Daughterhood the Podcast

How Policy Affects Nursing Homes with

Anne Tumlinson and David Grabowski, Ph.D.

• 47:05

David Grabowski, Ph.D. https://hcp.hms.harvard.edu/people/david-c-grabowski

Articles referenced in this episode:

America's long-term care infrastructure: A road to nowhere – **Anne Tumlinson, David Grabowski and Robert Kramer** https://thehill.com/opinion/civil-rights/558029-americas-long-term-care-infrastructure-a-road-to-nowhere/

The Forgotten Middle: Many Middle-Income Seniors Will Have Insufficient Resources For Housing and Health Care – **David Grabowski, et al.** - https://www.healthaffairs.org/doi/10.1377/hlthaff.2018.05233

Who could benefit from widening Medicaid eligibility – **Marc Cohen and Jane Tavares** - https://blogs.umb.edu/gerontologyinstitute/2023/04/12/study-who-could-benefit-from-widening-medicaid-eligibility/

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Rosanne 01:09
Hello, and welcome to a bonus episode of Daughterhood the podcast. I'm your host Rosanne Corcoran, Daughterhood circle leader and primary caregiver. At Daughterhood, we hear your challenges in navigating the healthcare system and how it can be both frustrating and disheartening. In each of these bonus episodes, I have the pleasure of speaking with Daughterhood founder Anne Tumlinson where we will bring the caregiving conversation to a different level with change leaders and policy experts. I hope you'll join us. David C. Grabowski, PhD is a professor of healthcare policy in the Department of Health Care Policy at Harvard Medical School. His research examines the economics of aging with a particular interest in the areas of long term care and post acute care. He has published over 200 peer reviewed articles, and his work has appeared in leading peer reviewed journals of economics, health policy, and medicine from 2017 through 2023. Dr. Grabowski was a member of the

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Medicare payment Advisory Commission, Medpac, which is an independent agency established to advise the US Congress on issues affecting the Medicare program. Today, he joins Anne and I in discussing how policy affects nursing home quality, the fragmentation of payments in the long term care system, staffing requirements, accountability, and how to advocate for change. I hope you enjoy our conversation. I think we can all agree the long term care system in the US is broken. The support for home and community based services is meager the nursing home system, we hear a variety of things that will quote fix it more money from Medicaid, mandatory staffing numbers, removing real estate investors from ownership, more regulations, less regulations, the list goes on and on. David, I don't know if you can pinpoint it to one issue, but what have you found to be the biggest challenge in the long term care system?

David Grabowski 03:03
All of the above. So thanks first, Rosanne, for for having me on, I think you just listed a whole series of problems and the long term care sector, if we're really going to transform how we pay regularly deliver organized care in this country, we need to take on all those issues. I think it probably starts with with payment and financing. We have this fragmented payment system, I've written a lot about it and written a lot about it. It creates all these unintended consequences. And we under invest in Medicaid and push a lot of costs over to the Medicare program and to families in their in their caregivers. And that's really the point of this podcast, I have a daughter hood, a lot of daughters out there bearing these costs that the system can't handle and cover because of the fragmentation. So I think if I was going to start somewhere, I think all of those issues you raised, I'd also want to highlight accountability that we even when we do pay enough, those dollars don't always go to direct caregiving, they often kind of get siphoned off into other parts of these very complex owned companies. And I'll try to be kind there and saying that, but we know we have real estate investment trusts and in private equity groups and the dollars don't always flow to where I think we in the policy community would like them to flow. So really payment and then on top of that accountability,

Rosanne 04:32
And with the change in staffing that just came out, how do you see that? Is this a positive thing? Is this something that they've done? Almost to be like we're addressing it, but it didn't go far enough? Like where do you see that coming in?

David Grabowski 04:46
Yeah, I'm really glad you asked about that. This is something in an nosis. While we've been talking about minimum staffing standards, at least a federal staffing standard back to the 80s with the 1986 Institute of Medicine report. So first of all, you huge credit to the administration for finally doing this. That said, they're taking a lot of heat from both sides, I think industry is wondering how they're going to pay for this. A lot of advocates have said this doesn't go far enough, I can see both sides of that I had hoped that the standard was going to be a little stronger than it actually is. So just very quickly, it mandates a minimum number of RNs, registered nurses and a minimum number of certified nurse aides. But it says nothing about licensed practical nurses. And so overall, we get a pretty low overall hours per resident day in terms of total staff. Implementation is also pretty, pretty slow here, some of the provisions won't be implemented for three to five years. And then on top of that, there's a lot of exemptions built into the rule. So I really worry about how much this is, this is going to move the needle.

