MILKEN INSTITUTE

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IN SERVICE OF BETTER HEALTH

THE BREAKING POINT: AMERICA'S 63 MILLION FAMILY CAREGIVERS

Richard Lui 00:16

I love that walk-on song. Maybe just play it throughout our entire panel, that would probably be good. Good morning everybody. How's the conference so far? Yeah, I heard the longevity session. Anybody, the longevity session? No innovation—got it. The Alzheimer's session? Okay, all right—four people. Okay. Welcome to "The Breaking Point: America's 63 Million Family Caregivers." My name is Richard Lui. I'm an anchor over at NBCU News Group, and it's really great to be here with all of you. Joining us on the stage today, sitting directly to my left, and I'll go in order: Les Biller, founding director, the Sheri and Les Biller Family Foundation. Good to see you. [LB: Good to see you as well.] Fantastic! Alexandra Drane, we'll call her Alex, Cofounder and CEO of Archangels. Good to see you. How come you didn't get any of that?

Les Biller 01:20

You stepped on my laugh line.

Richard Lui 01:21

Yeah, I did. I'm sorry. Sarita Mohanty, President and CEO of the SCAN Foundation—okay, we are warming them up. This is great. Jaelyn Smith, Youth Lead at Lorenzo's House. So as we look into this number, 63 million, and there are varying estimates that are out there. It's just a lot, right? It's just a lot of people in the United States, in North America, and globally—we could be talking about a billion globally. Sarita, I want to start with you on this. You've had many different lives, and you can tell us all about your different—she has the most letters, by the way, after her name on this panel. Mine is just dope. No, I'm joking. But as you think of all the careers you've had as an MD, PhD, as an MBA, and pulling this all together when we think of the idea of breaking point. That's not necessarily new to you, but what is new, if you were to describe to all of us who are thinkers or doers in the caregiving space, about this breaking point?

Sarita Mohanty 02:37

Well, thank you, and it's really a pleasure to be here. I—first of all, I know we often talk about a system, yeah, that we're part of. And I think that we're being overly generous about that word. You know, we're seeing this pattern—as we think about the caregiver breaking point, this patchwork, this—I mean, it's a fragmented system. And what I'm—we're—also seeing is that a lot of caregivers are struggling internally. It's like they're in a closed space versus being part of a systemic solution. And so that's really where I see tremendous opportunity. One of the things that we're doing is listening to caregivers and older adults as a philanthropy, we are bringing those data, those insights to meaningful policy change. And I want to give an example. We had a woman who basically said to us that—and her name is, her name is Claudia, and what she said is that she cannot—she needs to take a week off just to deal with her insurance. Okay? Because she knows it's going to take her that long to go through all the practice enrollment. And this is a woman. She's at Medicare Advantage, 138 percent federal poverty limit in suburban North Carolina. And she's like, "I cannot figure this out." So these kinds of insights are going to be critically important, because at the end of the day, we're going to need much more systemic change. And what I will just say in this breaking point is that we need to be thinking about a sustainable public support system of long-term care financing.

Richard Lui 04:18

Put it into the context of the SCAN Foundation, what it does and how you discuss this breaking point internally with your team?

Sarita Mohanty 04:24

Yeah. So we are a foundation focused on aging, mostly older adults that have been more historically marginalized, lower income, older adults, communities of color, those in under-resourced geographies, like rural settings. When we look at them, 90 percent want to stay in their home and community, when we talk to them, when we look at the data, AARP has done surveys. And so our work is about what are those systemic levers we need to help support pull to inform federal policy and state policy? We work in California and federally, and so some of our opportunities have been bringing the lived experience, the insights of older adults as we think about this work, so not just the quantitative. And we're letting legislators and other folks look at those data to inform effective, equitable policy solutions.

Richard Lui 05:18

Les, your foundation: How did it come about? And how do you discuss the breaking point with your team and the decisions that you've made for workplaces as you partner with them, as you invest in them, as you look at different communities, as you look at different businesses?

Les Biller 05:37

Well, our foundation was created in 2001, and it was based on the understanding that my wife, Sheri, and I had been very fortunate in life, had achieved a level of financial independence, and I recognized that my success, both financially and managerially, had a lot to do with others taking an interest in me, and so we decided we would focus on opening doors for other people in our foundation, and that's how we got it started. In terms of the area around caregivers, I'll call it supportive care. We're focusing, at the moment on cancer only because there's a lot of data and information, but this would apply to any life-threatening disease: neurodegenerative, pulmonary, cardiac, you name it. And what we found in studies that we've done is when you provide supportive care services—so there's the clinical side, radiation, you know, chemo, surgery, and then there's the support of dealing with symptoms, access to information, patient navigation, peer groups, all of those kinds of things. When you provide those services integrated into the care of a patient and the caregiver, a couple of very important things happen. The quality of life of the patient and caregiver grows up significantly, and the overall cost of care goes down while you're expanding access to services. So you have a better quality of life, and it costs less without denying service that should have momentum of its own. And of course, it doesn't. And so we brought together a group of stakeholders. We have employers, we have payers, we have providers, we have pharma, we have patient advocacy organizations, and we have policymakers, and we brought them together, and we laid out this concept, if you—your quality of life is better and it costs less. Why doesn't this have momentum of its own? And two things came out of that. One was no one ever brought these groups together to understand what the issues were on the other side of the aisle. And secondly, and very importantly, a commitment that they wanted to continue this, and so we launched something called the coalition for Together for Supportive Cancer Care. And it's one year old at this moment, and we're trying to tackle problems to increase the availability and utilization of supportive care services in the country.

Richard Lui 08:18

Do you need these groups and coalitions regionally? Do you need them locally? Is this a national approach at the moment?

Les Biller 08:25

Well, the coalition is national. So we have big players in all of the spaces that I mentioned. But, you know, like anything else, the execution is local, right? So we have pilots going on. When I say "we," it's not something we start, understand. Yeah, we're supporting these pilots trying to analyze their data and see what they're achieving. So states like New Jersey, states like Maine and others, have pilots going on, and we're supporting that, both financially and with access to their data. So we can highlight it and put a spotlight on it.

