

## NADTC Caregiving and Transportation Transcript: Module 1

**Eileen Schroff:** Hi everyone this is Eileen Schroff and I'm excited to kick off the National Aging and Disability Transportation Center's course on caregiving and transportation and I have the great pleasure today of being joined by our first speaker, Jane Mahoney, and she is going to provide us with our first presentation setting the stage on these two topics of transportation and caregiving and she'll talk a little bit about some of the ways that transportation is a critical support in the caregiving Journey and Jane is very well positioned to talk about this given her experience and her background and she'll go over that a little bit once she starts but I think you will all find her a wealth of information so before I turn the screen over to her I do want to give a little bit of a bio. Um Jane is currently working as a training and technical assistance specialist at the National Aging and Disability Transportation Center and prior to joining the team at NADTC she was an Older Americans Act Consultant and caregiver support specialist and there she provided training and guidance to family caregiver programs across Wisconsin. um Jane continues to be passionate about caregivers in her work at NADTC and promoting Transportation programs as a form of caregiver support. So as you can hear from that bio there is no one better positioned to talk about this than Jane and she's going to also join us in the discussion forums during the week when this is launched and she'll be available directly to answer questions about the information that you hear today. So Jane, I will now turn it over to you.

**Jane Mahoney:** Thanks Eileen I'm really happy to be here today as Eileen said my name is Jane Mahoney and for those of you who are not able to see me I am a woman in my mid-50s with dark blondes while they're wearing pairing glasses and as you heard in the introduction I do have a lot of background working in the field of family caregiver support and when I decided to take this job at NADTC I really wanted to explore some new topics learn about transportation and expand my horizons but honestly my passion for caregivers came right along with me and one of my goals here in this job is to work on this intersection of caregiver support and transportation and in my mind I see a Venn diagram as I have displayed on the screen here with a blue caregiver support circle and the green transportation support circle and in the middle is a nice blue-green section and that is where caregivers support and transportation intersect makeover lab and that's what this presentation is all about so before we can talk about where transportation and caregiving intersects I first want to give you an idea about what family caregivers are I want to help you understand who they are what they do and give a peek at what their lives are like and where the challenges lie in supporting them and then we'll talk a bit about how transportation and caregiver support intersects and finish up by talking about how transportation programs can improve their services to meet the needs of caregivers.

I'm going to start by defining what a family caregiver is so family caregiver is a person who helps someone to care for themselves I want to stress that this is not a

paid professional caregiver that works in a care facility or a Home Care Agency. This family caregiver has a relationship with the person they're caring for I'm usually a relative maybe a friend or a neighbor and the tasks that they help with are usually things that the person used to be able to do for themselves and for various reasons the person is no longer able to do them and now needs assistance the assistance that the caregiver provides tends to enable those people to live in the community. There's a really a focus on preserving independence and quality of life caregivers are tend not to be compensated for their work it is done out of love and out of off and out of a sense of responsibility or obligation caregiving can be short-term or long term sometimes it's helping someone to recover from an illness or surgery so it's a shorter term relationship but sometimes it's a longer term commitment and when they're providing care for someone who has a chronic condition or illness or disease and family caregiver may or may not live with the person they're caring for but no matter what the tasks that they are doing allows the person to live more independently and typically without the assistance of that family caregiver that person would likely have to live in a care facility so caregivers are extremely important to our society.

I want to give you a profile of what family caregivers look like. AARP and the National Alliance for Caregiving do a survey about every five years to learn about what caregiving in the United States looks like. Their most recent survey was completed in 2020. 7,309 people responded to the online survey and the statistics I'll be sharing with you today come from this survey. It's called 2020 caregiving in the USA.

So from the survey we found that 53 million caregivers... there are there are 53 million caregivers in the United States and that is about 21% of the adult population and as shown in the diagram with five people in one... one blue woman standing out that's one in five people are caregivers and I made the blue woman a woman because 61% of them are women. However in the in these last couple of surveys we are noting that more and more men are becoming caregivers so that the percentage of women is decreasing. We know that the average age of a caregiver is about 49.4 and in this survey 50% of the caregivers were caring for an aging parent and 12% were caring for a spouse or a partner. Some of the other caregiving relationships are a parent caring for a child with a disability, siblings, grandparents raising grandchildren or other relative relationships, as well as friends and neighbors. Also noteworthy is that 61 of the caregivers are employed.