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And I want to go back to the prior question. I started with financing and accountability. But I really think low staffing is a huge problem. But it's not the root problem. It's a symptom of a system that's broken. And it we need to take on this entire system. So the reason why we're going after staffing is because for years, I think we underfunded and not held nursing homes accountable. So finally, let let's let's hold their feet to the fire and ensure that there's a minimum number of staff in these buildings, but we still have a broken financing and payment system, we still have a broken oversight and regulatory model. There's a lot of work left to be done. So I hope the minimum staffing standard is the start not not the finish line.

Anne Tumlinson 06:40
Yeah, it's a little bit like I was trying to think of a really good metaphor, but I mean, it but David's been quoted, and I love this quote, which is that, you know, it is this, it just to restate, its this is not, you know, the staffing isn't, isn't the root problem, the problem is really the money, you know, that we're making available for, for care in this country, relative to the people who needed and the level of care that they needed. So I feel so sorry, in a way for the administration, because they are between a rock and a hard place. And they are, you know, getting no credit for doing a really hard thing. And trying to but but this is this is the worst time to try to like we're at this would have been really good if we could have done it 10 years ago, and then we would have been in a position to say, hey, you know, we don't have a pipeline of workers, that will, you know, we the injuries, you could have had a chance to prove that they could meet the standards, we could have had higher standards, and then we could have been in a position to say, we don't have the funding or the pipeline workers to continue with this level of care. And then maybe we could have gotten more into root cause. But we're, you know, we're really not there. And, you know, I think one of the things that I've seen policymakers really struggle with and I struggle with a little bit is like, Okay, I have sympathy for the nursing home operators, who can't find workers and are getting paid what we know, like a Medicaid daily rate is less than a holiday ends day. So you know, I get the challenge there. And, and yet, at the same time, we know that there are owners in this industry making a lot of money. So it's, it's so I think the frustration is to David's point, it's like how do we, you know, how do we divert that money into into wages that might actually attract staff, and one of the ways that they're one of the main ways they're making money is through this thing called related party transactions. So it's not, ya know, the Medicaid rates are low, but they're all these people living in a building, and those people use a lot of health care. And that helped those labs, prescription drugs, you know, PRP therapy, primary care to some extent, you know, so there's all of these things, and sometimes these owners, and this isn't necessarily a bad thing. Let me just be clear, but there are lots of different companies that are making money, and sometimes they're owned by the same people. So that can actually be good because it can deliver coordinated care. And if that's the way they make money, like we you know, it's not like Medicaid, state Medicaid agencies are gonna be like, You know what, let's not do that. And let's find this fully instead.

David Grabowski 09:53
So, yeah, it's absolutely complicated. And you describe this tension well, and I think Uh, I always, like when I first read the policy, the exemptions really jumped out to me because like, that just shows you how broken this is if you can't find staff at the existing prevailing wage levels and payment rates and and just went theory, you know, Medicaid is not a very generous payer of services, you're exempted from this minimum staffing center. So wait, you're going to put residents in those homes at risk

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shouldn't shouldn't the policy be we're going to give you a wage pass through we're going to pay, we're going to give you more Medicaid dollars, something to help you find the staff now, you can just snap below what we think is a state, you know, a safe level, and a level that's going to produce high quality care that shows you how broken this is. And final comment and you're exactly right. 10 years ago would have been the perfect time to do this yet. It's sort of ironic that the reason we have this is because of the pandemic. And yet because of the pandemic, we have an even greater shortage of staff RNs want to go to, they've always wanted to go to hospitals and physician offices for higher higher wages. And they'll continue to do that CNAs are obviously working across the economy at Amazon at Walmart and McDonald's. They're making higher wages and the jobs can often be less challenging, maybe less rewarding. And I do like something the administration has done that I've never seen before. And they they put in $75 million for training, they use civil monetary penalty dollars to help train the workforce. That's so important. I've heard a lot on the industry side say that's a drop in the bucket. That's not enough money. But it is really exciting. We all know that we need to grow this workforce. That's that's a good start. I'd love to see more kind of loan forgiveness, childcare type type subsidies, anything to get folks working in these jobs. And then Alright, so that was a final point. I gotta cut me off here.

Anne Tumlinson 11:55
We could talk about this for an hour.