Richard Lui 09:01

Yeah. I mean, the surprising thing, I think, for everybody on the panel and those in the room, is that you have a lot of actors and doers out there that may be in the same city, yet they may not know each other. You're talking about this nationally, and that's why I was bringing up the idea of regional and local. It's very simple, but we need that connective tissue. And to talking about connective tissue, Alex, as you are touching, you have a lot of touch points, right? You speak to a lot of businesses at various stages of development, various sizes. You try to help them understand the importance of caregiving within business, and within and organizationally. Has the breaking point been more receptive or less receptive as you're describing the severity and the needs to address it with those that you are consulting with?

Alexandra Drane 09:53

First of all, my heart is beating so loudly, if anyone can hear it, because I think this room is so exciting: like the fact that this is a panel at Milken that gets all the attention, that's an example that we're at a breaking point because it's getting this level of attention. So thank you, and thank you to Milken. You know, I think the thing that's interesting to me is the term "unpaid caregiver." And when you look up there, you see "family caregiver." But the thing that you know: the system pays attention to things that get paid, and unpaid caregivers are kind of invisible because they don't get paid, right? So because we do all that work, review books like, oh, they'll just keep going—let's just keep going. And so I think one of the reasons we're at a breaking point, you talked about that system, is because the system is breaking. And where the system is breaking, I think, is beginning to happen around employers, because employers can—you know, they're hiring folks—58 percent of unpaid caregivers are in the workforce, and they have this other job called being a caregiver. So they want to be at work. Because for many caregivers, work is respite, right? It's where they can go to pee by themselves. It's where they can go to, like, work on things in purpose, and they really believe what they're doing, plus they need the money that comes in from being an unpaid caregiver so that they can keep paying for the people in their lives. So I think what's extraordinary to me watching all this happen is, I wish these changes were happening, because the good souls in the world were like, "Wow, we should care about this population that makes up over 40 percent of our nation and is doing so much work." But in the absence of that happening, what is happening is employers are saying, "if I do not find and love on my employees who are in this role, they are showing up at the door of HR, and they are taking a leave, or they are quitting, and then I can't open my doors, and I can't make money, and I can't—." You know, in the state, as an employer, and the state is seeing these things and things happen. So it's a massive hit from a cost perspective, but it also could be flipped between us of opportunity if we started seducing people but being kind to them because they're in this role, and seeing them and inviting them into the system and having special lanes for them and ways to talk to them that are like, "you frickin rock. You're single handedly opening up, like, holding up our our nation. We want to support you." And I think employers are like, I want to be an employer of choice. I want to keep my employees. And I recognize that an activated employee is also smarter out with our customers, and so it's a win, win, win. And I think that's happening. I wish, because people were like, Oh, that's a good thing to do. I think it's actually a top and bottom line responsible thing to do.

Alexandra Drane 12:10

Jaelyn, you and I were talking before we walked up here, and I think our reflection together was, "I can't believe we're up here talking about this topic." You as a youth lead at Lorenzo's House. I mean, 17 years old, is that right? Yes, you probably when you're in middle school, not thinking that you would be leading conversations, leading conferences on this topic. First of all, talk about Lorenzo's House, what you do and talk about this breaking point and how you talk to other people about it?

Jaelyn Smith 12:46

Yes, so Lorenzo's House, I've been involved with for quite some time. I—they have an annual Youth Summit. So we do that every year. It's online, it's global. They have many countries involved. Almost all 50 states are involved. And it's basically a space where people are able to talk about their experiences, because a lot of times, people aren't able to get together and talk about what they're going through and get advice from other people. And Lorenzo's House provides that space for people to be able to do that, especially our youth caregivers. I mean, we have people as young as, I think, four or five that are on these Youth Summit calls and are talking about their experience and how they're dealing with it. So I think that, I mean, it's just a really nice space to be able to kind of have a somewhat of a break away from caregiving. It's like a full day event, but also a space where I can talk about my feelings and my experiences with other people that are able to understand what I'm going through.

Richard Lui 13:38

How did you get into this personally?

Jaelyn Smith 13:41

So my mom was involved. She was involved with them, and they told her that they had a space for me as a young caregiver. And so at first I didn't really want to do it, because I was young, I didn't really want to have that responsibility. But I realized, I mean, this is my dad, and I'm always going to want to be there for my dad, so it's like the least I can do for him, after all he's done for me as my father. So I wanted to be able to get involved and advocate for him and advocate for this.

Richard Lui 14:09

When did you realize you were a caregiver when you were caring for your dad?

Jaelyn Smith 14:14

I probably wouldn't say as soon as he got diagnosed—

Richard Lui 14:14

Diagnosed with—

Jaelyn Smith 14:14

—with young-onset Alzheimer's, he was diagnosed in 2020 when I was 12. So I definitely didn't think I was going to be a caregiver as soon as it happened, because he hadn't really progressed that much anyways. But, like, a couple years later, I started realizing, like he was forgetting more things, he wasn't able to, kind of, like, communicate with us as well as he used to. I mean, he was a very strong, independent man, and so seeing my dad, like, not being able to kind of, like, talk about, like what he wants, was kind of not only hard for me, but also hard for him as well.

Richard Lui 14:52

We talked about how it's breaking bad. I want to move now to breaking good. And so, Alex, you were hinting to that, what is your practical advice to businesses and organizations? You can break good on this? Yeah, it is. It is lot of breaking bad right now.

Alexandra Drane 15:13

So a couple of thoughts on that. One. I'll use as an example, financial services or a pharmacy. Who, you know, financial services right now the data is anywhere from 60 to 80 percent of inheriting individuals, right? So my dad has an account with a bank, and I am his daughter, and I will take tell you the bank makes my life impossible, like I'm his power of attorney. It's like I never got the power of attorney. I have to keep re-proving, and he has Alzheimer's, and it's devastating to him enough to keep going through these questions. So if, instead of doing this to me, this financial services company was like, 'hey, Alex, you're incredible. We have your POA, wait, I see that. And by the way, here's some information for you. Here's resources that are available for free for you, from us, from your employer. Here's how you get them from the state and community.' So it's actually like, how many of us wait on hold for hours with the pharmacy, right? In order to get the medication that's been prescribed 18 fricking times and it's definitely covered, those are hours that has taken me. And there's a slow rage building, and it's actually not slow. And if somebody were to, like, be kind to me in that, I would give them my forever loyalty. So it's easier to retain a customer, and in so doing, retain everyone in their circle, than to piss somebody off so royally I can't wait to leave. So I think that's a ginormous thing. And the other thing I'll say is often people, when they approach unpaid caregivers, are like, oh gosh, I'm so sorry. Jaelyn, you're so—look at you, Sarita. Like, I don't want freaking pity, right? These folks are badass warrior angels, and so I think having a strength-based you crush, we see you, we support you. No one wants pity. Unpaid caregivers, they're getting it done because they have no option. And so if you approach them—they're going to ignore you and be enraged. If instead, you see them, you support them, you cater to them, they will be your forever lover, not literally, yeah, maybe you, Richard.

