of time, I probably would buy that if it weren't too expensive. But that isn't really even on the market anymore. So, I don't know what I'm going to do about that. I will say just I'm sort of Robert, very much of the same. My kids are part of blended families, et cetera. So, between my stepdaughter and my two kids, there are 1, 2, 3, 4, 5 of us, three kids, five of us. So, I think about that a lot. And for me it's a lot of thinking about where will we live and how can we think about paying for whether it's a state and a community and a place where we can be, where a lot of things will be organized to support us as far as we can possibly be supported. And that's about as far as I can get.

Jordan Rau: That's great. I just want to mention that one of the stories that we did that's in the package is a guide to long-term care insurance. In that there's a very good... There should be a link to the National Association of Insurance Commissioners, has a really detailed, I thought it was fantastic, document that gives you guidance of whether you should need it, what to look for. It's a very complicated product to purchase and hasn't become easier. Reed, do you have thoughts? I don't want to speak ahead of or out of turn for you on whether you wanted to share your personal long-term insurance portfolio situation?

Reed Abelson: No, I don't necessarily, but I would say that I'm very aware. The other thing this taught me is, again, the inability to predict what you're going to need. And I think that that's one of the things, to figure out some sort of solution where

there's a lot of flexibility. I don't know what that is per se, but I think that that's actually really, really significant.

Anne Tumlinson: I will just say just really quickly to something Robert still challenges is that I have been very open with my children about, I think one of the best gifts you can give your kids when you're at my age and older is to say, "When you need to take the keys away from me, I'm giving you permission now take the keys away. When you need to find another place for me to receive care, that's what I want you to do." I think giving your someday adult children the freedom to make those decisions is a really nice gift that you can give them.

Jordan Rau: Warning, did not do this if you have a teenager at the [inaudible 01:17:05].

Anne Tumlinson: Oh yeah, a lot of jokes ensued after that like would be done with me.

Jordan Rau: Yeah, exactly. Your long-term insurance policy cashed in for a Xbox five, is not the way to go. We got a bunch of questions that I think are very good about caregivers and how you choose one. So, I'm going to start with Reed. You wrote a terrific story that was the fourth installment of our project that was online in The Times over the weekend it's going to be in print on home care and choosing a caregiver. Do you have any advice for people on how to choose someone? How important is it for someone to have a click with the parent or with the person being cared for?

Reed Abelson: Yes. One of the most important pieces of advice I thought was actually, again, to rely on community, to ask people you trust and know. Sometimes it's medical professionals. It could be your primary care physician who's overseeing your loved one, but it could be your church or other religious institution. But I thought that that was actually a good place to start. We have a guide. I also think, not to be shy, if you're going to have an agency, to have them come to the home, talk frankly about what your needs are and actually grill them about how they vet their caregivers and how they do all those things. Don't be shy. Be really open. Again, a lot of this is communication, but that's basically my thought. But I do think really lean on the people you trust for recommendations. I think that that's I really true. And you have to check checkout references.

Jordan Rau: That's great. Robert and Angela, did you guys have any, from your experience, any advice for people?

Robert Ingenito: When it comes to the home health aide question, there are two roads you can follow. One road is working with an agency and then the other road is hiring someone on a private basis. I think when you're trying to figure something out,

you have to also consider the risks and liabilities that are involved in the event of an accident, either to your loved one or even to the aide who's coming into your home. In the end, we decided to work with an agency and there are added costs that go into that. There are a minimum number of hours that you can do for minimum number of days per week. And then there's also a difference in what the price is on the weekend or on holidays. But I think if you wanted to consider a home health aide, you really have to also look at what are the risks that you're willing to take if you want to go that private route.

I think it's also very important that you discuss what those risks are with your spouse. My wife and I, we talked about this. We decided what are we comfortable with in terms of having this person come into our home? Also, be aware of the fact that you're going to have hours of the day where a home health aide may not be doing anything. They're just going to be at the bedside of this person and they might be on their phone during that time. Are you going to be okay with that? I think that's just an important thing to think about.

Jordan Rau:

Angela?

Angela Jemmott:

Yeah, this is where I feel where the church community can step in right away. This is that part of the plan that I'm talking about. It's like create a network of people who are willing to serve in this capacity and train them. It is a easy solution to help network. I'm telling you, I'm every day practically, I'm always talking to someone asking do you know someone? Networking is important, but it's hard. It's constant because I had a caregiver who her shoulder went out. She was our main one and she was gone for 10 weeks. That happened and now I'm stuck. So, I'm always in the lookout, like as a manager, always looking to keep your staff being appropriately staffed. And that's how I feel that we're at. We're constantly... With the volunteer group, they helped me with a contract development.

