ASHLEY: Do you take care of your parents, or maybe you know someone who does? As Americans age, millions of adult children are stepping in to provide care or oversee paid caregivers. For many families, this involves a great deal of time, angst, and money.

RICHARD: There's a pressing need for long-term care to help people as they age. This includes everything from caregivers to transportation services to stair lifts at home, and right now there's very little consensus about how to pay for it. This is Let's Find Common Ground. I'm Richard Davies.

ASHLEY: And I'm Ashley Milne-Tyte. In this episode, we break down the issues of long-term care and what's at stake.

RICHARD: Our first guest is former journalist Howard Gleckman of the Tax Policy Institute. He sets the stage for us, and then we meet two experts from different political backgrounds who used to strongly disagree about how America should pay for long-term care. Today, they're more closely aligned. We find out how they got there. First, let's hear from Howard Gleckman.

ASHLEY: Howard, when we talk about long-term care, what exactly do we mean?

HOWARD: So this is a confusing issue, and I'm glad you asked me. If you are somebody with a disability or with chronic conditions, you likely need some assistance, some personal assistance. That might be help getting started in the morning. It may be transportation to the doctor or the physical therapist. It might be respite care for your family caregiver, grab bars in the bathroom. These are not medical interventions.

RICHARD: So this is not long-term health care. This is long-term care.

HOWARD: That's right. There's long-term care, or sometimes called long-term supports and services. It is not health care. It's not medical treatment, and that creates problems in the United States because we have a very high barrier between the way we treat and the way we pay for medical care and the way we treat long-term care. So, for example, Medicare, the government program for health care for older adults in the United States, does not pay for long-term care for the most part. Health insurance, even supplemental Medicare insurance, does not pay for long-term care, but of course it does pay for health care.

The other place where this is a real challenge, of course, is in the physician's office or in the hospital. They're quite familiar with health care in their specialty but generally know nothing about the supports and services that their patients need. So, if, for example, you have some medical episode, you go to the hospital, you're discharged from the hospital, the hospital's private discharge plan will tell you all about your next medical appointment, but it's not likely to tell you very much about the support and services you need. For example, it may not tell you that you should have grab bars in

the bathroom because you're a fall risk or that you're going to transportation to the doctor.

ASHLEY: And you have personal experience with this, don't you?

HOWARD: I do. I was a family caregiver myself. My wife and I live in the Washington, D.C. area. Her parents and my parents lived in Florida. One day, the phone rang, and it was my wife's dad telling me that her mom had just had a stroke. We flew to Florida, and we discovered that my mother-in-law was on life support, and we discovered that my father-in-law was quite ill himself. My mother-in-law had been trying to care for him without telling anybody in the family how sick he was.

We had to make two very, very difficult decisions. The first one was to take my mother-in-law off of life support. And then the second one was we had to figure out how we were going to provide care for my father-in-law. We had no idea what to do, and that sort of set me on my own journey. A few months later, my own dad got sick, and I had to do it again.

It's important to keep in mind that most people who receive care get it from family members and friends. That's an enormous burden on family members. You know, my own experience was it was the hardest thing I ever did. In some ways, it was wonderful. I was able to give back to my parents. But it was very difficult, and juggling it and a job was not easy.

ASHLEY: What are the implications if we fail to address what seems to be a growing crisis in long-term care as, obviously, the population is aging?

HOWARD: This is often referred to as a crisis or disaster. It's important to keep in mind, at the beginning, that this is all a consequence of something that's wonderful, which is life expectancy of human beings over the last 100 years has doubled. At the turn of the 20th century, the average life expectancy of someone in the West was about 49 years. Now it's over 80 years. Because of advances in medical technology and advances in public health, we have done a remarkable job at keeping people alive for much longer, and many of those extra years are actually years in good health.

What we haven't been able to do is develop a system that can provide supports and services for somebody who does live a year or two or maybe more needing some assistance. This was never a problem before because before the invention of penicillin, for example, you fell off your horse, you got an infection, and you died. You didn't need long-term care. You were dead in a matter of weeks. Now you get an infection, you get penicillin, and you go on and live your life.

The incidence of breast cancer survival in woman has increased dramatically just in the last 20 years. It used to be that breast cancer was a terminal disease. You got it, and

you died. Now it's treatable, at least manageable, and it means that women with breast cancer will live, in many cases, a normal lifespan. But it also means they'll live long enough to get diseases of old age like dementia, for example, or severe arthritis.

ASHLEY: What are the consequences of these changes both for the healthcare system and for people who are now living longer?

