



EPISODE 54: DISABILITY AND AGING: COMMUNITY LIVING AND POLICY

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Presenter: Joe Caldwell, Director of Long Term Services and Supports National Council of Aging (NCOA):

Host: Pam Williamson – Assistant Project Director, Southeast ADA Center

VOICE-OVER ANNOUNCER: Blog Talk Radio. (Music) Welcome to WADA ADA Live! Talk radio. Brought to you by the Southeast ADA Center, your leader for information, training and guidance on the Americans with Disabilities Act, and here's your host.

PAM WILLIAMSON: Good afternoon, welcome to WADA ADA Live! On behalf of the Southeast ADA Center, the Burton Blatt Institute at Syracuse University, and the ADA National Network, welcome to episode 54 of ADA Live!

Hello, everyone! I am Pam Williamson, Assistant Project Director of the Southeast ADA Center and your host for today's show. During today's episode of WADA ADA Live, we are discussing community living and policy as it relates to disability and aging. Older adults and individuals with disabilities share desires to live independently in the community and age with dignity and respect. Unfortunately, our current system of long term services and supports (also known as LTSS) often forces individuals to become poor, it places enormous burdens on unpaid family caregivers, and is biased towards nursing homes and institutional services.

Before we begin, as a reminder, ADA Live! listening audience, you can submit your questions about community living and policy at any time at ADALive.org.

It is my pleasure, now, to introduce today's guest from the National Council of Aging (NCOA): Joe Caldwell, Director of Long Term Services and Supports. The NCOA is a respected national leader and respected partner in helping people aged 60 and above to meet the challenges of aging. NCOA collaborates with nonprofit organizations, government, and business to provide innovative community programs and services, online help, and advocacy. Joe, welcome to our show.

JOE CALDWELL: Thanks so much for having me.

PAM WILLIAMSON: Joe, can you talk about the impact the aging population in the United States will have on the need for long term services and supports?

JOE CALDWELL: Yeah. It's going to be a significant impact. If you look right now, about 12 million people in the U.S. need some form of long term services and supports. And right now that's pretty evenly split. So that about half of those people are under age 65, and half are over age 65. But because of the aging Baby Boom generation, every day more and more people are turning 65, and more significantly people are living longer, into their 80s and 90s. So what researchers project is that the number of people who need long term services and supports is going to rise from 12 million today to 27 million by the year 2050. So, you know, in my lifetime we're going to see the number of people that need long term services and supports more than double. And it's going to impact families significantly.

Some research indicates, some recent research that was done indicated that about 70% of people that turned 65 today are going to need some level of long term services and supports in their lifetime. So it's going to affect all of us, whether we, you know, whether we develop a disability and need long term services and supports or if we're a family caregiver that's trying to help somebody stay in the community and be independent. So it's going to be a dramatic increase, and I think it's going to affect, you know, the whole system of how we deliver long term services and supports in the future for younger people and older people.

PAM WILLIAMSON: Joe, those numbers are staggering. It really kind of brings to home the idea of folks who are aging and those of us, such as myself, that have become caregivers for older parents in this realm and trying to keep them at home.

And one of those things that really has impacted my life and my parents' life is paying for these services. So how do these older adults pay for and access long term services and supports?

JOE CALDWELL: It's really difficult. And it's pretty similar to younger people with disabilities, as well. Most people end up relying on unpaid family caregivers and to some extent Medicaid, which is really the only, you know, funding stream for long term services and supports in the country right now.

Most people who are probably tuning into the webinar or the podcast know that Medicare doesn't cover long term services and supports. It may cover a little bit of nursing home care after you've been in a nursing home -- or been in a hospital and you need to recover a little bit. But after a hundred days, you know, it doesn't pay for

long term care. But the general public, survey after survey, they show that people think that Medicare will cover long term care. But it really doesn't. And I think that's something we need to educate people about.

So really the other options are private long term care insurance. That's been around for decades. And there are some people that have bought private long term care insurance policies, but it's very, very small. Only about 5% of people have long term care insurance. And if you look at older people, it's about 11% of people over 65 have purchased private long term care insurance. And there's a lot of reasons for that. The market right now is not a very favorable market. It's become very expensive.

So most middle class families really can't afford to buy private long term care insurance. And even if you can afford it, they've gotten stricter on the underwriting criteria so that excludes a lot of people, you know, with disabilities from buying long term care insurance, or really it's not just even disability. It's if you have any kind of health condition. Or if you're too old. If you wait too long. You can't even buy private long term care insurance. So what does that leave people? Pretty much on their own to pay for this. Either privately, out of pocket, which a lot of families do. They may hire personal attendants out of pocket. They may try to get some respite or a day program and pay for that out of pocket. But, you know, it reaches a point where you can't do that. That's not sustainable.