Richard Lui 17:11

Used the word 'seducing' earlier, 'forever lover,' yeah. Les, what do you see? How is this showing up in the businesses and organizations and the communities that you're looking at and you're investing time and effort into, how is caregiving showing up and—and let's stay on the breaking good side, too.

Les Biller 17:32

Well, first of all, let me say, Alexandra, as an ex-banker, I'm going to unretire just to fix your problem so that we get that issue solved. You know, the large corporations in this country have the unique position of being both self-insured and an employer, and the importance of the self-insured is they're not buying someone else's plan that says this is covered and this isn't. They're deciding what is covered, and so they can make that decision in their plan and then provide that to their employees. And when I say employees, I'm not just talking the patient, but it's the caregiver. Because the impact of the impact of in our case, as we look at cancer care, is on both of those. You have the patient who's missing time and in the office because of their treatment and their symptoms, but you also have that on the caregiver side, I believe there's an opportunity to move the needle quickly with employers. And here's here's why today in America, based on studies that we have done, 15 percent of people who have cancer currently are utilizing in a meaningful way, supportive cancer care—just 15 percent. If we could move those 10 percentage points to go from 15 to 25, the system saves $4.6 billion dollars a year, not by cutting services, by expanding them, and the quality of life for the patient and the caregiver goes up. So that's where we're focusing now to try to move the needle there. It's not only going to reduce claims costs for employers, but it's going to create a better environment. They're going to be viewed as an employer champion, as opposed to someone who just cares about nickels and dimes, and we're starting to get some response to this. We're working on some pilots with large employers so we can share their data, even if it's on a blind basis, with others, so that we can make the needle move quickly.

Richard Lui 19:38

That's great. And have you had any pushback about anonymizing this data?

Les Biller 19:44

Actually, more of the employers rather it be anonymous than because in—

Richard Lui 19:49

To release it, obviously that the one anonymized.

Les Biller 19:52

Yes—yeah that's, that's exactly right, yeah, some of them are, you know, somewhat concerned about, how do I go about this? What our foundation and our coalition, Together for Supportive Cancer Care, is all about, is helping them do this in a simple way, and giving them a toolkit on how to do this and not make it a huge lift for them.

Richard Lui 20:12

Yeah, because the issue is a lot of them want to monetize it on their own. It's their stuff.

Les Biller 20:19

It can be, I wouldn't say it's universal that way, but there are some people who are doing some things who don't want to participate, because they think, well, I don't get anything out of it. But to a larger degree, people are saying, look, I know we're not doing everything right. How do we learn from others? And how do others learn from us?

Richard Lui 20:19

And this is why your coalition has the breaking-good bat, if you will. You've got to do this because Les is coming around the corner along with your wife with the coalition.

Les Biller 20:47

Yeah, they're more worried about my wife than they are me coming around the corner. But yes, I get your point.

Richard Lui 20:52

Yeah, absolutely. No that's where an outside party in this space makes a difference. So it's not just a binary conversation. Jaelyn, you're definitely part of what's breaking good. We use the number 63 million—10 percent, the way my team has modeled it, is typically the youth caregiving portion of the whatever number you choose. So that's like 6 million folks that are 17 and younger that are family caregivers unpaid. Is that something that you see out there? That's a pretty big number that we don't talk about. People think caregiving usually means me, like this age group.

Jaelyn Smith 21:33

Yeah, I would say that it's a little bit difficult, because I feel like a lot of young people don't really put themselves out there in that space. I mean, yeah, that's a huge number, but Lorenzo's House has a lot of those youth caregivers. I just feel like there could be even more spaces where youth caregivers are able to share their experience and kind of like connect with each other, so they can see that they're not alone in this journey, and see that they have people that are going through the exact same things, just like they are.

Richard Lui 22:00

And so how do you bring that out? Because if you don't see a lot of like for instance, if I were to be 15—oh, how I wish! If, where would I find stories about me that say I'm a caregiver and I'm part of—I'm not alone. Where would you go? Lorenzo's House clearly, or else?

Jaelyn Smith 22:18

I feel like schools could also do their part in that, like schools and communities putting out resources to connect teens and youth to places like Lorenzo's House and other places. I actually was trying to make a high school group, so that way people—it's almost like a club where youth could, you know, kind of get together one day a week and talk about their experiences, and kind of make it more like a tight-knit community.

Richard Lui 22:44

That's great. And check out the movie, Sky Blossom, a little plug here, shamelessly, it's about young caregivers. And so that's maybe some content. Sarita, you and I were talking about something that I thought was signs of a healthy—it's one healthy indicator, and that's M&A that's happening in the care economy, like that shows that there is at least some growth, some attrition at the same time, the ability to bring equal or similar energies together. And you were saying that you were interested in one or two properties, and somebody else actually said, "Oh, we're going to buy that"—buy that particular caregiving company, which is actually somewhat of good news. Talk about that space, in terms of the different businesses that you are either investing/granting into or that you're partnering with.