HOWARD: The consequences of not getting supports and services are really twofold. In terms of money, we're going to spend much more. We do spend much more on the health care side because we're not providing the supports and services that people need. Simple example, you are an elderly widow who lives at home. You don't have good nutrition. You don't have those grab bars in the bathroom. You're more likely to fall. If you fall, you're going to end up in the emergency department. Then you could end up having hip surgery. That all costs the system a fortune, and it's unnecessary.

The other issue, more important issue to me is what it means for the quality of life of those older adults. That woman not falling is going to live a much better life than she will live after she falls and after she has the hip surgery and has to go through the rehabilitation and may never be as mobile as she was before the fall.

RICHARD: How many people are we talking about today who need long-term care?

HOWARD: We estimate that about 14 million Americans currently need a significant amount of supports and services. The really important number is that number will double by the middle of the century. The increase in the Baby Boomer population and the increase in the number of people with disabilities who are also living longer lifespans will result in a dramatic increase in need for long-term supports and services over the next 30 years.

ASHLEY: If there are two sides to this issue, what are they? What do different groups of people believe we should do about this?

HOWARD: Think about how we are going to finance this care, how we're going to pay for it, and then think about how we're going to deliver this care. So, over the last year during the COVID pandemic, the delivery issue has been the one that's been in the forefront. More than 150,000 older adults have died in nursing homes and other long-term care facilities in the United States. That has focused the line on the fact that the way we deliver long-term supports and services in this country is not very good.

So one thing we need to do is we need to think about how we're going to deliver this care. Can we do a better job delivering it for people who need to live in institutional settings? And can we do a better job of getting people who don't need to live in institutional settings out of those settings so that they can stay home and get their care?

The second related issue is: how do we pay for all this? Right now, the United States mostly pays for this with Medicaid, which is a program that's available only for people who are very poor and have very, very low incomes, less than $700 a month. The United States and the UK are the only places in the major developed world that do not have a public social insurance program for long-term care. Both the United States and England have a welfare-based system, programs that are available if you are poor enough, but they don't have programs available for the public in general, and we need to think about how we're going to pay for this for people who are not poor.

RICHARD: You mentioned COVID a few moments ago. What's changed with COVID?

HOWARD: This was an issue that we did not want to talk about. COVID has forced us to think about it. It's been on the front page of every newspaper. It's been all over the television news. It's been all over the internet. You cannot miss it. This has created a true crisis, but it's also created sort of a moment for people who care about long-term care reform. It's focused the public's mind, and, to some degree, it's focused the politicians' minds on the importance of dealing with this issue.

We cannot keep this in the closet, and you see it. President Biden has proposed a $400 billion increase in Medicaid spending for long-term care at home. No president has ever done anything like that. This would be the biggest expansion of Medicaid long-term care since the program was invented in 1965.

RICHARD: People who need long-term care, do they have to drain their finances first before they get assistance that's paid for by the government?

HOWARD: If you spend enough of your money out-of-pocket on this care, and some people do, you will go broke, and Medicaid will be there as a backstop for you. So there is a system to support you. It may not be very good. It may mean, for example, if you have to go into a nursing home, you may share a room with a stranger or you may have to share a room with three strangers. But you will get some level of care.

The real consequence of not caring for this is talk to an EMT, an emergency medical technician, in any place in the United States, and they will tell you that it is not uncommon for them to get a call to someone's home, and they will discover that someone in that home, an older adult or someone with disabilities, has died there and has been dead there for days. And no one even knew it until maybe the post delivery person smelled something bad. That's the tragedy, is people who do not get the care that they need.

RICHARD: Howard Gleckman on Let's Find Common Ground. Next up, our conversation with Stuart Butler and Paul Van de Water on their strong differences over how to pay for long-term care and how they found common ground. I'm Richard.

ASHLEY: And I'm Ashley. This podcast is a production of Common Ground Committee, and we're making the episode with cooperation and help from Convergence Center for Policy Resolution. Convergence is a nonprofit group that brings together people from different viewpoints to build trust, find solutions, and form alliances for action on vital national issues.

RICHARD: As you'll hear in the second half of our show, the Convergence team brings skilled facilitators to the process and attempts to inspire a collaborative mindset in others and help those who want to use the process.

ASHLEY: Now back to our interview. We bring in our policy experts from different sides of the aisle who gradually came together on how to fund this type of care. Stuart Butler is a Senior Fellow at the Brookings Institution. He's a Conservative.

RICHARD: Paul Van de Water is a Senior Fellow at the Center for Budget and Policy Priorities. He specializes in Medicare, Social Security, and healthcare issues, and his politics are to the Left of Stuart's. Paul has worked on long-term care issues for many years, and, like Howard Gleckman, this is personal for him.