What do family caregivers do exactly? Well there's really a wide range of tasks that family caregivers do and as each caregiving situation is different some things can be relatively simple like kind of household tasks maybe cleaning some laundry, home maintenance, preparing meals, maybe helping with paperwork, or paying some bills but these smaller tasks typically expand as time goes on some of the other tasks can include arranging for or accompanying people to medical or other appointments. It includes transportation for shopping, errands, socialization, and things like that. Caregivers also provide tasks such as addressing grooming and bathing, what we

call “activities of daily living”. They might need to help the person who walk like particularly long distance or stairs, they may need help getting in and out of bed or a chair, and so the caregiver is there to help with that. Caregivers also provide supervision and safety. This is especially true for those caring for people who have Dementia or Alzheimer's disease that need a lot of supervision. Caregivers also help set up medications and ensure the medications are being taken properly, and sometimes they even perform medical tasks like changing dressings or wound care. This is particularly true if they're caring for someone after they've been discharged from the hospital or from a surgery. Caregivers are frequently expected to do medical tasks that are rather uncomfortable for them to do so the range of tasks that caregivers do is really wide.

You may wonder how much time do caregivers spend in providing care and I find these statistics to be rather shocking on average from the survey again of from AARP, it's it says that caregivers spend 23.7 hours per week providing care. That's on average of the caregivers that responded to a survey and their median was about 10 hours per week but 32 of the respondents said they provide care for 21 or more hours each week which is equivalent to a half-time job and 21% of the caregivers that respondents said they perform 41 or more hours of care each week so that's the equivalent of a full-time job. And if you remember 61 of the caregivers are also employed and also 60 of those that are employed are employed full-time. That's a lot that's a lot of time and that leads me into the next slide which is about how caregiving affects the health and well-being um you see think about the kinds of tasks caregivers are doing and the time they are spending providing this care it probably isn't surprising to learn that caregiving can negatively affect the health and well-being of a caregiver in the AARP survey caregivers were asked to rate their health and 41% of caregivers rated their health as excellent or very good but compared to the general population that said 62 percent of them rated their health excellent are very good and on the flip side in the survey 21% of caregivers rated their health as fair or poor that would be compared to the general population where only 12 percent of people rated their health as fair or poor so we can see that caregiving does affect a person's health and well-being and this is one of the reasons why it's so important to support caregivers in any way we can not only are they providing service to keep people living in their community but they're also affecting their health negatively so we need to do what we can to support them and that leads me to my next slide about caregiver stress.

I just want to talk about this a little because this is really a huge concern caregivers do have quite a bit of higher levels of stress and that's caused by several things um one of the things is an emotional stress so if you remember they're caring for someone that they love and that they have a relationship with and it's really difficult to watch one of your loved ones change and to lose their ability to do things that they used to be able to do and this is emotionally stressful for people role confusion is another thing that causes caregiver stress for example I'm caring for my mother who's having some pretty severe memory issues so I used to call her and ask for help and advice but now I'm the one helping her so you she used to take care of me

but now I'm kind of her caregiver it's confusing this also applies a lot for spouses they met and they've had years of a mutual relationship but now one of them is doing things for the other that they used to do themselves I mean maybe they're helping them get dressed maybe they're making sure they take their pills and things like that and so they're kind of wondering am I the spouse or my caregiver it's confusing and it causes stress workbook we've already talked about the number of hours that they're spending on providing care so um it's it's a lot and that's very stressful also these people like I said many of them have jobs many of them may have um children of their own that they're also caring for caregivers tend to place unrealistic expectations of themselves to do more than they really can do and this can be physically and mentally exhausting and this can this definitely leads to the caregiver stress but it also leads to the last bullet point which is a lack of time for self-care now caregivers are great at providing care for other people but they're not so good at taking care of themselves they really tend to put their own needs at the bottom of the list the time that they used to spend with friends or rejuvenating by doing a hobby or something they've put that to the side and they now spend that time caring for their loved one and this again really increases stress and leads to burnout and decreases their health