David Grabowski 11:59
But the LPN's I've always loved these latter programs that allow CNAs to graduate into that I'm worried if they keep the rule as is. We're not going to have LPNs in nursing homes anymore. It's going to be RNs and CNAs. And I think LPN is a really important, oftentimes, they're the workhorses in a lot of these facilities. So that's a part of the plan that if that, yeah, they need to be in there.

Anne Tumlinson 12:24
I don't know what I wonder what the rationale, I don't know what the rationale was for that.

David Grabowski 12:28
There is a report that was released last week, I guess that that showed, you know, in terms of the production of quality care, LPNs were less important, but I would still argue they're important. And I really worry, you're going to see a change in skill mix towards CNAs. And meeting just the minimum number of RNs and then fill out the rest of the staff. Yes, CNAs. That's not a good model. Yeah.

Rosanne 12:53
The, the problem, part of the problem is, it's the lack of focus on the residents. I mean, there are people that are living in these buildings. So you're talking about these numbers, and I don't think anybody that is making the numbers is actually thinking about the care that has to happen in these buildings. And, and that disconnect is a huge disconnect. Because that's, that's it, we're talking about people, and the fact that it's been 40 years, and I think it's, it's part of that we've all changed, we've grown up, and were different, the older generation accepted whatever they got, they just went along, and now we're coming up and being like, Wait, this doesn't work like this needs to change, I realized that this is how it's always been. And people are turning a blind eye to it. And now it's different. But the care that people receive or

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don't receive in these communities is is horrible. It's just I there's not a strong enough word for me to use. Right, you know,

David Grabowski 13:54
Couldn't agree Yeah, you're 100% on there. And the rules as they're currently written, they don't specify a staffing number, obviously, this, this new real rule will, but it says you know, your your to maintain your to staff at a level that maintain safety and well being of the residents and that well being parked there is going forward, really important. I think that's what you're driving at. It's about quality of care and quality of life. And we've all been in nursing homes that are understaffed, and you can tell the difference very quickly. And so, yes, a resident may be safe, but that doesn't mean they're well cared for. And I think there's a real gap there. And we have we have we have a lot of work left to do. And the final point here is that, you know, in the original sort of work by CMS going back, you know, 40 years, as you said, there was a lot of interest in time and motion studies and your point figuring out how long does it take to actually do that? I don't know how much CMS went about those kinds of studies this time with it's not just that the labor market is tighter today. The kind of person receiving care in a nursing home is much more has much greater needs today than they did 40 years ago. So the idea that we can rely on time and motion studies from decades ago and not even staff up to that level is alarming.

Anne Tumlinson 15:12
I was like, just thinking for a minute about the human being and that bad, you know, two hours or two and whatever, two and a half hours a scene like, like, think about all the needs a human has for the day to go the bathroom, to get dressed, to get showered to get fed, doesn't feel like enough time. And it is a weird thing, that we're going to talk about nursing homes this entire time. But the weird thing is that, so yes to everything you said yours. And I love tensions, obviously I like yes, but but the, but like, at the same time we hear from caregivers. And there actually is a young man on my team at ATI who is in the situation right now who are fairly desperate to find a nursing home bad because they've just the situation in the family. And this is somebody who can pay privately even this is the situation the family has become so unraveled, for a variety of reasons that they really need to have an institutional level of care for a particularly complicated situation in person. And, and they they haven't been able to find one they like. And so the administration comes along, and they put their staffing thing in place. And meanwhile, already these there are empty beds in this, this is a like a suburban like a outside Cleveland, Ohio, I think so you know, like semi suburban rural. They, it's they can't put this person in the bed because they don't have the staff to take care of him. And so like we this is not this is these are not good situations most most of the time, and then and yet families are somewhat desperate. We don't because if this gets maybe a good segue, like we don't have the home and community based system in place, right. And that's a harder, I'll just sort of chime in here and say, I feel like that's a really hard kind of boat to row because it's hard as it is to deliver services of that level within a facility where there are lots of people who can be served efficiently. You get people into individual homes, and now we're talking about getting caregivers into individual homes, interacting a lot more with the family and the family dynamic and all the family issues. And it's it's a challenging, it's a challenging thing, and we're doing it in Medicaid. And, but and David, you've recently written about this, but I you know, there's that's just we're just scratching the surface. I mean, the people, number of people being served in the community through Medicaid, which is the only other real payer out there, compared to the people who need those services. It's like, it's just a tiny fraction. It's just really small. So that leaves the nursing

home. So here we are talking about savvy standards, when really we should like it gets back to the system, the big system, Rosanne and the way you posed that question, originally to David.