Sarita Mohanty 23:35

Yeah. So one of the things, you know, as a philanthropy, we are a grantmaking organization, and we also—and when I came in five years ago, I had a—I really felt that there needed to be more opportunity to think about public-private partnerships and think about creative ways to effectively work with entities like even venture and, you know, and even entrepreneurs in the space. And so a couple of years ago, we carved out a portion of our net assets to do what we describe as social-impact investing and really ensuring that our impact-investing policy statements really are tied to our priorities, focus on older adults and focusing on the populations that I mentioned as our priority populations, the mostly underserved, underrepresented. And so it has been a journey for us to really start to have conversations and source who's out there who really wants to help us elevate the needs of older adults. So I'll give a couple of examples. We did just recently, a direct investment in a company called PearSuite. They did their series A and the idea was that they are—they have an AI-enabled platform for community health workers to outreach, and mostly in low-income Medicaid dual space, we found that more than 40 percent of the 100,000 that these community health workers are reaching are old adults. So we actually wanted to be an LP with them, so that we could actually ascertain, like, what are, how are your—how are your services impacting older adults? And really use those. I mean, ultimately, we have a policy team at the SCAN Foundation. Can some of those insights be translated into effective policies down the road? That's one example. The other one is, you know, working with companies that don't focus on aging, but they have portfolio companies that touch older adults. So doing even side letters with those companies and saying, "We want to be able to work with you and understand how aging is being, you know, impacted through your portfolio companies." So those are some examples of how we're partnering with the private sector.

Richard Lui 25:11

And quickly, I mean, just to give a sense of maturity, or the idea to get to maturity, whatever way you want to define it, when you were at Kaiser, you were talking about teaming up, and I thought this is very—it's a good story that we all need to hear about when we think about the care economy and caregiving, at Kaiser you were working with 60 CBOs, and now, actually, my mom, in Northern California, is a customer of what you started six or seven years ago. And I was—we were talking earlier, and I was like, the services that my mom is getting from those CBOs is quite good, but you started it, what year again, when you—when Kaiser was working and teaming up with CBOs?

Sarita Mohanty 26:27

There's always been—I was at Kaiser Permanente for seven years, and my focus was on care coordination and really advancing social health, particularly for Medicaid and vulnerable populations. And what was really interesting is, you know, we—Kaiser has done a tremendous amount of investment in communities through the community benefit or community health arm, but at the delivery level, there seemed to be this wall between what was going on clinically—and I'm also a practicing physician at Kaiser. I'm still—and I would see that it was really hard to be able to say, okay, if somebody has a social need, whether it's food needs or housing needs, how do you connect to those community-based organizations? So when I was involved in the launch of a program at Kaiser Permanente called Thrive Local, which was really trying to build a platform where social workers could refer to community-based organizations, but it requires a really important partnership. You can't just be sending referrals through an electronic system. You have to understand what their capacity is and what their services are. So it's been a whole effort, and admittedly, I left in 2021 to run the foundation. I know the program is still going, but to your point, we really have to recognize the value that these community-based organizations do, and particularly for caregivers. I mean, you have companies like organizations that are offering tremendous navigation services and connecting the dots for so many caregivers and their families.

Richard Lui 27:59

And the point that I wanted to draw out from that is, and since Bechara can't be with us, you're now the Kaiser discussion point. And again, he can send, he sends his love to all of us in our conversation. But the point is the investment in 2020 to 2021, still is flourishing, is the point, and that it takes years of investment of learning and relationships that works in integrated care like at Kaiser, one solution, right? We're talking about care economy.

Sarita Mohanty 28:31

Well, and it also just it helped us really start to think beyond just this platform. Talk about the fact that we're not just talking about clinical care here. We have to talk about the total health. If Bechara was here, he would talk about the total health of the population, the social, the physical, the emotional, those types of things. And that really engendered a conversation and then some action over the years.

Richard Lui 28:52

Yeah. I mean, it also brings in the complexity that you're describing. Talking about complexity to you, Les, on this is that, as from your foundation's perspective, and as you've said in the past, it is caregiver and caregiving recipient. They must be seen as one and treated as one—basically whole patient, or 360 views of the way you might approach that. How have you applied that?

Les Biller 29:14

Well, we're, we're applying it in several ways. We're trying to understand what are the big obstacles to a patient and a caregiver in terms of really feeling empowered and part of this journey, where they're not just getting "here's what you've got to do" and doing it, but where they're involved in—there are several places for goals of care—is an important part of this. This is where you sit down when, not long after you've been diagnosed, and the doctor said, "Here's what, here's your situation, here's what we're going to be doing for you. Tell us about your goals for your treatment (not that you're going to die or or what have you), but tell us about the goals for your treatment." When that happens, the caregiver and the patient feel empowered, and also the caregiver hears what the patient is saying, so that if things progress down the road, they know what was the desire of their loved one, and they can act more freely accordingly. But there's so much going on in this field. It could be in employers, you know, employers who are at the forefront of this have care coordinators in their organizations who basically—

Les Biller 30:30

You know, we're seeing it more and more as we're starting to talk to more and more employers. They may not call it what I'm calling it, but they have someone who's doing that kind of stuff. And as I said, in a corporation, you've got both the patient and the caregiver as employees, and so that's trying to make it easier. I think the thing about supportive care is to help the patient and the caregiver address what's going on in this cancer journey. And we like to say, if it's done well, you live healthier with cancer, and we've seen this over and over, that if it is done well, patients thrive more, they're in the emergency room less, and that affects the caregiver as well. Let me just give you a point there. If we're dealing with symptoms, which is part of supportive care: if you're depressed, getting you counseling. You're in pain, getting you pain management. What ends up happening is the patient doesn't end up in the emergency room as frequently because those symptoms are not getting to a point that they're so acute that they have to go to the hospital. And part of this is try to manage those symptoms and be proactive and give the patient and the loved ones a resource that they can call and and get advice on. And so this makes a ton of sense. It just is the right way to be doing these things, and we just have to make it a national standard.

Richard Lui 31:32

How often have you seen that?

Richard Lui 31:53

Alex, you—we've done this before. You have an app, and we can go through it, and we can self-analyze. You should check it out later. There's a QR code, I think, somewhere around. If not, we'll get it to you. But you've started to bring in data on folks, on where they're at, what type of caregiver they are. What are the touch points? What are the key levers along the way? What have you learned from the data that you've gathered so far with all the different client sets where you're trying to say, how are you as a caregiver? How are you doing at the moment? What have you learned in the data?

