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Episode #9: Supporting Family Caregivers
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SHARON PARMET, HOST:

On this episode of INside the OUTcomes, we'll be talking about family caregiving. Family caregivers can be spouses, partners, children, siblings, friends, or even neighbors. Approximately 53 million Americans serve as family caregivers to older adults and people with disabilities, and this number is expected to grow.

Our guest today is Conor Callahan, a senior policy associate on the Caregiving and Workforce Policy Team at [ADvancing States](https://www.advancingstates.org/index.php/). In this role, he coordinates with senior leadership to evaluate state and federal policy related to caregiving and the workforce, designs and implements surveys, evaluates data, and provides technical assistance. Conor is also the author of a new policy brief produced in collaboration with the [Rehabilitation Research and Training Center on Home and Community-Based Services](https://www.sralab.org/research/labs/rrtc-home-and-community-based-services) at Shirley Ryan AbilityLab, and I'll place a link to that resource in the show notes.

Welcome to the podcast, Conor.

CONOR:

Thank you, Sharon. Happy to be here.

SHARON:

So this episode is on family caregiving. Can you kind of give a description of who family caregivers are, what they do?

CONOR:

Sure. You hit the number already. It's over 50 million, and so if we live long enough, if we're lucky to live long enough, or the people that we know, love, and live with live long enough, that caregiving in some form is a nearly universal experience. Rosalynn Carter, there's a great quote by her. She was a big champion of caregiving in her lifetime, and she said there are only four kinds of people, those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers.

For a more technical definition, it's interesting that the Centers for Medicare and Medicaid Services has, since 2023, a new definition of caregiver that's much broader than before, and before it was limited to just relatives. So I'll read that definition, if that's helpful. An adult, family member, or other individual who has a significant relationship with and who provides a broad range of assistance to an individual with chronic or other health conditions, disability, or functional limitation.

And this may include a family member, friend, or neighbor who provides unpaid assistance to a person with a chronic illness or disabling condition. And likewise, the Administration for Community Living, which includes the Administration on Aging and the Administration on Disabilities, has encouraged recently the broadest possible definition to include as many people as possible who are caring for older adults and folks with disabilities. Because historically, people that, you know, are helping to take care of older adults, people with disabilities, have not identified as caregivers, but rather we think of ourselves as this is just part of being a dutiful son, daughter, spouse, grandchild, friend, etc. There has been an issue with uptake of self-identification as a caregiver.

And some people may react negatively to being labeled as such. People will say, no, I'm just a daughter. This is just, I'm just taking care of my wife, for example.

And so we have a problem with the definition of caregiver in English. And there is also not an easy translation into some of the more common languages that are spoken in the United States outside of English. But as you mentioned, regardless of whether people identify as a caregiver or not, the number of caregivers in this country is estimated at over 50 million.

And because caregiving can involve tasks that range from running errands to wound care and helping with eating, dressing, bathing, and toileting, the number may be higher. And if we get even more technical, because Medicaid is the number one payer for home care in this country, and Medicaid being funded jointly by the federal government and the states but administered by the states, states have different and sometimes narrower definitions of caregivers that may limit access to caregiver supports for some.

SHARON:

Why do we rely so heavily on family caregivers? Isn't there an entire professional workforce out there that can provide the same services?

**CONOR:**

That's a great question. And it's important to talk about paid caregiving or direct care work or direct service work. And I'll talk about that in just a minute. But the short answer of why we rely so heavily on family caregivers is that we want to age at home.

The vast majority of folks want to age at home and in the community. And there are certainly needs for facilities like memory care, assisted living, or skilled nursing or even nursing homes. But for the past 40 years, the United States has been moving away from institutionalization.

And contrary to a lot of public anxiety, I have to mention that only a small percentage of older Americans are in nursing homes, and that number is declining. But so this system as a whole is just heavily reliant on family caregivers. In order for us to stay in our homes, we need help.

Now you mentioned the workforce. This is a major topic. And for our members who are the states, the number one issue in almost every state is a severe workforce shortage.

And that is because of the conditions and pay for this type of work. So, working at home, in people's homes, in institutions can be isolating. It is also very physically and emotionally and mentally demanding for low pay.

And so the turnover in home care, personal care is quite high. And it is the fastest growing area of the workforce in the country is in personal care. We have this huge group of folks that is aging out, excuse me, aging in and wanting to stay in their homes. But we have a workforce that is already overburdened and really stretched to the limit.

Family caregivers fill in where workers cannot and workers fill in where family caregivers cannot. So the another really important thing to take away is that policies and programs that support the workforce also support family caregivers and vice versa. And as a whole, if you're supporting workers and family caregivers, then you're supporting the people that they all care for folks with chronic conditions, disabilities, older Americans.

SHARON:

Now, I know there's been some research into outcomes when people are cared for by a family caregiver. Can you talk a little bit about that?

CONOR:

Sure. Caregivers, family caregivers, are the closest observers of folks with chronic conditions, folks with disabilities.