David Grabowski 18:26
I couldn't agree more. And it's about balancing the system. And people always ask me, Why are you talking about nursing homes, nobody wants to go to a nursing home. I said, it's about building a strong long term care system. These countries in Northern Europe, like the Netherlands that invest far more than we do in the long term care, guess what, they also have nursing homes, they just have much better nursing homes, they're better staff. They're more home like, and guess what, on the other side of the fence, they also are working on the system in terms of home and community based care. And that's where they're really outpacing us. And there's hundreds of 1000s of people on waitlist for Medicaid. And I would imagine there's a lot more people out there that just haven't put themselves on a waitlist that need these services. So I think Kaiser Family Foundation had a number like 700,000 individuals on these wait lists. I mean, it really kind of makes your head spin and really kind of angers me. The Biden administration did try at several points to put dollars real dollars more dollars into Home and Community Based Care. They've largely been unsuccessful. I I would love to see us grow those services. You mentioned we had done some research recently, we looked at what happens when states invest in home and community based care. Guess what they do actually generate some savings for nursing home care, they draw some dollars out of their out of the nursing home side. So $1 spent on Home and Community Based Care actually saves 26 cents in nursing home spending. So it's not it's not free. There are no free lunches. You still got to spend money but it's a great way to grow the system and is what people want. So there is both that savings in terms of less nursing home use. But guess what, you're also getting care in the home. And that's what people really want. And I, and I sure you're still waiting to hear somebody say they want to go to a nursing home. Nobody, nobody. Nobody wants that. But I've heard lots and lots of friends and neighbors and colleagues and on and on, say, How do I get care into my home? Or having have my family member go to some go somewhere in the community?

Rosanne 20:28
You wonder, because that's everybody wants to age in place, right? That's the thing. I want to stay in my house, I want to age in place, but there aren't those supports. So when you look at this quagmire? How can we try to move that to support in a better way? People living at home? Because there there are gaps in that system? And there's, there's waste that's built into the system? So how do you how do you tease that out to make it actually productive?

David Grabowski 20:55
So two points, I'm sure Anne, I'll take the easy ones and and can take the hard ones are there actually, every one of these wouldn't have got it, they're all hard there are there's no low hanging fruit, we would have picked it. Everything's way up way up the tree. And it's gonna be hard. But the first is what I just said, spend more money like we under invest in these services, especially in certain states, let's give credit, some states have been ahead of the game, the Minnesota has that, you know, there are states out there that are really further along in terms of growing community based long term care. But there's other states that have been have lagged behind the other. And this actually goes back to a piece that Anne and I wrote with Bob Kramer, it's about navigation. First we need to build these services, but to

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we need to help families find these and I and I thought of our piece, just just earlier this week, I had a colleague, he's a physician, email me and say his mom was starting to look at services in the Boston area. Where does he start and, you know, very smart guy has some resources, but no idea kind of what's legit, what's not legit in terms of these services, which places are good, which aren't, he needed some some navigation of the system. And, and, and I wrote a piece in the hill called a road to nowhere. It's really like, we don't have, we don't have a compass. And we don't, we don't have anywhere to go with our system so that we both need to get some direction and help people kind of where to go. But we also need to be able to ensure that folks can afford these services. And those services need to be there. So and I'll pass the baton to you. And you can

Anne Tumlinson 22:30
Oh, no, that was great. It's funny, I have knee deep right now in writing a blog for Daughterhood about this, like what I'm calling kind of the meta question, you know, because it's like, it's like, Where do I even start? How do I start? How to it's like, where's the front door to the front door? It's the question about

David Grabowski 22:51
If you can find it. And I tell us, because I don't know that it's, where it is