Alexandra Drane 32:30

Can I make two other quick points? First, I know, I feel you. Like two quick ones. Okay. Number one, Jaelyn, I just want to say I was a cashier at Walmart for 18 months, so I could sort of have a different experience. And so many of my coworkers were in intergenerational families that were living together, and on any day, an eight-year-old, a 12-year-old, a 16-year-old, would be staying home from school so that other generations could be working. And so we saw so firsthand, and one of the things I'm really excited about is states like Rhode Island and Florida are beginning to have as a regular question to ask in some high schools, when they start to see somebody and they'll be like, "oh, you're a truant. You're not showing up at school." What if we flipped that and said, "is something else going on?" Because when they do, then this unpaid caregiver, who's whatever age, suddenly—not only do they get tapped into support so they can go to school. We know the longterm economic implications of somebody getting educated. But on top of that, this kid goes from feeling like, "I'm the only one, I'm a loser, I can't do well at school," to everyone be like, "dude, you rock!" And I'm in that role too. And then these schools are helping these kids get placed in jobs with the skills they learned because they were unpaid caregivers. So I think there are bright spots on that and the other one, really quickly, when we talk about M&A and the care economy, when is that M&A dollar gonna flow to that unpaid caregiver? Because it goes to the companies that are like, wait, look over here. Big, fast-growing market. Let's go make money. But still, here's the unpaid caregiver who's not getting their dollars. So when I think about opportunities, and I think about somebody like a retailer, unpaid caregivers, their basket is 70 percent bigger than their food shopping basket because they're buying food for their people. If I were—I don't know Walmart or Kroger's, you name it—I might give 10 percent off to someone who was in this role, because I want them to be loyal to me, and I know how much it matters. So, very quickly, we put people in clear yellow or red. We call it intensity, not burden. Please never again say the word "burden." If my dad ever thought he was a burden to me, he would literally walk off into the woods and he would never come back. And he's not a burden. It's intense, intensity of love, of fear, of effort, of anguish, of, you know joy and exhaustion all at the same time. So right now in the US, 29 percent of people are in the red. If you are in the red, yes, 90 percent of us have mental health impact, 50 percent of us have a reduction in productivity. We are costing the system four times more.

Richard Lui 34:58

Has it ebbed? Is it going up higher in some of the categories? Are we going more red? We going more middle? What's happening in the last year?

Alexandra Drane 35:04

So before COVID, it was 8 percent; as of COVID, 8 percent. Remember the good old days for unpaid carriers for COVID? Then it tripled to 24 percent. Since COVID, it's been between 24 and 32 percent on average. And you see spikes when there are massive weather events. During the election, it didn't matter if you were in the 49 or 51, you were stressed out—if there's a fire. The other thing that we see is population. So let's say I'm caring for somebody with Alzheimer's or dementia or cancer, much higher on average. If I'm caring for someone with a stroke, on average, 66 percent are in the red. We used to really focus exclusively on those who are in the red. And what we do, by the way, is run unorthodox campaigns that use strength-based language: do not say "caregiver, curiosity-based, and omnichannels." We're shameless hustlers that way. Then when we get them, we help them get their score, 79 percent before they get their score. Like I'm not a caregiver, 79 percent on a Likert scale of one to five, or a 4.2, and then that serves as a priming mechanism. Takes two minutes, and then we match them to resources like what you're talking about. Employers have resources that already exist. I'd like people to spend more money; if you don't want to, just unbundle what you already have under your EAP. Health systems have things to support unpaid caregivers. We've just got to make sure they realize they're in this role. Match them over those resources. And then communities, as you know, have beautiful things. All this stuff exists right now for free, if we can help get people to it.

Alexandra Drane 36:34

I think the thing that gets people more than anything else is when we when we say data like "unpaid caregivers are increasing their use of drugs and alcohol at four times the rate of everyone else to self-medicate and to cope." Unpaid caregivers are self medicated with food. Fifty percent of us do. Unpaid caregivers were in the red, 54 percent. I'm going to say something naughty because, you know, I like that topic, but it's because it's real. They're impacting their sex lives, right? They're thinking they're going to have to quit. If you're a sandwich caregiver in the red, it's over 60 percent, and the reason I love data is because we'll have people say to us, "I gained 70 pounds and went on antianxiety medication, and I thought it was because I was (insert every derogatory thing we say in our mind); you're helping me realize I'm actually beautiful. What I'm doing is incredible. I look forward to yoga and jogging, but until I get that, I'm going to stop beating myself up and I'm going to say to my partner, it's not that I'm not madly in love with you. It's at the end of the day I've got nothing else to give." And so when we share this data, so folks know you're not alone in this, you don't have to add this additional thing to something you're failing at. Instead, you're actually doing something gorgeous. Then people start talking about it and sharing it, and that's how culture changes.

Richard Lui 37:19

What number do people hear? There's a lot of numbers there, but what's the one number people hear?

Richard Lui 37:50

I see your comments and questions. We're going to get to it very soon. Jaelyn, is there a number or—that you share with other young caregivers? You tell them, hey, there's 63 million of us out there. Or what's the way that you're able to reach other caregivers when you're talking to them, if you only had like, one sentence, do you put a number into that conversation at all?

Jaelyn Smith 38:11

Not really. I would probably go based off of just, like, experience. So I mean, if I'm talking to somebody that has been through the same thing as me, I would just let them know that they're not alone and that there are way more. Like, I don't use a number, because sometimes it's hard to kind of see that, because, you know, as we know, like, there's not that many spaces that are known for young caregivers. So I would just let them know that they're not alone, and even if it feels like they are, that they have so many other people that are going through similar things.

Richard Lui 38:39

What is it when you are reaching and, let's say you're speaking and you've used different stories and different points that you've made, what is the message that really gets to other young caregivers? How are you really able to bring them into the fold that they're seeing?

Jaelyn Smith 38:58

I'd probably say that I always talk about how the most important thing that I've learned is patience. Like I said, my dad was a very independent man, like you could not tell him "no," he would always find a way around it. But knowing that, trying to be there for him when he's going through this, because, I mean, it's hard for him, it's hard for him to know—like to not understand what people are saying, not recognizing people's faces even though they're around him all the time, and just knowing that he's having a hard time dealing with this diagnosis, too.