And so they have a good understanding of what's going on with the individuals, mood, their status. And often they're in charge of things like medication management, as I mentioned, wound care, helping them move around the house. And so the more support that's given to caregivers, we see reductions in ER visits, lower hospital admission rates, lower institutionalization rates and supporting caregivers costs a whole lot less than a hospital stay or a hip surgery, for example.

So if caregivers are supported, trained and feel less burdened, then they are able to provide better support to the folks they care for. And we can see a cost savings as well. It's also important to note that caregiver burden is a really prime risk factor for elder abuse.

When folks are overwhelmed, very tired, they're more likely to commit elder abuse.

SHARON:

What are some of the resources available for family caregivers?

CONOR:

So there are a wide range of resources that are available. It really depends on where the caregiver is at.

Caregivers tend to seek out help in moments of crisis when they feel totally overwhelmed. So for healthcare professionals, I would say the goal is to help caregivers identify as such as caregivers and to know that there are resources available before things become too overwhelming. And then also how to help a caregiver who is overwhelmed.

Doctors and nurses are the primary way caregivers get information. So keeping them included in a care team to the extent desired by their loved one is super important. The main thing that folks need to know about is Area Agencies on Aging.

These are the local government administrators of Older Americans Act programs and other programs for older Americans and their caregivers. They also operate the National Family Caregiver Support Program. Some states like New York or Pennsylvania or Texas have many Area Agencies on Aging.

We call them AAAs. There's a lot of them in some states. And then some states like Delaware or Alaska function as a single service area.

And they go by different names. So Googling Area Agency on Aging, going to Eldercare Locator, calling 211. These are great ways for caregivers to get in touch.

I do want to mention because I have never seen this in popular media before, but there is an episode of The Pitt, which was the number one show on HBO Max recently, where there's a young doctor. I'm not going to spoil anything, but there's a young doctor working with a really burned-out family caregiver. She's very isolated, caring for her older mother, who has the regular needs of an older adult as well as mental illness.

And this is the first time that I'd heard Area Agency on Aging in popular media. And it is recommended to the caregiver to get support. So they can be contacted.

They have information and support professionals who can help caregivers find supports for themselves and their loved ones, like figuring out Medicaid eligibility, how to hire home care, how to get respite, how to get a break from caregiving. And depending on the state that folks are in, there may be more or fewer services available. It's really

important to note that Older Americans Act services offered through AAAs, through Area Agencies on Aging, are not means tested.

So there's not a cost, though services may be targeted to those in greater need. They are open to any person, for caregivers, open to any person providing care to someone in this country 60 and older, any person caring for a person of any age with Alzheimer's or related dementia, and any older adults 55 and older caring for children under the age of 18.

A great resource to get in touch with is respite. And respite is available through the Older Americans Act, through Area Agencies on Aging, and is also available through Medicaid. And this is the way to give a caregiver a break. This might be a few hours in a day, a week, or part of the day.

And respite, however, is challenging because of the shortage of respite workers. There are respite volunteers through community-based organizations like churches and other non-religious organizations and AAAs. Through the AAAs, folks can also get supportive counseling, including group counseling.

In many cases, this is now, since the pandemic, offered virtually, which is great for caregivers because kind of the last thing that you want to do when you're caregiving for someone who needs attention is drive a half an hour or an hour to spend another hour away from that person to participate in a support program.

SHARON:

What are some other resources outside of the AAAs and the organizations and the resources you spoke about?

CONOR:

Sure. So health plans. These are folks like Aetna, Blue Shield, acting as managed care organizations. They recognize the role of family caregivers and will offer supports. So getting in touch with them and seeing what caregiver supports they have.

As I mentioned, because supporting caregivers is tied to lower ER visits and hospital admissions, health plans recognize that supporting caregivers is much cheaper than more expensive medical procedures. There's also AARP has some great caregiving resources through their website for different kinds of caregivers, for dementia caregivers, other traumatic brain injury caregivers. There's also something called Powerful tools for caregivers, which is typically offered free.

It's powerfultoolsforcaregivers.org. It's offered in person and virtually all around the country. I believe it's a six-week program and it's evidence-based and has been shown to reduce stress, help caregivers better manage their time, take care of themselves and their loved ones. Caregiver stress.

So the stress that's placed on a caregiver taking care of their loved one is linked to all types of deleterious effects, heart disease, stroke. So we're really multiplying the number of individuals with chronic conditions if we are not supporting caregivers.

SHARON:

What would you say to someone who is just beginning their family caregiver role?

CONOR:

I would say, you know, welcome.

This is something that I've gone through personally. I helped care for my father-in-law with Lewy body dementia for the last few years of his life in-home with him. And that caregiving can be a really rewarding experience. For me, it was really gratifying and rewarding. And it was also very, very difficult, especially when working full time outside the home. And there is help.

There are, you know, there are supports for caregivers. It is best to not do it alone. Caregiving can be one of the most isolating and lonely experiences.