Anne Tumlinson 22:55
I know, it's like the question. It's like, where's the one place you can go that will help with all of the questions. It's like the question about where to go for the question. So anyway, it's it's a, it's a hard thing for I think, a lot of folks to wrap their brain around because it's, it's not as that infrastructure is, is missing. There are we do have agencies and we do have, I think that many, many hard working amazing people in the public sector trying very, very hard to meet the need for that. But I had somebody tell me, and I'll get back to the bigger question was, I had somebody tell me, I won't say where there was a Department of Aging in a big city. And they said to me recently, we have some great programs to help caregivers, both in terms of respite and in terms of navigation, but we're afraid to advertise for them. Because we won't be able to meet the demand if we do. And I was like, so this. This is where we're at. This is where we're at that this poor, awesome person who's trying so hard. It's like, she can't be like, hey, caregivers, this is what we do. Here's who we are. Come here, and we'll help you because God forbid, all 1 million caregivers in this large city were to rush home. They would be having to turn people away. So so I kind of, you know, I feel like that piece is important in the in the funding is important and investing in in the services. I'll say just two things. One, about the services and about Medicaid in general is like I think the more we have a colleague David and I have a colleague, Mark Cohen, and he's doing I saw paper that he's either just published or is in draft and just how very poor people are, who have this need and live in the community and still aren't eligible for Medicaid. Like Medicaid really is not There are a lot and we call it a forgotten middle. And David's done a lot of work on this, it's, that is a big middle. Like there's a lot of people who are low, middle, and even not even middle, who are not getting services. And I don't know, that we got a note from somebody into the daughter had inbox one inch, you know, it was like her father's house was caving in, and it had roaches, and, you know, she, so she moved him into a trailer. And now there's all these expenses, and she doesn't have the money to pay for it. And this brings me to kind of the thing I want to make sure to mention, which is I do think we have to give when we're investing services, infrastructure, housing, so

we don't have good housing options for low, even middle income seniors, we have this very expensive world of sort of senior living and assisted living, and hasn't really figured out a financial model that will enable it to serve more people who are more of a middle income. And David's done a lot of work on this as well. So I think it's like the investments need to be in the in the services, the workforce, the infrastructure and the housing, you know, just everything, just everything. And you know, what we're not talking about at all is insurance. So we're not even talking about like, how would we pay for all of, you know, when somebody does have that need other than Medicaid, even if we could get Medicaid paid for more people, we still have all these other people, and how do we get the services? We don't have an insurance based system? And it's probably I don't know, is it too late? I feel like it's too late. We are baby boomers are already, like, the idea of insurances that you know, you buy it before you have the need.

David Grabowski 26:54
I think and I thought you're gonna met Marc's done a lot of great work. And one of his real areas of focus has been on federal long term care benefit. And yes, it's expensive. But gosh, all these gaps that we've been discussing need for community based services, paying the workforce, caregiver support, home, like nursing home care, those could all be addressed with a with a federal Long Term Care Benefit. Obviously, that's not the end all be all. But it's a start. And something that a lot of us have have advocated for, but it's expensive. You don't hear a lot of enthusiasm. And as Anne said, we're going to start doing this the time to do it probably would have been five years ago, 10 years ago, we still could, but it's getting dicey. And it's challenging. Washington state has obviously embarked on a program and they're, they're doing this and same thing you're paying in for a period of time to get this benefit. But it's it's, it's challenging to set up. I've wanted to also reflect down on this forgotten middle very quickly, these individuals who are we like to get to rich and quotes, they're for Medicaid, yet not wealthy enough to buy services out that are out there in the marketplace. That's the group that would really benefit from a federal Long Term Care Benefit. A lot of people point say, hey, we already have Medicaid, why don't we have public entrepreneurs? We do not. There's a lot of individuals that are falling through the cracks right now. And that's the group I think about when people say, Well, wait a second, doesn't everybody either self insure, and they can they can buy into an assisted living community on the wealthy side, or they qualify for Medicaid. And this is not a bimodal distribution. It is. There are folks at every point in that distribution in terms of income and assets. And unfortunately, given the Medicaid rules, there's a lot of people in that forgotten middle. In that paper you mentioned, we kind of estimated the numbers, and it's increasing with the boomers. And I'm really glad you raised housing because that's this like third rail that very few of us in long term services and supports even want to talk about or address and people tease me but there's a whole housing group on at Harvard's campus that we don't have a lot of interaction with, they tend to do their thing, we tend to do ours. And it's it's not just a Harvard problem. Like we have plenty of them. It's a it's a kind of a problem in our field of just how siloed we are about housing. There was a great piece in The Boston Globe this week about just there's not enough subsidized housing in this in this state and a woman who had gotten services sort of saying, I feel like I've won the lottery. It shouldn't be winning the lottery, it should be something that we're providing for older adults. Otherwise, as Anne said earlier, they're going to end up in a nursing home.

Anne Tumlinson 29:35
This is a really cheerful call.