Richard Lui 39:30

Sarita, since we're talking about numbers, we were talking about pair codes earlier, we really wanted to get into that, and she brought three. We're not going to go through all three of them, but we're we were saying we should have, you know, I have a bill. You remember that series, We Need To Do Something? I have a pair code to show the life of a pair code. That'd be very helpful. But let's bring those two together: Idea of pair codes and caregiving. As you were looking through pair codes related to this space, what did you learn about pair codes and caregiving?

Sarita Mohanty 40:02

Yeah, well, I think, first of all, I would just say with caregiving, you know, first of all, it is a public health issue. You know, we screen for hypertension, we screen for diabetes. Why aren't we effectively integrating and screening for caregiver stress, anxiety? I mean, we know that caregiving is this act of love, but it is primary care, the medical, the health-care system. Yeah, I have my doctors but, and I—you know, I have a number of stories that reflect where, you know, for example, you know, I saw this patient, actually, this woman, I'll call her Angela. She's in her mid-50s, caregiver of her mother, who has Alzheimer's, and she's sitting in the corner of the urgent care room where I was seeing her mother. And I mean, she looked really stressed. And I looked over as, are you doing okay? Is there anything you need? She was like, "Well, first of all, I have two jobs. I came from a rural part of LA, like, outside of LA, so it took me forever to get here." And she's like, I just—"and if you ask me about my medical care, don't ask, because I don't have time to be a patient." That's what she said to me. And so my—the point being, is we have, there are codes out there, you mentioned—but there they haven't been. There's not been a lot of uptake. It's hard to manage how to integrate. Like, one example, it's 96161, I think this is CPT code. And if I mix up the numbers, I will. But it is a code that, it's screening for depression of caregivers. And I looked at it, actually, when I was reviewing codes. And actually it, you know, it takes about 15 to 20 minutes, they say, on average, and they have certain specifications of who can do the screening. It's hard. I mean, if I have a 20-minute visit as a physician, I'm not going to do that. So you've got to really rely on a multi-, you know, disciplinary care team, you know. And it probably has to be somebody who can—who can take the time and address some of these issues. That's one, for example. But there, there's actually a caregiver-training code that started happening through CMMI, the Centers for Medicare and Medicaid Innovation. I think CMS, it was last year and actually that is—also the uptake has been slow. So I think we have to be figuring out education on this.

Richard Lui 42:04

The codes are just as complex as caregiving.

Sarita Mohanty 42:04

It really is but it has to be part of the norm. Yeah, it has to be part of the norm.

Richard Lui 42:25

I love that he's talking about pair codes, right? Yeah. All nerding out on it for a moment. I have to ask about and I want you all to go quickly on this one before we get to the questions and comments from the iPad that all of you put in, as well as those who might be watching remotely, and that is, I am fixated on data. I'm part of a project at the University of Michigan with the medical school, the business school as well as the engineering school, looking at the last three feet of care and data. So I want to know, if you have any group of data, what would it be related to caregiving and the care economy? What's that like? I'm just going to give it to you, and this will help, what you care about, in your space of the care economy, thrive. Who wants to go first? I'll go, since you're sitting here, Les, and you're nodding, and go quickly though.

Les Biller 43:20

But I wasn't nodding asleep. I was—so there's, you know, there's wonderful data out there, and it affects—what affects the patient, also affects the caregivers. So 50 percent of emergency room visits are preventable for patients with cancer, and the way that happens is by having supportive care. Imagine a 50 percent: you're never going to get it all, but that's a huge number, and nobody goes to the emergency room as a Saturday-night date night, right?

Richard Lui 43:46

No, they don't. But if I could give you any data that you don't have right now, what would you want?

Les Biller 43:59

The data that I'd want would be the impact of—on employers, of caregivers who are not being productive because they're stressed and going out and dealing with—

Richard Lui 44:15

Based on disease path, based on age group, based on profession—

Les Biller 44:19

What do you see as the employer? Because they're seeing it in terms of turnover, they're seeing in terms of productivity, and absenteeism. So having that information will help make the case for what we want to see happen.

Richard Lui 44:37

This is my indirect AI question, Alex. What is the data set if I could give you—if I just said, "Hey, you can have it," what would it be?

Alexandra Drane 44:37

So we have a ton of data on everything we have control over, like, we can get access to, which is what percent of folks are in this, everything's published, blah, blah, blah. What we don't yet have is a partner who is like, "I'm going to give you the claims data that goes along with it." Because in the end, I can tell you that caregivers in the red cost four times more. I can tell you caregivers who feel supported cost three times less. I can tell you that in New York state, as one of our partners, 27 percent of folks who are in the red get out of the red. I can tell you that's a five to one ROI, but until it appears the health-care system is obsessed with, but what is the actual clinical cost? Now, I can tell you there's a lot of other costs you're not measuring, too, like how much time it's taking, or broken marriages, or all these other things that actually cost a lot of money to society. But in the end, anyone here who's got a clinical data set that wants to partner with Archangels so we can push that, chase that dollar, to the ground, that last three feet, three inches, we are all in to do that study.

Richard Lui 45:36

I like this because so far, I mean, I'm noticing in this session this year is at, it's like, caregiving church. I'm hearing a lot going, oh yeah, okay, yeah, let's go. Every time we're going through a question, you're getting, like, positive reinforcement. Appreciate that. By the way, my dad's a pastor. I always bring this up. Sarita, if you have any data set, what would you—let's give it to you, what do you want?

Sarita Mohanty 45:56

Yeah. So we are working, and I want to really call out and am really pushing for that—we can't. The quantitative data is critically important, and we need to have that, but we also need to pair that with the stories, the lived experience. And, you know, I've shared a few anecdotes. One of them came from a platform that we developed with the Public Policy Lab called The People Say, and we have over 150 participants in about 11 states, representing 11 states. Now, why is that important? Because we are about how do we ultimately influence the hearts and minds of policymakers and make informed policy solutions? So this database allows you to go in, and we're just starting here, we want to build this. And I've talked to Alex about this too, is we want to be able to say, like a legislator could go in, and it's tagged, all these stories, all the interviews are tagged. So if I want to, I'm in the state of Alabama, and I want to look up transportation, I can filter by that. And actually, you can then look at stories, and you can go by caregiver, and you will see numerous stories from caregivers talking about the things we have all discussed today on this panel. So I mean, Jaelyn, I really appreciate what you said about, you know, that those experiences are so important. And I think that's going to—you know—and I'm seeing this more and more: people are saying the quantitative data is not enough. We've got to be asking, because there's too much diverse perspectives and experiences, and how are we going to capture that without those data? So that's—that would be my—my call is, you know, creating this and we're doing this for older adults and those with disabilities, including their caregivers.