PAUL: Personally, I've had involvement with long-term supports and services particularly with my mother-in-law and her mother, both of whom developed dementia in their later years. And my wife and, to a lesser extent, myself were involved in caregiving and particularly in an institutional setting for my mother-in-law. So I've been very involved on a personal basis, as well.

ASHLEY: Stuart?

STUART: My main interest in getting into this issue was actually much more from the budget side. I've been very concerned about the growth of the federal deficit and the federal debt. So that was one issue, in terms of the cost, particularly from Medicaid. But also, I work in the health area, and so looking at this from personal services and health care for old adults was another factor.

Then, also, like Paul, I had personal experience, too, in this case my father-in-law who, while he didn't have any great special needs, had to live in assisted housing for a number of years. And he was literally running out of money with us essentially committed to support him when he did run out of money. He was literally running out of money at almost exactly the time that our older daughter was about to leave for university, and we were thinking about, in this case, $50,000, $60,000 a year for tuition. So it was like a double whammy for us, and I have to say that really brought it home to me that people in a middle-class situation really face these enormous concerns.

RICHARD: You worked with Convergence. This is the Convergence Center for Policy Resolution that helped the process.

STUART: Yes, I've been involved with Convergence for many years, and the idea of Convergence was to tackle exactly these sorts of issues where you have people who all want to solve a problem but have very deep disagreements or differences about how to do it. And Convergence uses professional facilitators and mediators. I sometimes call it family counseling for policymakers. It uses these techniques to get people to, first of all, trust each other and explore their underlying motivations, if you like, and their goals and so on and allow everybody to understand that as a prelude to really focusing on: where are the areas of commonality, and also how we can address some of the areas of differences in ways that we can make progress?

RICHARD: Tell us about the nature of the deliberations involved.

STUART: Even a few years ago when we were working on this issue, there were just deep disagreements, and people who knew each other were at an impasse in terms of how to move forward. So it was an important ingredient in terms of how people like Paul and I and others could reach a significant measure of agreement by going through this process of really searching for our visions of the future, our values, and getting to know each other in a way that allowed us to go outside our comfort zone.

ASHLEY: Paul, Stuart's been outlining how Convergence works. Can you go in and describe how the two of you disagreed over long-term care? How did you differ from each other?

PAUL: Well, of course, at the end of the day, we came to substantial agreement on a lot of these issues. But going into the process, Stuart and I had rather different perspectives. Stuart has said to me in other contexts that his initial preference for emphasizing some sort of a private solution involving saving and private long-term care insurance. Based on my previous work on the topic, I had concluded that the private long-term care insurance system wasn't working properly, and it was unlikely to be able to be put back in working order on its own without substantial federal involvement. So those were the two different perspectives that we were coming from to start with.

STUART: I think my reluctance, if you like, to embrace readily a government solution was partly philosophical. I'm a Conservative and not a big fan of increasing government. I was also very concerned about the potential unfunded obligations of a government program. I'd been working for many years on reforms of the Medicare system and Social Security, the two big programs that have long-term deficits associated with them. I was, if you like, in no mood to say, "Let's add another one to this." For me, insurance was the logical area to really build on, private insurance. My instinct was very strongly in favor of working to strengthen the weakened private insurance system and to build that up.

RICHARD: Okay, so we've kept our listeners in suspense for long enough. We've heard about the disagreements. We've heard about the problems. What did you come up with as a solution?

STUART: Paul, do you want to go first?

PAUL: Sure. Well, I think what we came up with was an idea for the federal government to establish a catastrophic long-term care insurance program, catastrophic meaning a program that would not kick in instantly for the initial needs for long-term supports and services but which would start to apply once people were incurring larger amounts of spending because, in part, that was what the private long-term care industry was becoming increasingly unwilling to do. That is, it wasn't willing to take on open-ended obligations, which, as Stuart said, could turn out to be quite substantial.

Another piece is to make various improvements to the Medicaid program. This was an issue which Stuart and Howard Gleckman and others were particularly concerned about, as well, quite correctly. So we also proposed making improvements in Medicaid for those people who would eventually have to rely on that to the extent that these other elements in our proposal proved not fully adequate.

ASHLEY: Stuart, do you have anything to add?

STUART: Yes. Of course, my initial reaction to that was not particularly favorable, particularly the first part. I felt initially that this kind of program, a so-called limited federal catastrophic program was sort of the nose under the camel's tent, in a sense. I've been there, seen this, small programs that just grow and grow. I was pretty reluctant initially to go down that road.

