



## **Webinar Transcript:**

### ***Transportation, Dementia, and Caregiving***

**April 25, 2018**

**Julie Dupree:** Good afternoon everyone, and thank you for joining us for this webinar on dementia, caregiving, and transportation. My name is Julie Dupree and I am with the National Aging and Disability Transportation Center. We have a few quick housekeeping items that will make your experience more enjoyable. We are delighted that you are all with us today to address this important topic and we look forward to having you as a part of this webinar. This session is being recorded and will be available as an archive on the NADTC website. Closed captioning is available for today's session, and you can access captioning by clicking on the CC icon at the top left of your screen, or by using your keyboard command Control plus F8 together. We would like to thank our captioner for being with us today and providing this valuable service to us. If you are having any difficulty with Blackboard or any technical components of the webinar, you can email [contact@nadtc.org](mailto:contact@nadtc.org) and we will do our best to troubleshoot any problems you may be having during the webinar. One other thing before I turn it over to our moderator today. To submit questions, which can be done at any point during the session, you can either enter your question into the chat box if you are in Blackboard, or you can email your question to [contact@nadtc.org](mailto:contact@nadtc.org). A quick reminder that the chat section is public. We will address as many questions at the end of the webinar as time allows. If we don't address your particular questions, we will follow up after the event is over to

address your question. Before I turn it over to Virginia Dize, who is our moderator today, I'd like to do a quick poll. The poll is just one question, and that question is "is your work primarily on dementia and caregiving, or transportation? Or all of the above?" And to answer this question on the top left of your screen in Blackboard, there is a little box that has a lowercase A in it that enables you to respond to the poll. So again, if you do work on dementia and caregiving, press A. If you do work on transportation issues, press B. And if you do work in all areas, dementia, caregiving, and transportation, press C for all of the above. We will publish the results of the poll shortly. And with that, I'd like to turn it over to our session moderator, Virginia Dize.

**Virginia Dize:** Thank you Julie. Good afternoon everyone. Welcome to this webinar that is sponsored by the National Aging and Dis Trans Center. We are very pleased today to have a really well-informed expert panel to share their knowledge and experience with us today. I'll kick things off as you can see; I'm the Co-Director of the NADTC. And I work here at n4a – the National Association of Area Agencies on Aging. I'll be talking a little bit about the NADTC and our work in this area. And then I'll turn it over to Meredith Hanley, who is the Director here at n4a of Community Capacity Building, and she also leads our work on Dementia Friendly America.

Following Meredith will be Greg Link, who directs the Office of Supportive and Caregiver Services at the US Administration on Community Living. And then we have I think a really important aspect of this webinar, because we know that there are a combination of folks here who are participating with us who come at this from different arenas. So Steve Yaffe, who is a transportation consultant and recently retired as Transit Director with Arlington County, Virginia will be talking to us about the role of public transportation and paratransit in serving individuals with dementia and their caregivers. And he is going to do an overview of some of the options to consider that may or may not be available in your community. But I think this educational component is really a critical part of our discussion today. And then following that will be a presentation from Dr. Claudia Thorne, who is State Coordinator in Maryland of the Dementia Friends program, and is also a professor at Coppin State University in Maryland.

So with that, let me move on. And hopefully we will have some time for some discussion and as Julie mentioned, if we don't get to your question today, we will hope to respond to that question at a later point and offer you the opportunity to send an email to [contact@nadt.org](mailto:contact@nadt.org) to ask a question after the webinar as well. So moving on. I want to just mention why we here at the NADTC thought it was important to make this connection between transportation and caregiving.

We know that about 60 per of people with dementia are living in their own homes and communities. Many of them have caregivers. There are 44 million caregivers in the US. We know that an important function of caregiving is either providing or arranging transportation. On average, about 78% of caregivers actually fulfill that function. And as you can see, there are some real differences. Among Asian Americans, 9 out of 10 caregivers actually help with providing transportation. If people are white, about 78% help with transportation, and 72% of African American caregivers help with transportation. And there are I'm sure many additional nuances and differences among those populations, these are averages.

But we know that providing transportation can be a very heavy duty activity and one that takes a lot of time. We also know that unfortunately, only 23% of caregivers have used any formal transportation services. I think pointing out the importance of educating caregivers about options that may be available to help them in the community. So for those of you who are unfamiliar with the NADTC, let me just say this. The big focus of our work is all on accessible transportation of older adults, people with disabilities, caregivers, and communities. Most of our work is with professionals within the field, and with communities. We work with disability organizations, aging organizations, public transit, and other transportation providers. Primarily those are our target audiences. We have a relationship with the Eldercare Locator, so if people call our toll-free number, we connect them right away with options for rides. We do a lot of training and webinars and online courses. We have a partnership strategy, because like you all in the community, we recognize that transportation covers a lot of different arenas. The healthcare arena, the isolation area that affects so many older adults, people with disabilities

and caregivers, that we do spend a lot of time and energy developing partnerships. We also invest in community solutions and I want to point out a couple of opportunities on this slide.