And so people turn to Medicaid at that point and, you know, Medicaid for better or worse is the primary funding stream for long term services and supports in the country. And, you know, it forces people to become poor. So to get Medicaid, people have to spend down all their, you know, assets and, you know, whatever they might have in savings that they've saved their whole life to have. They have to spend that down to, you know, only about \$2,000 to be able to qualify for Medicaid. And then, you know, the disability community knows this all too well. Even if you can get Medicaid and get on it, that doesn't mean you're going to get home and community based services because there's an institutional bias within the program that you can get nursing home care.

But if you want to stay at home in your community, which is what older people do want to do, you know, it's not easy to get those services. And waiting lists have also really increased over the last couple decades. There's a lot of seniors and people with disabilities that are waiting for those services. So it's not an easy, it's not an easy picture for younger people or older people disabilities, and trying to patch together, you know, the supports that they need.

PAM WILLIAMSON: So we're looking at this, and as you were talking about, there's the bias towards nursing homes and other types of institutional care. Are there states

that have rebalanced or refocused and are trying to move more towards cost effective home and community based services?

JOE CALDWELL: Yeah. We've actually made a lot of progress over the past two or three decades. I thought it would be interesting for your audience to kind of pull a couple dates. If you look at 1990, so that was passage of the ADA, and you look at Medicaid spending. So as a country, we were only spending 12% of the total Medicaid funding for long term services and supports on community based services. So only 12% was going to community based services. You look at 1999, the passage of the Olmstead decision. At that point we were up to 25% was going to community. And now as of the most recent data, we're up to 55%. So the majority of money is actually going to home and community based services. So, you know, just in the last couple decades that's been truly remarkable how that's shifted. And it's happened because of the ADA, because of the Olmstead decision and enforcement. And also been some key pieces of legislation like the Community First Choice Option, the Money Follows the Person program, another program called the Balancing Incentive Program. And that's really helped a lot of states make progress to expand access to home [and] community based services.

So that's the good news. But the bad news is we still have a long, long ways to go. There's a lot of variation between states. So if you're lucky enough to be in a state that's made a lot of progress, you might have access to home and community based services. But in a lot of other states they're very far behind. And it's also varied a lot by population. So for people with intellectual and developmental disabilities, as a nation, now we spend 76% of the funding in the community. And some states for people with developmental disabilities spend all their money on community based services. They don't have institutions anymore.

But when you look at older people and people with physical disabilities, and people with mental health disabilities, the progress has not been as dramatic. And actually, if you just look at older people, and people with physical disabilities, there's still seven states that spend less than 20% of their money on the community. And I think that's just, you know, deplorable that they're still spending less than a fifth of their money on the community and 80% on nursing homes. So, you know, like I said, we got a lot more progress to go. But we've made some good progress over the last couple decades.

PAM WILLIAMSON: Well, I am encouraged by the progress that's been made. And I was recently at a meeting regarding Olmstead implementation in Georgia and I'm hearing the same thing that you mentioned here with the varied spending on long term communities for supports and services from state to state. As well as people who are

aging versus people with intellectual and developmental disabilities. So hopefully we will continue to see forward progress.

So ADA Live! Listening audience, if you have any questions about Community Living and Policy, or any of our other ADA Live topics, please submit your questions at any time at our online forum at ADALive.org. I want to pause for a minute now for a word from our sponsor, the The National Council on Aging.

ANNOUNCER: The National Council on Aging works to improve the health and economic security of older adults. NCOA is the respected national leader and trusted partner to help people aged 60 and over to meet the challenges of aging. National Council on Aging partners with non profit organizations, government, and business to provide innovative community programs and services, online help, and advocacy. Their goal is to improve the health and economic security of 10 million older adults by the year 2020. The vision of NCOA is to build a just and caring society in which each of us, as we age, live with dignity, purpose, and security. To learn more visit their website at www.ncoa.org.

PAM WILLIAMSON: Hi, folks, welcome back to our show. We're talking with Joe Caldwell of the National Council on Aging (NCOA) about community living and policy in relation to aging and disability.

Joe, NCOA does a lot of work promoting evidence based healthy aging and fall prevention programs. Can you tell us a little bit more about these programs and their importance to promoting community living?

JOE CALDWELL: Yeah, these programs are really part of the whole picture of helping people maintain their independence, being independent, and preventing people from going into nursing homes and institutions. So these are two big areas that we kind of focus. Let's take falls first. You know, falls is a huge issue for older people. Actually, a fourth of Americans over age 65 fall each year. I mean that's pretty amazing. Every 11 seconds, an older adult is treated in the emergency room for a fall. And every 19 minutes an older adult dies from a fall. You know, falls are really the leading cause of people going in to nursing homes and really losing their independence that they have.