And it does not need to be that way. In my caregiving experience with my father-in-law, my mother-in-law was the primary caregiver. And then she built a care support team around her that included her children and other friends and folks in the community.

So it is not something to be done alone. And it doesn't have to be.

SHARON:

I know that you've written a policy brief on family caregiving with the Center for Rehabilitation Outcomes Research at Shirley Ryan AbilityLab. Can you talk a little bit about what's in that brief?

CONOR:

Sure. A lot of it is a kind of general caregiving info and some more targeted info for health care professionals to help caregivers that they encounter really understand, you know, how to get help and what's available. It can be really overwhelming.

The systems are intimidating and confusing. And a lot of folks start their caregiving journey with some misconceptions, the biggest one being that Medicare pays for home care or nursing home care or caregiver supports. It generally does not. Medicare offers very little in long-term care support compared to Medicaid. Medicaid is the primary payer for long-term care. And Medicaid, of course, is means-tested. There's an income requirement that most Americans don't qualify for. So health care professionals also need to understand that the way that they communicate with caregivers can help their patients improve, that caregivers, when included in the care team, we see better health outcomes for the patient and for the caregiver, and that there is now training available for health care professionals.

The University of California, San Francisco, has created a training program with the support of the Administration for Community Living called Caregivers as Partners in Care Teams. And that link is provided in the brief. There is also some training there because Medicare now does have billing codes for physicians for their time that's spent in caregiver training or time spent with caregivers. And so there's a billing code guide, as well as training on how to work with family caregivers.

And yeah, I think just it's important for, you know, listeners to understand that Medicaid pays for two-thirds of home care and that long-term service and support, so supports for folks with chronic conditions, older Americans, folks with disabilities, this is a small percentage of the Medicaid population, about 4% overall, but 28% of the total budget. So it's a very expensive part of the pie. And targeting caregivers for support is a way that states and the federal government can, you know, reduce pressure on the healthcare system and reduce costs and improve health outcomes.

SHARON:

Well, I'll be sure to link to the policy brief in the show notes. Is there anything else you wanted to add or talk about?

CONOR:

Sure, I guess one other thing I'd like to talk about is whether caregivers can be paid, if there's options for caregivers to be paid. And most caregivers are uncompensated.

As I mentioned, in order to qualify for Medicaid, you know, an individual with a chronic condition needs to be Medicaid eligible, which is an income requirement, an asset requirement. But this uncompensated labor is huge in this country. It's estimated a few years ago at over $600 billion. I'm sure that has increased.

A handful of states now offer tax credits for caregivers. So you want to look up in your state if that is available to you. AARP has been leading the charge on that. There's also a proposal in Congress to offer a $5,000 caregiver tax credit. It's called the Credit for Caring Act. It has bipartisan support. And the president publicly supported such a measure when he was running for office last fall.

Otherwise, for payments for caregivers, we're talking about within Medicaid. And there's a couple ways that can happen. One is through self-direction. So I just kind of want to talk about self-direction a little bit.

You may have heard of consumer-directed services, aka participant-directed, or also known as self-direction. This allows enrollees, so folks with a disability or chronic condition, to directly hire people, which in many cases includes family members, to provide their personal care. This includes bathing, dressing, and toileting. So that means the person with long-term needs can act as their own care manager. They hire, train, pay, and fire the personal care worker if needed. And in many cases, this can be a relative.

And almost every state has a consumer-directed waiver option. For caregivers of folks with dementia who, or other reasons, would not be suitable to direct their own care, states have been offering something called structured family caregiving. And it's a little bit different. It's also a waiver, also in Medicaid. But the caregiver must live with the individual needing care, which is not required in self-direction. And support is offered directly to the caregiver in the form of payment, usually a stipend, as well as training and education, and importantly, support in the form of a caregiver coach.

Again, caregiving is not something that should be done alone, and it does not have to be. I hope that we see more recognition of caregivers. States have been leading caregiver awareness campaigns to raise awareness that caregiving is more than what we think of as, you know, helping someone eat, or dress, or tend to their medical needs, but rather things like sweat equity, taking them to appointments, etc.

So we have the more people that identify as caregivers, the better understanding we have as a country of this massive number of us that are dealing with this. My hope is also that employers become more sympathetic. An AARP analysis a couple years ago found that employer supports for working caregivers contributes to increased productivity, enhanced loyalty to the company, they better support recruitment and retention, and they even increase company share prices.

So the better support we have for caregivers, it's also better for our economy.

SHARON:

Well, thank you for being a guest on the podcast. And thank you for all the information you've provided. As a soon-to-be caregiver myself, I'm going to take advantage of all these resources that you mentioned. So thanks again for being on the podcast.

CONOR:

Thank you very much.

SHARON:

This podcast is supported by a grant from the National Institute on Disability, Independent Living. and Rehabilitation Research. This is your host, Sharon Parmet, signing off.