We made a contract and [inaudible 01:21:59] exactly what I wanted. I wanted for the spiritual part of my mother's support, the physical. My mother is a housekeeper. So, I wanted them to know, don't just do the work, help her, at the time when she could, let her be a part of it. So, we detailed all those things out in our contract and then the salary and the hours and who to call when you can't come. All those things we had to develop in a contract for the caregivers, but it was all privately done. I went to the company and I'm not going to badmouth them at this point in this conversation, but I wasn't successful with company support. The network was my avenue and that's what we continue to do. I think that those who are in that place, it's hard. You networking, who do

you talk to here, especially if you're teleworking, you work in the house all day long, who do you telework? Who do you network with?

I just think that we have to start coming out in terms of creating organizational structure to tell people, here's a list of folks who are interested and see the profile that matched. My mother's 91, she's used to types of people. If you get too familiar with... Well, now she'll take anybody, but at the time there was a point in life where she's like, "Who is this coming to my house?" All these things are, Robert knows, you got to check all these different things about your parent, your loved one, and to develop it. But it is a networking process for most of us who are out there. [inaudible 01:23:34] I've talked to, in my experience.

Jordan Rau: Fantastic.

Anne Tumlinson: It's not a quick fix, sorry Jordan. It is not a quick fix it. It's not like, oh, we're going to just get somebody in here and that's going to help. It's an intimate relationship and it requires management.

Jordan Rau: Do you have any one or two most important tips that people wouldn't think of if they hadn't had the experience?

Anne Tumlinson: I think Angela and Robert covered it. Really? Yeah. No, they got it.

Angela Jemmott: Pay well.

Anne Tumlinson: Overpay a good caregiver.

Angela Jemmott: I just think that if you just pay a living wage, you'll get people interested. I know that, as Jordan said, people at a lower wage, if you give them 50 cent more to go to the hospital, they'll take off on you. You really do [inaudible 01:24:35] a living wage and it is not an easy thing. I have to say that I'm constantly asking questions, asking people do they know someone? That's the opportunity in our society to fix.

Anne Tumlinson: [inaudible 01:24:56]. We just have to have some infrastructure for this. We've got Angela and Robert, so incredibly resourceful, smart people, figuring this out. If we really are going to keep people in their homes using home care aids, there has to be more of an infrastructure for us to bring aids to this industry, train them, pay them, and give people access to them. Otherwise, we're all out there in the Wild West.

Jordan Rau: Fantastic.

Robert Ingenito: Oh, sorry. I can I also just-

Jordan Rau: Okay. Yes. But just so we all know, we're going to wrap up in the next couple of minutes due to time constraints and possible issues with fire alarms, I don't know. No. Anyway, we're almost done. So, Robert, go ahead.

Robert Ingenito: For all of the policymakers and congressional staffers who are watching this, I just want to say yes, your job is cut out for you. We need a much more comprehensive system, but I also feel like there needs to be a better knowledge source in place so that when folks are in these crisis situations and we're forced to have to make decisions that are so monumental, we're not making those decisions under the stress of that moment. I had to figure out on the fly what the difference was between a CCRC and an FFSCCRC. That's ridiculous. While I'm having to transfer my father from the bed to the commode [inaudible 01:26:41] to understand what on earth is the difference between assisted living facilities. It's unheard of.

Anne Tumlinson: It's crazy.

Robert Ingenito: And I think there just needs to be a knowledge source in place so that those of us who are going to try to start figuring out what to do, we are educated and we know what to do when these crisis moments come up.

Jordan Rau: That is so well said. And that's a great place to end. I want to thank everybody, Reed, Anne, Angela, Robert, thank you so much for your time. This has been a great conversation. I'm supposed to say that a recording will be posted online later today and all registrants will be sent an email. That will be one more email that you will get. But this will be floating around.

I just want to say that I think I can speak for Reed and me, that really the most satisfying part of this project was talking to people like Angela and Robert. A lot of times, we just dropped into people's lives, parachute in for a quick story, but we stayed with people. We had several people whose parents passed while during the reporting stage. I hope readers will find that the series is more full because of that. But anyway, thank everybody. All of the people who attended, we're going to put up a card, there it is. If you have a story idea or if you have a tip, this is my email. This is Reed's email and please feel free, please send us something. It's in confidence. We are still working on this subject and other subjects. Thank you to everybody. Thank you to KFF and hope everyone has a good day.

Reed Abelson: Thank you.

Robert Ingenito: Thanks everyone. Bye-bye.

Reed Abelson: Bye-bye.

Jordan Rau: Bye.

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