Then, I think, on the Medicaid area, Howard, who you've spoken to, and myself and several others, were more interested in the Medicaid area of saying, "How can we make Medicaid a lot more flexible in terms of how it operates?" I think the key to what happened in this conversation was us finding a compromise in that area. The central agreement on this government program designed to stabilize private insurance and also, I would say, reducing long-term costs for Medicaid by allowing middle-class people to avoid falling into the Medicaid program, that was linchpin of really everything that we agreed.

RICHARD: Stuart, you come from a Conservative background, and your proposals really involve an expansion of federal government spending and federal government reach when it comes to providing for and helping people, money that could amount to a very large amount. Do you have mixed feelings about that even now?

STUART: Yes, I do. Even though I'm very supportive of, actually, legislation that's being introduced that would essentially set up the program that we talked about, yes, I'm very nervous about it and was at the time in terms of what might happen in the future. But let me make clear that what we didn't agree to, those of us on the Center Right, was what some argued for in the Convergence project, which was essentially to do away with private insurance and say, "Let's create some form of, really, an expansion of Medicare to provide long-term care services and do so very generously."

ASHLEY: Paul, can you give us a sense of how this process of compromise felt to you? I'm particularly interested in what Convergence does and how that feels to you as a participant as you work through these issues with people who feel differently than you?

PAUL: We all agreed that we wanted to work together in a way that everyone could be content with. So there was a basic amount of goodwill that was there from the start. And then the discussions, which, in fact, extended over several years, the initial notion, what, Stuart, was that this project was supposed to be finished in, what was it, 18 months? It was some brief period of time, but it extended far longer than that but, in part, because we thought we were making progress.

ASHLEY: Part of that progress had to do with data. With outside help, the group developed a data model that helped them come up with estimates of what long-term care costs would look like under various scenarios. Before that, different members of the group would often argue over the numbers. So that was one hurdle cleared. But Stuart says he and others would get frustrated with Paul because they thought he was digging his heels in on Medicaid, resisting ideas they wanted to implement.

STUART: In terms of reaching agreement, some of the more Conservative people in the group said, "Okay, look, we're going to swallow this big item called a new federal program. If we're going to do that, we want to see some of the changes that we think are necessary in another type of program, Medicaid. We want our side to be represented in the agreement, as well." More particularly, which we found really confusing when we were talking to Paul, was we wanted to see it more flexible.

We wanted to see Medicaid able to cover things and Medicaid funds to be used in dealing with a lot of other issues hat were non-medical associated with older people, transportation, other services and things like that, and he kept pushing back on that. And Howard and I particular would say, "We don't understand why you're... This is a perfectly reasonable idea." I think for many people who worked, like Paul, in Medicaid for so long and so hard and just all these incremental steps that they had to use to move the program forward, they were very nervous about opening up this program and saying, "Okay, let's use the money a little differently." They were very concerned that the basic existential nature of Medicaid might be undermined.

I think I really began to understand that after conversation, particularly with Paul but some others, and it affected me both at the time, and I think Howard, too. We kind of backed off because we said, "Okay, we understand a little bit better now why you are so intransigent about this." And it's affected me since because even now, I think I'm much more sensitive to that when I am involved in public policy conversations. So it's been a lasting impact on me.

PAUL: Well, Stuart has expressed that very well and very kindly, and until recently, I'm not sure appreciated how intransigent I may have seemed at the time.

RICHARD: We are passionately divided as a nation. Did you learn lessons? Can we learn lessons from how you came together and found some areas of agreement?

STUART: I think the core of this, and it's exemplified in just our conversation today in terms of the issues that we looked at, is the importance of listening to the other person first before you start peppering them with questions or arguing with them. One of the reasons the Convergence projects do actually last so long... It's not like we get together for one weekend and try to hammer out a deal, which is often the conventional thinking about how sides get together. No, it took a long time to really understand each other.

We probably all agree that one of the big dangers that we're seeing now is that people are not listening to each other. Not only that, they tune into different television programs, networks that just tell them what they already believe. It's an enormous challenge that we face, but I don't know any other alternative.

RICHARD: Thank you, Paul and Stuart, for sharing your ideas, your thoughts with us on Let's Find Common Ground.

STUART: Thank you.

PAUL: Thanks.

ASHLEY: Yeah, thank you very much.

RICHARD: Paul Van de Water and Stuart Butler on Let's Find Common Ground. Convergence recently published Rethinking Care for Older Adults. It's a report that came out of a series of conversations that Paul and Stuart and Howard and others were involved in. It has recommendations on improving care, housing, and services for older Americans.

ASHLEY: We'll be back with another episode in a couple of weeks. I'm Ashley Milne-Tyte.

RICHARD: I'm Richard Davies. Thanks for listening.

ANNOUNCER: This podcast is part of The Democracy Group.