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David Grabowski 29:37
I know if we haven't

Anne Tumlinson 29:39
Podcast I should say

Rosanne 29:44
No because it makes you feel like oh, well then what do we do and and I think part of that issue is people don't think about this. So in the in the general public idea, it's you're gonna pay for assisted living, not realizing how much assisted living costs per month, you're gonna go to a nursing home, again, not realizing anything that happens there, or you're gonna stay in your house. And that's the way it is. And then when they get into the situation and go, Wait a minute, this is too much money. This is not where I want to be. And then it's it's kind of like, I just, what do I do? And it's too late at that point, because there isn't that understanding. So what's the ask how do we fix this? How do we how do we break? Because there's a lot of there's a lot of branches on this tree. So what do we do?

David Grabowski 30:32
I think you frame that really well Rosanne, that when we do these surveys and other groups have done them where they they ask older adults or middle aged adults, like how are you going to pay for your long term care? They think it's Medicare, by the way, Medicare does not pay for long term care. And they're like, what does it cost? People don't have a good sense of what these services cost. And so they're all over the map. I think there's really poor information for middle aged adults about long term care. And a lot of them I think, go back to thinking this is a family issue, and we'll deal with it, you know, I'll care for for mom or dad or you'll care for your spouse. And yes, it's a family issue. But I don't think there's an appreciation of the idea that this is also a policy issue. And our old colleague, late colleague, Josh Wiener used to say this a lot that it's both and we really need to think about both the family side, it's always going to be a family, there's always going to be caregiving daughters are always going to be a part of these caregiving teams. We know that but how many of us know in our, in our in our 50s or early 60s that, hey, it's also an important policy issue. And we should be contacting our representatives. And we should be advocating for increased Medicaid home and community based service coverage, you know, starting on along the path towards a federal Long Term Care Benefit. Why is that the missing piece, you know, and we were talking earlier about fragmentation, all of our health care services for the most part are covered under Medicare. The one big gap, the largest source of kind of uncovered spending for older adults out of pocket spending is long term care. Why? Why did we choose to go this way, and these other countries actually have pretty generous benefits, like I hear I, unfortunately, I think we're the we're the ones that are not not sort of seeing the the real problem and how beneficial these services are. So I hope that we can, we can educate more more families, and this is where daughter had really is important, like really hammering home to representatives, this is a policy issue we care about, we want to advocate for increased coverage, increased benefits, living wages, for our caregivers, you know, Cash and Counseling support for family caregivers. And on and on and on, you said all those branches, this is I can't list all of them. But it we need all of that, that those services, but we need to continue to educate our policymakers. Because otherwise, I think it's going to continue to be this this, you know, forgotten middle who's basically these are families that are then going to have to

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figure this out themselves. And it's not going to it's not going to go well for most of us. So, you know, just we've seen this time and time again.

Anne Tumlinson 33:23
Yeah, I totally agree. And I would say, you know, one of the things that we are hoping to do in daughter hood more and more is to sort of hope we've even had a daughter head circle on how to be an advocate. How to, you know, working with our partner organizations, obviously, there are many working in this space. But I think we're all a little nascent, you know, family caregiving hasn't really been a, you know, I think we're, we're like a little bit of a Malcolm Gladwell tipping point, you know, I think as, as the over age, as we go with our older adult population, where we've had mostly 65 to 75 year olds, we're getting ready to shift in terms of the growth rate into the older older adults, and that there's just, I think, bam, you can sort of feel I think the momentum a little bit around family caregiving is like, oh, there's just more and more people being affected by this, and it's getting elevated. And so hopefully, as these all of these other organizations that have been in this space a long time are strengthened by that. We can work together and give caregivers a voice in the you know, in the policy conversation that that I think will resonate and what am I like mentor and guru of policy Chris Jennings was said to me, it was like how do we get the drug pricing law but not the Medicaid home and community based services and he's like, it's just because people were furious about drug prices, right? Like this is a redo Nicolas situation and constituents at the grassroots level, were just like, Are you kidding me? And it's, uh, my mom was, you know, asking about this the other day, and I was like it was mom, it was bipartisan. Like there was, this wasn't really I mean, other Republicans are complaining about or whatever. But really at the end of the day, nobody wants to go back to their constituents and be like, hey, you know what, we really want you to pay more for insulin.

David Grabowski 35:25
And that's great Anne but like, and I love that we're going down that path. But why are drug prices policy issue and family caregiving?