These are live links to our 2<sup>nd</sup> annual photo contest. If you go to our website at [www.nadtc.org](http://www.nadtc.org), the hero photo on the homepage was the number one winner of our photo contest last year. And we use those photos in our publications, and they are scattered throughout our website. We are doing a 2<sup>nd</sup> annual competition that closes on May the 18<sup>th</sup>. Finally, I want to mention that we have a grant announcement we just announced last week. Getting Ready to Innovate. Those are planning grants that we hope to fund, up to \$20,000 each. We hope to fund up to 10 communities. Those applications are due on May 31<sup>st</sup>.

So in terms of the work that we have embarked on in the area of dementia, caregiving, and transportation, we have a couple of important objectives. One is to really do an in-depth look and explore this area that we think has been under explored. People don't say these words dementia, caregiving, and transportation usually in one sentence. We want to explore that, learn more and hopefully educate folks about opportunities for coordinating those important services. And finally, to provide guidance to communities on how to do that. On the right side of this slide are a couple of recent publications, including a brochure on dementia, caregiving, and transportation that we are particularly proud of. Those pubs are available on our website.

And finally, I want to talk about some of the things that we have done up to now. We at the NADTC have developed a working relationship and partnership with Dementia Friendly America. We did an online course on this topic and as a matter of fact, some of our presenters were faculty for that online course, including Steve Yaffe and Dr. Thorne. And from that course, there were about 130 registrants in the course, we have developed a toolkit. Now that toolkit includes links to all of the PowerPoint presentations, and access to a video from a meeting that we helped convene in Prince George's County, Maryland last December that Dr. Thorne is going to be talking about later in this webinar. All of that info is accessible in that toolkit. Finally, for those of you who are coming to the n4a conference in Chicago this year, we will be doing a pre-conference intensive on this topic, on July 29<sup>th</sup>. With that, what are the results of our poll, Julie?

So in the area of dementia and caregiving, it looks like about 7% of you all work in that area. That 20% work in transportation and about 13% of respondents, of which there are total of 59% have responded that you work in both arenas. So that's really great to know, thank you for responding to our poll. And with that, I will turn it over to Meredith Hanley.

**Meredith Hanley:** Thank you, Virginia. My name is Meredith Hanley. I'm a Director with the National Association of Area Agencies on Aging and serve as the Project Lead for Dementia Friendly America as well as Dementia Friends USA. And as Virginia mentioned, Dementia Friendly America recently partnered with the NADTC and Dementia Friendly Prince George's County to convene a local meeting on transportation and how to best serve individuals with dementia and their caregivers. And that's really what Dementia Friendly America is all about. We are on a mission to foster dementia friendly communities across the US and we now work with communities across 40 states that are engaged in the dementia friendly network of communities or are beginning the process to get involved.

I'll just provide a little bit of background on how the dementia friendly movement began. The White House conference on aging in 2015 really served as a platform to scale up work that had already started in Minnesota earlier on a program called the Act on Alzheimer's Initiative. We took that model and made it viable nationally with a lot of resources to help communities engage in this work. So in 2015, we started with a handful of pilot communities across the country. Prince George's County was one of these initial communities, and we couldn't be more proud of the work that they have done. And as I mentioned there are now lots of communities across the US engaged in this work. N4a does administer the program.

I want to briefly mention Dementia Friends as well, Claudia Thorne is the lead for that for the state of Maryland. That is a program that's all about public awareness training aimed at a general audience with the goal of changing the way people think, act and talk about dementia. You can become a dementia friend online or in-person in states that have that initiative. So with that being said, what is a dementia friendly community? Dementia Friends America believes that a dementia friendly community is one that is informed, safe, and respectful of

individuals with dementia as well as their care partners. And it's a community that fosters things that help with quality of life, such as transportation, which is a really key element in dementia friendly communities.

Just a couple of additional statistics, and Virginia had some great ones and I know Greg will have some as well. This slide shows demographically why Dementia Friends' work is so important in communities. As we know, the population is aging. Age is the greatest risk factor for Alzheimer's disease and we know the number of people with Alzheimer's disease is growing. Right now it is estimated there are five million people living with Alzheimer's disease and by 2025, so now less than 10 years away, its estimate there will be seven million people living with dementia, and that's a 40 percent increase. But not only that, people living with Alzheimer's disease or related dementia live in their communities or in their homes. And many in fact live alone. It's estimated that one in seven people with dementia live alone.