Richard Lui 47:38

You're talking about 'stories are just important as data, and they need to work together,' right? And you need to give the tools to lawmakers who need to tell stories to their constituents, to be able to center in Washington, DC, to be able to bring home what they might be doing in policy overall. One of the things that is happening in the last year that's, I think, breaking good, is that we have more stories coming out. My good friend here with caregiving, sitting in the second row, and I see you with Bradley Cooper, is a good example. We're getting Emma Willis, who's also here with us as well, is fantastic. These are all stories that are now coming out in a major way. So I agree with that sort of parallel that's breaking good in the last year. Jaelyn, for you on this, if I could give you any data in the world, what would you ask for?

Jaelyn Smith 48:26

I mean, I would say, going back to the whole idea of like youth caregivers knowing about spaces for them, spaces that they can show up in. I would want to know how many youth caregivers know about these spaces, and know that there are spaces for them to talk about their experiences and talk about their stories.

Richard Lui 48:45

Great. I'm going to get to the questions now. I'm going to read three questions, pick one to react to. Pick only one and do that in 30 seconds. All right, I want to make sure to get a lot of good comments. I know all these restrictions. What's happening here? What role do breakout AI startups in this space? What do they have? Orgs like, is it Dina or Lana Care? Is that right? That's one question. What in your view, is the potential role of technology, specifically AI, in caregiving? And let's stick with those two. Any reactions, first off, from anybody? Go.

Les Biller 49:29

Yeah, I think there's a important role for AI for caregivers. If you think about it, if you had access to information, let's say a website and it would tell—you'd put in one time—what kind of cancer you have, where you're being treated, what your zip code is. And all of a sudden, it would provide you with all of the resources that are in your zip code for what, and whether they're paid for or not. Those kinds of things can be enormously powerful for caregivers, because they're doing most of the research for the patient, right? They're having to try to find, how do I help my loved one? And so I think AI is going to play a big role in helping us simplify that process.

Sarita Mohanty 50:13

I'll just say, you know, and we talked about this, Richard, so, you know, I think about, there's a lot of AI ambient technology for providers now. So if you're interviewing or seeing a patient now you can—with AI, you don't have to type your notes as you're speaking to the individual, the person. And so what we were talking about, where I think AI is already doing this and it's going to continue to get better, is what it does is once you're finished with your assessment, your history, and physical, it actually will create a note for you. And you obviously have to review it before you put it in the chart, but what it ultimately has is like starting to tell you codes.

Sarita Mohanty 50:25

Imagine a world where that caregiver, Angela that I spoke to sitting in the corner is saying something, and it is actually identifying caregiver, financial health or stress or intensity, right? That's as you call it. So how amazing that would be. I think that is going to be revolution.

Richard Lui 50:53

That woud be awesome.

Sarita Mohanty 51:08

Apparently I didn't know I was and so I prepared for this.

Richard Lui 51:08

You are our payer code sherpa today.

Richard Lui 51:11

Any other AI responses?

Alexandra Drane 51:18

I would say, go—you go first.

Jaelyn Smith 51:21

I've actually a more personal note. I've actually used it one time, or a couple of times, relating to my dad. So my dad is a very busy person. He's always walking either up or down the stairs. We used to have the sort of issue of, like, leaving the house and just wandering. But I've been able to use it, and I've also helped my mom use it as well. It's kind of like putting in your situation into, like, detail, like going into detail about what your situation is. And I've been able to get a lot of suggestions of things that we can do, for like places to go, things to see, what activities that he can do at home. And it's just been really helpful, especially since it's just me and my mom at home.

Richard Lui 52:00

Do you feel that your chatbot connected to the LLM, whichever one you were using, is that another friend in the conversation about caregiving? Do you see it that way? Somewhat?

Jaelyn Smith 52:13

It definitely could be. I definitely feel like not only can you use it for that, but you can also use it for like advice, or like just like to talk about like, certain things, because, like, I said, like, there's not too many, not a lot of youth caregivers know about these spaces, but being able to have such direct access to something where you can easily ask a question or talk about something I feel is really helpful for anybody.

Richard Lui 52:38

The reason why I asked that I was, convened a meeting at Penn yesterday about the care economy, 10 different researchers from different spaces, and one clinician was saying that they're playing with that very idea, taking chatbots, putting a super, super wrapper on it, if you put an AI wrapper on top of it, and it becomes like another person you can talk to, if you will, a person about something that's very complex, and there's been positive outcomes for not only caregivers, but also patients. That's why I was asking you that. So you're right in that space. You've got something on this.

Alexandra Drane 53:12

So I'm 54, and I've been in health care, in health, broadly defined, my entire career. We got to get the right message to the right person at the right time in the right setting. We've always said that I feel like AI lets us do that to 11. You know, what hook is going to get me? AI will do a really good job feeling, you know, Alex always responds to something slightly scandalous. So what about that? Can we use in terms of getting her signed with caregiving? What are the resources that are available for me right now, fully paid for in whatever context I might be in right now? Which of those places that you're hooking me over to are working and are not working? And I think on top of that, when we think about the ability to feel less alone, whether it's through a chatbot or just feeding me the data to see other people, and we're turning that data to whoever has the power to make decisions to get more money here, the only thing I'd ask all of us and all the companies that we're building to do this, please stop yourself every day and say, but what's in it for the unpaid caregiver? Like, what are they getting out of this new technology? How is what you're doing with AI, that's super sexy, by the way, and your valuation just went to 85 trillion, but how is that increasing the value that's actually getting lived by that unpaid caregiver who's doing the work that's creating all this value?