Anne Tumlinson 35:33
I know I know.

David Grabowski 35:34
It just blows your mind that we're not going to our policymakers and advocating for increased support for Family Care.

Anne Tumlinson 35:47
Sorry, I'm so sorry. I'm very excited. So

David Grabowski 35:51
No, no no, I want to hear you on this.

Anne Tumlinson 35:53
No, I think we have to build that bridge, just to your very point, I think we have to help people understand. It's not a personal and this is one of our big things at Daughterhood is in why people, I lots

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and lots of conversations about the name. plenty, plenty, plenty of people taking care of family members who are not a parental daughter relationship. But sure, but I have observed that women tend to encounter a difficult situation that is systemic, and say, Oh, I'm failing. This is a personal problem that I need to solve. And so what we want to begin to do with Sir, normalizing contextualize it, this is not this world that they've suddenly entered into is not a personal problem. This is a societal problem. And we even had somebody, I think, or one of our daughter hit circles recently say something so profound, she was like an F with the self care. Where's the community care? Right? I was like, yes. That's it, we have to take care of each other. And the way we do that is through our systems of government, and they're not so broken, that we can't, we can't make them work if we try really hard and to sort of help rap a little bit on a positive note. I mean, David, I'm excited about the dementia model. So the administration came out with this new model, they want to test on dementia care, and it's essentially going to pay primary care providers to deliver care management and navigational services. Now, I know primary care providers don't know how to do that. So just hang on, Rosanne know where you're going. Bear with me, they don't. But But what what these, what these with these additional funds will allow them to do is is essentially kind of partner up with organizations that do have those capabilities and, and essentially generate a revenue stream for that and keep it the cool thing about all of this is that, for the first time ever, CMS is recognizing that family caregivers can actually be the receivers of services and Medicare, which is like a very big, I'm sure there are a lot of bureaucrats who are just kind of biting their nails, because they're like, that's the Medicare Part was for Medicare beneficiaries. But we are going to actually pay for services that are directly going to be delivered respite, and other things that are really for the caregiver. And that is a big change and a big shift that, you know, shows that there's a recognition I mean, yeah, so

David Grabowski 38:38
I You said it well, that for the first time. I think caregiving is having a moment. And it's just at the beginning here of that moment. And that that policy by the Biden administration, wasn't it? Was this really representative of the start of that moment? I like supporting caregivers, like this is not your older brothers Medicare, right? That's not that's something you would never have seen. I just finished my stint on on Medpac. And like, I can't remember like the Medicare payment Advisory Commission sorry for the acronym but so we advise the US Congress are actually meeting today and I'm here with you. So I'd rather I'd service so this is a good way to spend the spend the day not not in DC in a government office building meeting, but rather talk.

Rosanne 39:27
Yeah, we appreciate you. Thank you. Yeah.

David Grabowski 39:31
But this kind of issue is not coming up six years ago on the commission. So it's really been a huge pivot. And it's incredibly exciting that we're starting to support caregivers and we're starting to think outside the box and maybe even I'll say this very quietly, maybe starting to fund long term care and Medicare, I guess, you know, we did some of this on the Medicare Advantage side, but maybe this is starting to creep over to the traditional Medicare side and so I it's it's very exciting. I think and maybe breaking some of those those silos down a little bit that we that we've traditionally had across Medicare and Medicaid and people paying out of pocket.

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Anne Tumlinson 40:08
Yeah, that might be the path. I definitely am. Like, I think of myself as like Robin Hood, you know, I'm like, we get the money out of the hospitals. Yeah, bring it over here and put it in this pocket. You know,

David Grabowski 40:22
I'm so glad you said that. Because people asked me that this won't be popular with your physician listeners here. So I'm sorry in advance, but or maybe those who hospital CEOs, if they're out there listening, maybe they're not. But that's where like, people say, Well, wait a second, you know, the Netherlands in these countries, you mentioned all the time that spend so much more on long term care, they spend a lot less on health care, that's how they do it. And my response is exactly we need to, we need to change our sort of national spending and kind of reallocate and our money away from medical care in the hospitals and towards families and long term care services and supports.

Anne Tumlinson 41:00
And yeah and another like, plug for, I mean, pat on the back for the hard working people at the Centers for Medicare Medicaid Services is that they did a take on the specialists in the physician world in order to create some of the money that we need to provide training services for caregivers, both inside the regular Medicare program and in this demonstration program. So like, good for that was clever. And I think they're gonna get away with it, and we're gonna, we're gonna be able to, we're gonna be able to do that. And that's, that's a, that's a, I think, for many caregivers out there right now who are dealing with this really huge sets of challenges on a day to day basis, it doesn't feel like much. And I want to be very respectful of that. Are you kidding me?