So supporting people living in in their homes with services and supports is absolutely essential, and of course transportation is a really key element of that. And Dementia Friendly America is all about community impact. This slide highlights how communities work with broad partners to become more dementia friendly. Our belief is every part of a community plays a role and to work together to take steps to create a dementia friendly culture. So whether its transportation, looking at how to best support people with dementia, or businesses supporting customers with dementia, or healthcare systems promoting early diagnosis and options for care, or communities of faith providing a welcoming and engaging environment, every aspect of a community really plays a role in helping a community to be dementia friendly. And this highlights where we are across the country.

As I mentioned, we started in 2015 with seven pilot communities, and now there are hundreds of dementia friendly communities across the United States. And we work with communities across 40 states that are directly engaged with this work. As I mentioned, Dementia Friendly America has a great website, [DFAmerica.org](http://DFAmerica.org). Our role here at the initiative is to support communities that are engaging in this work. And so we do that by laying out a roadmap that communities can pick and choose pieces from. So we have a lot of tools. We have a whole

toolkit to help groups identify which resources are most helpful to them. You can customize or download our tools – we provide webinars and have a monthly newsletter. We encourage anyone interested in this work to check out our website but also be in touch with us to discuss how we can support your efforts in this area. But next up we will hear from Greg Link with the federal perspective on resources in this area.

**Greg Link:** Thank you, Meredith. And thank you everyone for tuning into this webinar. It's great to be here. I'm with the US Administration on Community Living. I actually sit within the Administration on Aging and my office of supportive and caregiving services has responsibility for administering a number of programs and grants. But I really appreciate the opportunity to provide some perspective on family caregiving. Former first lady Roslyn Carter has been quoted as saying there are only four kinds of people in the world. Those that have been caregivers, those that are caregivers, those that will be caregivers, and those that will need caregivers. And if this is true and I suspect it is, at some point in our lives nearly every one of us will be impacted in some way by the family caregiving experience. And that experience is unique for everyone who is touched by it.

Family caregiving can range from the most simple to the most complex. It can be as simple as calling a friend or a relative to see how they are doing on a regular basis. It can be helping with or doing routine tasks for someone such as grocery shopping, household chores, or transportation. It can be assisting with meds and personal care, or it can be as complex as nursing and medical care and wound care. For a number of years now, the National alliance for caregiving and AARP have worked to better understand the family caregiving experience in all of its diversity. Through their surveys, which are typically done every five years or so, there has emerged a profile of what we can call a "typical caregiver."

This national survey looks at the family caregiving experience as it relates to children, adults, and older adults. But when we look at the national numbers, we see it's estimated there are approximately 44 million family caregivers, as Virginia pointed out earlier. And when we average the results, we come away with the typical profile. It's usually a 49 year old female

caring for a 69 year old female providing care for 24.4 hours a week for four years. And they help with four activities for daily living, they are a high school graduate with some college. The care recipients either live with the caregiver or close by and have been hospitalized approximately once per year. When we look at the numbers of family caregiver of adults age 50 and over, we see there are approximately 40 million adults who have provided care. Again most are female and the average age is slightly higher. What is also striking is that nearly eight percent of caregivers are older than 75 themselves.

For caregivers caring for someone age 50 or older, 24 percent are doing so for five years or longer. And memory problems like Alzheimer's and dementia are a bit more prevalent. When we think of caregiving, we think of two areas: one is activities for daily living – like walking, bathing, grooming, as well as instruments for daily living, like healthcare, finance, and transportation. I think anyone who has worked in the field of human services knows that transportation is critical. Without it, access to external services becomes increasingly difficult, as does access to remain socialized and engaged in your community and to interact with friends and loved ones. When you add dementia into the mix, transportation becomes even more important. Integrated transportation is a major, major service.

The Administration for Community Living was established in 2012, and here I want to talk about some of the programs and services we administer. ACL was established in 2012, and it brought together the Administration on Aging, the Administration for Intellectual and Developmental Disabilities, and the HHS Office on Disabilities. Since its creation six years ago, it has grown to help ensure all persons with disabilities and their family caregivers have the supports they need to remain independent for as long as possible. We work to maximize the independence, wellbeing, and health of older adults and persons with disabilities across the lifespan and their families and caregivers. For older adults, in general ACL administers a number of programs, in addition to the Eldercare Locator that sees approximately 20 percent of their calls each year related to transportation needs, we also fund the National Alzheimer's Disease Call Center, which is a 24 hour information line that works to connect families and individuals to resources that help address their support needs. They receive 300,000 calls per year.