So the good thing about it is that falls are not a normal part of aging. They're totally preventable. We can do things to prevent people from falling and injuring themselves and losing their independence. There's a lot of things you can do. I mean there's environmental assessments where people can come into the home and look for risks of within the home of barriers and risks that cause falls. You know, there's a lot of

adaptive equipment out there. There's home modifications and grab bars and all this stuff that can prevent people from falling.

At NCOA, we do a lot of what's called evidence based intervention programs. And what these do are programs that really help seniors kind of take charge of their lives and build up their strengths and their balance and reducing the fear of falling, which actually causes people to fall. So these are proven interventions and strategies where people kind of meet in groups and they do tai chi, for example. That's one intervention. But there's a whole host of them. They've been proven to work. They actually can actually reduce the incidence of falls. And so we help community based organizations that want to deliver these programs sort of provide T.A. [technical assistance] and help them to implement these programs.

We also just try to raise awareness about falls and falls prevention. There's what's called Falls Free Coalitions that 42 states have formed now. On the first day of Fall, we do a falls awareness campaign to help seniors and caregivers be more aware of falls and how to prevent them. So that's one area where we do a lot of work. The other area that you mentioned is management of chronic conditions.

So chronic conditions are things like diabetes and arthritis and hypertension or heart disease. And the thing about this is if people manage those, you know, they can prevent secondary conditions. Or they can prevent those conditions from worsening and people [acquiring] really secondary disabilities. And again, there's good news because there's a lot of evidence that shows that if people are empowered to kind of take more control of their health and know how to do that, that you can prevent conditions from worsening. You can help people stay independent and in the community. And it's a big issue for older people. You know, about 80% of older adults have at least one type of chronic condition and about two thirds have at least two different chronic conditions.

You know, one of the most evidence based programs is a program called the Chronic Disease Self Management Program. So it's got a long name. But it was a program that was developed by Stanford University, and it's available in the community where people go and take this in groups. And it's also, there's versions that are available online if people can't make it to an actual community event. So that's one particular program that we promote and help community based organizations to deliver.

And I also wanted to just add, on both of these issues, falls prevention, and managing chronic conditions, these aren't just issues for older adults. They're also really important for younger adults. There's a lot of research that shows that younger adults with disabilities have risks for falls and, of course, high rates of chronic conditions that they need to manage, as well.

So we've been trying to figure out what we can do to help include people with disabilities more, younger people with disabilities. And we've been, for example, working with Ivan Molton at the University of Washington. And he leads a Center on Healthy Aging that's funded by NIDILRR, the National Institute on Disability, Independent Living, and Rehabilitation Research. So we've been working with him and hope to keep working with him about adapting some of these programs so that they better serve the younger people with disabilities, as well.

PAM WILLIAMSON: Joe, this is all very interesting and helpful information, and I'm really excited to learn about the target both on older adults and younger adults. And I will say I've actually used some of your materials personally, because when my father's health started declining several months ago, we were able to use some of the information in my parents' home to move some of the things out of the way that might impact his ability to move around -- and to help with the falls and just teaching him how to fall. We did that in collaboration with his doctor and home health, and it's been a wonderful resource. So, I thank you personally, and I know our listeners will also benefit from the information.

Well, you've got so many great things going on. I want to talk more about the collaboration between National Aging and Disability Organization, because we know it takes people working together in order to be able to advance community living policy. Can you talk more about these and tell us why it's important?

JOE CALDWELL: Yeah. Most of my background was actually in the disability community as far as my education and personal experience, and one of the reasons I came to NCOA is because they really are open to working with anybody, and there was this opportunity to kind of bring together aging and disability groups. And I would say it was really one of the first efforts at the national level to really do this successfully. And it goes back to 2009. And just to put that in to perspective, that was, you know, before the Administration for Community Living (ACL) was formed. At that time, the ADA Centers were over in the Department of [Education]. They weren't in ACL. So that's going back a while.

And the reason that the groups finally came together was that we were trying really hard to get long term services and supports included in health reform, and we knew that there was this big health reform being, starting to be talked about. And they were starting to form different proposals. None of those proposals included anything on long term services and supports. It was all about medical care, acute care. And the aging disability communities realized that, you know, if we don't come together and work together on this, we're never going to get long term services and supports included as

part of health reform. So that's what brought us together, was sort of that common ground. So we formed this little coalition.