So in my many years working with caregivers I found that it really isn't always easy to provide support to them no matter how much you want to help it can be challenging and like I said they are helpers they're really good at giving care and not so good at receiving care so I wanted to share some of the Care common caregiver responses that I found working with caregivers um it's just to give you a picture of sort of what you might be facing if you are going to be working with caregivers the first thing that you're going to hear is they just don't see themselves as caregivers they're going to say I'm not a caregiver I'm a daughter I'm a spouse I'm a grandma I'm a sister this is just what I do it's expected of me so I don't really need your help this is my job I'll do it or you'll hear that I'm just too tired to look for help it's just easier to do it myself um you know yeah there might be a transportation program that could take my mom to get her hair done every week but I got to figure out who to call I gotta make that Arrangement too much work I'm too tired for that I'm just gonna do it or we hear oh no no I nobody can do this as good as I can um I I just don't trust anyone else to do this or the caregiver might be willing to but they'll say ah my husband would never let someone do that he wants me to do it um so these are some of the things you're going to hear another thing we hear is I didn't no one hope I meet you know there would be well-intentioned people that will say let me know what I can do to help I can tell you're stressed out tell me what I can do but caregivers don't necessarily know what they need they know they're tired they know they're exhausted but they don't necessarily know how to get that help they don't know what to ask for and then uh the last bullet point I have is kind of a tough one to hear and that I didn't know that was available, I would have used that had I only known and sometimes we hear this after the caregiving situation has ended and it it hurts because it's like I wanted to help but they didn't know and you might have even told them you might have given them the brochure about what's available but in their stress it didn't even register or they couldn't take the time to

comprehend what that might look like so um that's another thing we often hear and also sometimes there is just a resource overload they're giving they're given so many options it's just too much and they just shut down so those are some common caregiver responses when you're working with caregivers so now you have a little peek at what caregiving is what it looks like and some of the struggles caregivers face so I want to move next to talk about can caregiving and transportation that inner circle um so in that same AARP survey caregivers were asked what types of activities they do for their care recipient and you won't be surprised to see that the most common activity that caregivers do is transportation so in the in the survey 80 percent of caregivers said they provide transportation as one of their caregiving duties and 78 said they help with grocery or other shopping those are the top two tasks that caregivers do and both of those involve transportation in 2021 NADTC also did a survey as part of their diversity equity and inclusion initiative and the results basically mirrored what the AARP survey said and that was that 78% of the caregivers said they provide transportation and then 42% also said they arranged transportation so this is where transportation and caregiver support interacts this is that sweet spot in the middle of my Venn diagram

We went on to ask in our survey of the where caregivers are taking their loved ones where are these trips to and their answers were the top answers were medical appointments in the pharmacy grocery shopping and other stores social activities which included Church community events visiting family or friends and then finally day programs employment volunteering so if you're a transportation provider could your agency help with any of these trips and I'm sure you're saying yeah of course these are the kinds of trips that we provide now here's the real Zinger the next question we asked was have you ever used a transportation service to help you with your caregiving and 25% of the respondents said yes I've tried that I've tried using the transportation service and 75% said no I've never tried using a transportation service wow that's a lot this is a real significant finding and it makes the discussion that we're having about caregiving and transportation even more permanently so why aren't caregivers why aren't more caregivers using transportation services the trips are taking are trips that you can provide but they're not using it so in addition to the quotes I shared earlier that helped us understand why caregivers aren't really utilizing other support services in general we know that there are plenty of potential barriers specific to using transportation services as well and some of these barriers include the following they've just never used transportation before my mom, my spouse, person I'm caring for they've always just driven themselves they don't know how to use public transportation they don't know how to use the bus they don't know how to do a dial-a writing they just don't know how I'll just do it for them um another barrier is how are they going to get to the bus stop and how are they going to get from the bus to where they're going if I have to take them to the bus stop in life as well take them all the way they're kind of thinking um and but you know that this is a real common thing it's called it's the first my last mile issue um this is a typical thing that you are addressing in your programs um another barrier is issues around accessibility getting how will begin on and off the bus is the vehicle accessible do the drivers know how to help or are they even allowed to help will

they be safe safety concerns um also a need for supervision um a lot of people just think that their loved one can't go wrong I know I wouldn't be comfortable sending my mother who has memory loss issues alone they need supervision so that's a barrier for them to use transportation and then it's just the overall lack of knowledge about transportation services caregivers just don't really know what's available and they certainly don't know about the additional support services that could help meet their needs and honestly they probably don't even think about the fact that Transportation could be something that could help them out I know in my work with caregivers I did caregiver support groups for many years and sad to say I never had anybody from our local Transit come and do a presentation about the services they offered it just isn't talked about a lot in the caregiving circles that's what I want to change I hope so um so these are some of the barriers to explain why caregivers may not be using transportation services so I'm hoping that understanding some of these barriers will help Transportation professionals improve their services to support caregivers so how can they do that how can Transportation programs better support caregivers so I'm going to talk about some things that include the existing services that you already have and how you can talk about transportation to caregivers seeking input from caregivers as well as forming Partnerships with caregiving professionals