David Grabowski 41:50
It's but it's a start. And I think this hasn't been the most uplifting podcast in some ways. But this is a sign that things are are pushing in the right direction. And obviously policy is slow to catch up. But this is an area where as we continue to advocate and do research on these models, I'm certain that we're going to see an expansion i i One of my favorite quotes is from Bill Scanlon. There's, there's no reverse gear and health policy, and that once you give people something, it's really hard to take it away. And like the drug benefit, and Part D. And there's a lot of examples of, you know, once you do this people, people realize how good it is. And once we start covering their long term care and giving them caregiving support at home, guess what, they're going to become very reliant on these services, and you can't take that away. So that's my hope. Also, with a minimum staffing standard that as we get this in place, it's a start to a lot of reforms, but we won't go backwards.

Anne Tumlinson 42:46
That's a good point. That's a great, that's a great positive.

David Grabowski 42:51
We found it took us like 40 minutes when we got there.

Rosanne 42:55

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But I think as a dementia caregiver, the paying the primary care office to be that point person is huge. It's it's a gift because an all of the Dementia Caregivers I speak to, you know, you talk to them and you leave the office and it's like, well, good luck to you. Hope you can find stuff. Nobody helps you. And if there could be that, okay, we can talk to you, we can at least give you an outline of what you can look for, instead of getting in your car and driving away and being like, I don't know what I'm supposed to do with this. So that for me is even though it's little, that's a huge and, and that it feels like it's a turn like somebody's got to the right person to explain that this is this is something that needs that is that is needed. And so that that's a positive for me, so I feel like that's a win.

Anne Tumlinson 43:49
It's an it is a real thing, you know, unlike, well,

Rosanne 43:56
Oh boy, she stopped.

Anne Tumlinson 43:57
I'm just gonna stop myself this is real okay, this is real. This is real Medicare money going to caregivers and for me, so it's you know, is it I just want to emphasize this CMS did kudos like yeah.

David Grabowski 44:15
Absolutely. Anne you can have me back for a sequel podcast and you can wrote tell us what is it real money and we can think about that'll be our teaser for the for the next one that's right.

Anne Tumlinson 44:30
We'll, we'll just leave that alone.

David Grabowski 44:32
Leave that alone. don't don't some poor person has been working on that program and they're the best they can but yeah, there's there's a lot of examples unfortunately Yeah, underfunded and

Anne Tumlinson 44:42
Under and under attended, attended to.

Rosanne 44:47
So that so for positivity sake, going forward, actually calling your congress people and writing those letters and talking to people and trying to make your bring your story to them. And is helpful going forward?

David Grabowski 45:03
Absolutely. And I think it helps kind of personalize this for representatives who get a lot of data put in front of them from people like Anna and myself. And that's helpful. But I think the stories matter more, and I've had the opportunity to testify several times to Congress and I can say that the showstoppers in those hearings weren't people like me giving you telling you percentages or numbers, it was a family member telling her story about what happened to her mom in a nursing home, or what what happened

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caregiver, a CNA at a facility and what happened when COVID hit that facility and losing one of one of her colleagues, those are those are the stories that really resonate with with our representatives. And so I'm not saying there's not a role for data. There's a role for both and, and and I promise to keep writing papers, but great to have lots of people writing letters and telling their story to

Anne Tumlinson 45:59
Fully agree. Well said.

Rosanne 46:01
For more information about David Grabowski, you can find him on the Harvard Medical School website at hcp.hms.harvard.edu I hope you enjoyed our podcast today. Head over to Daughterhood.org and click on the podcast section for show notes, including the full transcript and links to any resources and information from today's episode. You can find and review us on Apple podcasts or anywhere you listen to your podcasts. We are also on Facebook, Twitter, and Instagram at Daughterhood the Podcast. Feel free to message me on any of these sites and let me know what issues you may be facing and would like to hear more about or even if you just want to say hi, I'd love to hear from you. Also a very special thank you to Susan Rowe for our bonus episode theme music, even my guitar. I hope you found what you were looking for today, information, inspiration, or even just a little company. This is Rosanne Corcoran. I hope you'll join me next time in Daughterhood.