Richard Lui 53:12

Who asked that question in here, by the way, back there? All right, great. Yeah. I mean, I was talking about that group that gathered at Penn yesterday: multimodal data in caregiving. It's a treasure trove, and we just don't have enough of it. They all, like three or four of them, stood up in the middle of the conversations, and that's what we got to get, and that's the opportunity. And I think bringing in big thinkers—like the Fei-Fei Li, the ImageNet teams, if you will, that her team that did it before, bring them into caregiving, and they were really excited about that when they're looking at AI and what it could mean for the services and the products that might come from this. I'm going to move to, we got five minutes, and I'm going to ask some more. But first and foremost, amazing personal story, Jaelyn—did you write that, Alex? What does the panel see is the future of caregiving? How do we solve this so that things will be better in the future, public-private partnerships, which was discussed. Where is the magic here? I'll add one more question into this. How can we, number one, get employers to pull back on return to office policies. Number two, get providers to acknowledge they have two patients. The caregiver is often seen as only the transportation to the appointment. So again, the invisible caregiver, and I'll throw one more in there. [Inaudible]

Sarita Mohanty 55:46

Oh, that's hilarious.

Richard Lui 55:47

I guess we don't [inaudible]. Who is that?

Alexandra Drane 55:56

No, but that's probably someone's child or mother calling for the 80th time.

Richard Lui 55:59

Les mentioned the immense savings opportunities of expanding supportive services. Even though we have this data and proof of concept, it hasn't been widely adopted. Why do we think that this is the case? Why has it not been widely adopted? So three questions, who wants to go first—30 seconds, please.

Les Biller 56:17

I'll go, okay? Widely adopted [inaudible] I think the reason it hasn't been widely adopted is because too many people have a stake in each of these issues. An insurer may not want to adopt it, even though they know the cost is going to go down, because they're spending the money today and the cost savings are two years from now, and an insurer told me that patient who I provided those services to won't be one of my insured lives two years from now. So those are obstacles, whether they're really legitimate or we should be able to overcome those. My feeling is everybody who has a stated obstacle, we should take seriously, and then figure out how we go around that, and not by goring that person with that obstacle, but basically providing a solution that doesn't challenge the issue that they have. That's why we're looking at employers, typically, because they're the insurer and the employer.

Sarita Mohanty 57:17

Okay so I, actually, I think one of the things is that when we think about the health-care systems, there's an opportunity, because they stay engaged with caregivers all the time, right? And yet they're not capturing the data and not seeing the fact that a lot of the reasons for the caregiver stress or intensity is causing avoidable high cost utilization because it's hard to manage. So there's an opportunity for the provider system, and the end-payer system, to collect these data, whether it's through EHRs, through screenings. Obviously, you have to have incentives to be able to do this effectively, but I think there's a real opportunity that we—to really understand that space.

Alexandra Drane 58:01

You asked us what our what our word was, and I was going to be apocalyptimist. Because I think you have to recognize that apocalypses can happen. So that you can be optimistic about doing something. We're not going to have a choice about dealing with unpaid caregiving. It's coming. The demographics are there. So you can be somebody who, like, admires it until whatever you're doing gets screwed by it. Or you can be someone who's like, "wow, what a gorgeous population!" I'm going to serve it, and in so doing, I will further whatever that is, because there is caregivers—are over 40 percent of us, each of you right here, has the ability to start thinking about the unpaid caregiver and figure out, where can you make money on that or not lose money on and save the planet process?

Richard Lui 58:36

Jaelyn, there's a question here about hidden helpers, somebody from the Dole Foundation here in spirit. Okay, there we go. All right, raise the hand. So the Dole Foundation focusing on hidden helpers, young caregivers in military families, and a really important part of our population, actually a big, bright North Star, to be honest, when you are out there and you're talking to other young caregivers, do you encounter those that are in military families. And if you do, what do you say to them? And what do you think about young caregivers that are aged five to 17 in military families?

Jaelyn Smith 59:10

I mean, I haven't met anybody that was a part of a military family, but I feel like, I mean, it kind of just goes to show it adds on to the whole idea of that, like caregiving, especially as a young person, takes a lot of effort, and it takes a lot of energy, and there are so many things in their lives that are important, not just the caregiving, but also these other things, like the school and whatever other events that they're doing, and so kind of, like going back to what I was saying, like there needs to be some type of flexibility and leniency when it comes to kind of like what you said, like these schools like allowing—or allowing certain things to just, recognizing that it is going to be hard for young caregivers to kind of like do what they're doing, and also like balance it with their schoolwork or their, you know, work.

Richard Lui 1:00:01

Last question, and this is what gives you hope in this space? What? It's a could be a business model, it could be a person, it could be an idea. But what gives you hope in the care economy, in caregiving right now? And I'm going to start with you, Alex, 30 seconds, please.

Alexandra Drane 1:00:18

Every single person in this room, this stage, reality gives me real hope, because humans are survivors in the end, and we are going to have to get through this. And we can get through it with grace. And I think we will, in the end, using data, using stories, those two things married together, the fact that we're beginning to, with intention, sustainably, scalably, marry this story with the data. Nothing changes if you only have one.

Richard Lui 1:00:41

Any business models, any companies that give you hope?

Les Biller 1:00:47

Well, I think the fact that everybody's here today talking about this subject gives me hope, because it wouldn't have been talked about this way five years ago. And so the conversations are happening. People in this room who are caregivers are part of those constituencies that we're trying to bring together to find solutions. So I'm encouraged by this, and we're going to keep working as hard as we can to make this a reality.

Sarita Mohanty 1:01:13

Yeah, I'm also, I mean, similarly, just the fact that we're having this conversation, that we're actually trying to think about the caregiver, the breaking point as an opportunity to really identify system change, policy change, really making sure that their voices are heard and that we're looking at all the data to really make sure we affect sure because I think in the past, they've been put to the sideline. As I said.

Jaelyn Smith 1:01:36

I agree with Alex, I say that everybody in this room gives me hope, because it shows that people are able to advocate for themselves and advocate for their loved ones, to make sure that there is some type of acknowledgement that caregiving is important and is essential, and not just something that, you know, you just want to do for fun.

Richard Lui 1:01:39

What gives me hope is that we're being more complex in our thinking around the space, being much more complex. And that's really, I think gratifying. How many caregivers are in the room? This session was for all of you and all everybody else as well, because you will be a caregiver, or someday need caregiving. So thank you all for joining us today.