So many Transportation programs already have services that offer the kinds of support caregivers are looking for you don't necessarily have to rethink how to provide services just for caregivers you do a lot of it already caregivers just don't necessarily know about it or the service you have might need to be adjusted or tweaked just a little bit to individualize it to meet some unique needs that caregivers have and the first one that comes to mind is mobility management having Mobility manager to help a caregiver find the options that will work best for their care recipient could be just the thing that a caregiver needs to have you have them access your service travel training is another common service that a lot of agencies have that caregivers probably don't know about and this is a perfect thing for the caregiver who says hey my person just doesn't know how to do this she's never done it so travel training it's a service that could be expanded on to health caregivers bus buddies is another great program um maybe not everyone has this but it's a relatively common program and that's a great support and a great response for caregivers will say you just can't go alone now I would send my mom if there was a volunteer bus buddy to ride with her that would make me feel comfortable comprehensive driver training another thing that you guys do but caregivers don't necessarily know about it they don't know how the drivers are trained and this is actually another area that could be enhanced or individualized to meet the caregiver's needs better I mean there might be an opportunity for a caregiver to help provide some training to the drivers if it's going to be an ongoing service that would provide the training that the driver needs and comfort for the caregiver to realize that they're going to be okay uh as mentioned before first mile Last Mile Services this is not a concern unique to caregivers and it's something that Transit providers are working on a lot so this can also be worked out with a caregiver and then door to door and door through door services are definitely

things that would appeal to caregivers some people are not concerned so much about how things are going to go on the ride it's how you're going to get them ready for the ride into the actual vehicle and then to where they're going so these are services that are common to be provided that could be really beneficial for carriers especially if they could be modified a little in certain situations some other services that also can make Transportation more realistic for caregivers include again things that you may already provide such as the fact that caregivers could ride along 3 in charge this may make a big difference to our caregiver um cashless payment options is another helpful service removing the need for the person to carry cash or having count out change is that is a great service for a caregiver reminder calls now this sounds really simple but um I can set up an appointment or a transit to pick up my mom to take her to her hair for an appointment for example but by the time the person arrives my mom's not going to remember and I know I could remind her but I'm working and I won't forget so it's just something simple like providing reminder calls could be really helpful for a caregiver um having adding the ability for the uh the driver to stop at the pharmacy after a medical appointment again a relatively simple thing that can make a lot of difference to a caregiver any small barrier that can be removed can be the difference between a caregiver accepting the ride or saying you know never mind I'll just do it it's sincere to do it myself right and then I've highlighted the last bullet which is Outreach to caregivers about Transportation options caregivers as I said just don't really know about what's out there so getting doing a better job at outreaching specifically to caregivers could really help improve your services

When I take just a little just a pause here to talk about something a little different um and that is how you would talk about transportation to caregivers and caregiver support professionals. So in the world of caregiver support, respite is a real big buzzword it's an integral part of supporting caregivers. Respite care is just huge um and respite is defined as a short rest for a short break from something difficult. And for caregiver support to respite care is typically provided by a home care worker, for let's say going into the home taking over caring for the care um carrying taking over the caregiving responsibilities so the per caregiver can get out and do something for themselves or it might be provided respite might be provided through a day program where the person would go for socialization and some supervision and activities and maybe meals for a few hours for the day and again this allows a caregiver to go to something else but respite could also be defined as having someone take over a responsibility or a task to give them a break now we know from the statistics that transportation is on the to-do list of 80 percent of caregivers.

So we know then that if we could provide transportation and take that off of their to-do list and we are in essence giving them respite because we're giving them time to do something else so as you were talking about transportation with caregiver support professionals and caregivers instead of um introducing it as sort of a different service that might be helpful Freeman as a respite if you say transportation is a type of respite, it might be seen as a more legitimate service to consider

promote and use so and it might get the attention of caregivers and caregiver support professionals and help them to be more open to it so that's my buzz for the day is thinking about Transportation as restful.

Another way to improve services to caregivers is to really intentionally seek caregiver input filing out from caregivers themselves what it is that they want and need is really the best way to improve Services each caregiver has different needs and may have different responses. And so I think it's just super important to do what you can to get input from caregivers this means you're going to have your surveys for your coordination plan get them to caregivers take them to caregiver support meetings or events interview caregivers if you can or caregiver support professionals and get their input on how Transportation could serve them better you may consider convening a focus group made up of caregivers in all of these ways you're going to be learning how to better serve your family caregivers in your community.