At that time it was called the Friday Morning Collaborative, because we met on Friday mornings. And it was a very small group. It was about, originally about maybe 15 groups that included the major groups like NCIL, you know, the National Council on Independent Living. It included the Association of University Centers on Disabilities. NCOA, AARP. So some of the major groups. And, you know, I'll say the first meetings we had were really kind of tense because, you know, people -- and I know people listening -- if you've ever tried to work in coalition or bring together aging and disability groups, there were a lot of myths and stereotypes and uncertainty about if we should work together. But we worked through that. And the good thing is we were really successful. We actually got a lot of stuff in the healthcare, the Affordable Care Act, on long term services and supports. We got this program called the Community Living Assistance Services and Supports Act, the CLASS Act, which unfortunately was repealed. But that actually led to the formation of ACL, the Administration for Community Living. That's kind of where they got the name "community living," because they needed a place to put this program while they were working on it.

And then we got a lot of good stuff on Medicaid, like the Community First Choice Option, the balancing incentives program. We got some protections for spouses so they don't have to become poor when somebody goes on Medicaid to get community based services. So we were really successful. And should we keep meeting together? And everybody wanted to keep meeting. So over the last, really, eight years this coalition has continued. We changed our name. We're now called the Disability and Aging Collaborative. It's national groups, but now there's about 40 national groups. And we meet twice a month for the past eight years, and we work together on strategy. We share information. You know, we try to really have a more powerful voice on long term services and supports, and we've continued to make progress and, you know, in terms of implementing things and weighing in on regulations at the federal level. And, you know, working on the next versions of legislation at the national level. So it's been an amazing experience. And the thing I would really stress to people listening is, you know, it's not easy, but if you're able to bring together these groups, you really, really can have a much more powerful voice for change.

PAM WILLIAMSON: Joe, that is amazing. It really reminds me of my favorite quote by Helen Keller, which is, "Alone we can do so little and together we can do so much." I actually have that quote on my wall in my office to remind me of that, and the story you just told about the Collaborative really highlights that because you've made some great strides. And I'm really excited about that.

Just a quick follow up question on that. If people want to learn more about what the Collaborative is doing, do you have a way for them to be able to find out more about the Collaborative's work or is it...?

JOE CALDWELL: We do. If you go to our website, NCOA.org, there's some additional information there that lists the organizations that are involved in the Collaborative. And one thing we started to do over the years is webinars, so that we can reach the state advocates. Because in order to be successful, the national advocates and the state advocates also have to work together on issues. So we started this webinar series as a way to kind of do that and make a connection there. So all those webinars are up on the website. And I also want to give a plug that a NIDILRR-funded center has really helped tremendously with those webinars -- the Community Living Policy Center that's at University of San Francisco, or University of California at San Francisco. They've provided support for us to be able to do that.

PAM WILLIAMSON: Excellent, excellent. Well, Joe, we are about out of time today. So I would like to have you give a quick statement here about what you see as the biggest pressing policy issue and maybe one of the biggest challenges that you see for the next few years for older adults.

JOE CALDWELL: Yeah. Well I'll start with something we're working on right now that I think is very doable, and our collaborative is working on trying to get this to happen this year. And that is extending the "Money Follows the Person" program. That has been a really successful program. It has tremendous bipartisan support, and it helps people, you know, transition from nursing homes back to the community as well as helping the states to make more progress on rebalancing. So we got a lot of support for that and we're trying to get that over the finish line this year.

But I would say big picture, and this is a little bit of a teaser for Leslie Freed who is going to be on a future podcast. But I think the issue of economic security for older adults is a huge issue for this country as we go forward, and that's tied to long term services and supports. But, you know, most seniors in this country are really struggling to get by. They live on very low income. About 25% of seniors actually live on less than \$30,000 a year and that's barely enough to pay, you know, the bills and just food and so forth. And, you know, what happens like we talked about? You develop a need for long term services and supports and that just wipes you out completely. So that's an issue we got to address. We got to figure out a better way to pay for long term services and supports in the community that doesn't require people to become poor and give up everything they have. So, you know, that to me is the big issue that we got to work on in the future.

PAM WILLIAMSON: Well Joe, I want to thank you so much for being with us today -- and listeners, just as a reminder, this has been Joe Caldwell from the National Council on Aging (NCOA).

This episode and all previous ADA episodes are available on our website at www.ADAlive.org. They are archived in a variety of formats including streaming audio, from our web accessible transcripts of the audio, and they are also available to download as podcasts to listen to at your convenience.

I also want to thank our ADA Live! listening audience for tuning in today. We are thankful for your support for listening to the series of ADA Live! broadcasts. As a reminder, you can submit any questions on these topics or any others by going to ADAlive.org.

Please join us for our next episode on April 4th. We will be talking with Steve Kuusisto about his new book, "Have Dog Will Travel".

If you have a question about the Americans with Disabilities Act, contact your ADA Center at 1-800-949-4232, and remember all calls are free and confidential.

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