How are you going to find these caregivers and that's going to lead me to the next piece of next suggestion and that is to connect with caregiver support agencies and challenge you to learn about the caregiver support programs that are available in your community and discover where they intersect with your transportation programs and there's a Venn diagram again support um find out what kind of support programs are available you'll likely find support groups or classes there might be a caregiver conference that's happening those happen frequently in November during caregiver family caregiver now are there things that your agency could do you could perhaps provide transportation to the conference you could have a vendor booth at the conference or provide a presentation about your services at a support group um see if there's day programs in your area day programs are a wonderful support to caregivers it's especially a wonderful support if transportation is provided so the caregiver doesn't have to drop off and pick up their loved one at the at the day program um what about home care agencies they are find out what what's available in your community and then talk to the providers and find out where your programs intersect because they certainly do so as you are forming relationships with these agencies you may end up wanting to invite one of them to participate in your transportation Coordination Committee or they may find that they would like you to join a caregiver Coalition because they too are seeking other agencies to help talk about improving caregiver support having these collaboration really break down those silos and improve the kinds of services you can offer you could even consider partnering on some mutually beneficial projects as I mentioned earlier providing transportation to conferences or for a Day program but you've got to get conversation started not sure why my slides keep jumping on me.

I like Helen Keller's quote here alone we can do so little but together we can do so much so you know I think this is a really big takeaway I want you to go with away with and that is seeking out these caregiver support agencies and getting to know these programs and work together with them I want to close by sharing a few examples of programs that are working directly to serve family caregivers you'll see



how Community Partnerships between Transportation providers and agencies that support caregivers can result in some really great programs my first example is a program that the Bayside Community Network has in Elkton Maryland Bayside Community Network offers residential and day programs for adults with disability developmental disabilities and they provide tailored transportation for all of their services which includes camps for kids with disabilities day programs social and recreational outings employment volunteering Etc they have partnered with their local Transit Agency to provide the transportation for their services this Transit Agency also provides travel training to their participants that's designed to meet the needs of people with disabilities so for example we give a longer time to learn the skills and they present materials in different ways such as they use more visual diagrams and more verbal rather than written directions that enables for people to understand and learn the materials they also place value on the importance of providing a consistent driver which really can make all the difference in the world to helping someone get comfortable using transportation their overall idea is to meet people where they're at and get them successful at their transportation programs so this is a really great example of the transportation and caregiving program partnership that benefits everyone

The next example is the Area Agency on Aging of South Central Connecticut who has a chaperone Transportation program that utilizes a program called trust and rights certified this program uses volunteers as chaperones to provide door through door service so the volunteer here does not drive but instead companies the person to a medical appointment the volunteer will meet the person in their home help them get ready for the appointment and then stays with the person um on the right to the doctor or the medical facility and through the entire appointment and is there when that's time to go home and then on the way home the volunteer can also assist with filling the prescription and get some settled back at home after the appointment they're really hoping to expand this to include non-medical rights as well and it's providing really great support for caregivers and it's a good example of a partnership again the last example is a Home Care Agency in Saint Cloud Minnesota called home watch caregivers this agency offers the typical Home Care Services where they send personal care workers goes into the home to provide care but it also has a volunteer driver program by separating out the transportation services the personal care workers are freed up to provide the type of work they are trained for then the transportation service that they're providing is a door through door which we know is a critical piece for serving older adults and people with disabilities so volunteers are providing reminder calls in these cases and they're also their trips include up to two stops so there's a really high demand for this service and it's another great example of transportation and caregiver support agencies working together to serve caregivers and then my final example is a partnership between a dementia friendly Coalition in Rock County Wisconsin and the Transit Agency who are working together to provide dementia friendly transportation and you're going to learn more about this in an upcoming module and that's the end of my presentation I have a list of resources here that might be

helpful for you and these are also going to be found on the course page and I really encourage you to check them out.

I look forward to interacting with you in the discussion forum please feel free to ask me anything suggest some ideas I might not have addressed or haven't thought of um and share with me a response to the suggestions I offered and please let me know if there are barriers that you are facing as your serving caregivers are thinking about certain caregivers I'd love to keep the communication in this conversation about transportation and caregiving going so I look forward to interacting with you um in the Forum thank you so much and have a great day.

**Eileen Schroff:** Thank you Jane so much um we only have about a minute left in our recording so maybe we can just do one follow-up question that I had. You talk a bit about the community caregiver support programs and the great work that they do but also the difficulty that some people have and not knowing where to find that support both individual caregivers and maybe professionals so where are these programs housed and how my professionals be able to connect with them?

**Jane Mahoney:** yeah um many of the family caregiver support programs are housed in Area Agencies on Aging or Aging and Disability Resource Centers Human Services often have caregiver support programs that could connect you with the agencies that do provide that support as well as like centers for Independent Living also the Alzheimer's Association is available in most communities so there's a lot of professionals out there but I would probably start with your Area Agency on Aging.