ACL also administers several programs to provide support to caregivers. We also administer the Alzheimer's and Dementia supportive services program and the Alzheimer's and Dementia and specialized supportive services programs. That works on building dementia capabilities very similar to Dementia Friendly America principles. Our grantees in these two programs sometimes run these two efforts side by side. These programs replicate and translate evidence-based options for dementia and Alzheimer's to help people with dementia remain in their communities for longer periods of time. These programs in 2017 served nearly 70,000 persons with dementia and their family caregivers.

When we consider the services that are provided, the Older Americans Act requires that states and AAA's give priority to services providing care to older adults and persons with dementia. I want to show some key statistics to show that when we are looking at the services provided, we see that approximately five - well first I'll talk about transportation services under title 3B – 5.2 percent of older adults who receive transportation under title 3B have a reported diagnosis of a memory-related disease. And of that 5.2 percent, 58 percent of those individuals live alone. So that has some implications on service design and delivery. Of the transportation clients that have dementia, 64 percent use the service to get to a doctor or health care appointment. 16 use transportation to get to shopping versus 25 percent who don't have dementia and 51 percent report that having family and friends who help them arrange services.

A couple of data points for our national family caregiver support program – of those that are served, 62 percent of them are caring for someone with a memory related disease and fewer than 15 percent of those people receive trans services. Which tells me that caregivers are very heavily involved in providing transportation. What I find surprising though is the high percentage of those transportation clients who live alone. And even though that may be a relatively small number, I think it begs the question of: what do we as an aging network need to do with outreach, communication, scheduling, and having emergency backup plans? I finally just want point out a couple of resources you might be interested in. These are some tools you can download, and I also want to point out the tremendous recourse we have in the NADTC. So with that, I will turn it over to Steve.

**Steve Yaffe:** Mobility is critical of course to maintaining ones independence and morale. And I want to use my time to talk about transportation specifically because it really comes in a wide spectrum of services – from trains, to heavy rail, light rail, buses, to smaller vehicles. This slide is concentrated on the bigger transit vehicles – trains, street cars, most bus services operate on regular routes just service assigned bus stops. People with dementia accompanied by caregivers and sometimes not, may be able to safely use transit – but bus drivers need specific training to help. Now other varieties are more flexible, such as the three examples on the right. These allow the bus to deviate off-route and someone can be picked up or dropped off at an on-demand bus stop. To do that, one would call the transportation office and the next available bus would be rerouted.

Now on the second slide, we will get into paratransit. A term basically meaning alongside transit. This is a widening variety of options including Human Services rides, public dial a ride trips, group shopping trips, and Non-emergency Medical Transportation. Paratransit service may be provided by dedicated small buses or mini-vans, taxis, buses, volunteers, and now Uber, Lyft, and similar companies.

Flex Zone transit or micro transit cover neighborhoods that cannot adequately support fixed-route transit. Now to show the economics of this, a bus route usually requires 12 boardings for every hour of service. A flex zone service can work with 4-8 boardings per hour. Dial a ride and human service transportation can be maintained with just over 2 boardings an hour, though 3 is more sustainable.

Now let me go into specific types of paratransit services, starting with adult day transportation which is typified by hand-to-hand transport where the transportation provider arranges with caregivers to meet the caregiver on each end of the trip. The client file should always have an emergency drop off option if they have to have someone receive them at home and that isn't always possible. The transportation provider also needs to know if the rider has a friend who is riding. Drivers and bus attendants if present receive training in disability sensitivity and assistance in passenger assistance techniques.

The next thing I want to talk about is the program for all-inclusive care for the elderly, also known as PACE. PACE provides an interdisciplinary medical and social service to certain frail and elderly individuals who are dually eligible for Medicare and Medicaid benefits. PACE clients can continue living in their community rather than being institutionalized in nursing homes. Characteristics of PACE transport are that every bus has a care attendant. The bus attendant is part of the care team. The team generally has weekly meetings to discuss how each client is doing. PACE provides rides to medical services, therapy, and adult daycare. PACE clients must be eligible for nursing home placement, but are given the supports needed to stay in the community.

Now ADA Paratransit is for individuals traveling in the service area but cannot ride transportation for some or all of their needs due to a disability. If you ride ADA Paratransit, you can ride for any reason you want but everyone goes through the local ADA certification process. Who qualifies? Those who don't know when to board, alight, or how to transfer between bus routes, as well as those who can't reach a bus stop due to a disability. Riders are expected to travel independently from the curb to the vehicle, and if necessary to the buildings entrance. ADA services are not door-through-door. The fare is expected when boarding, it's usually double the regular bus fare. Every rider can bring a personal care attendant at no extra charge but ADA paratransit services do not provide care attendance.

Now I'll group several types together. Dial a ride, NEMT, and group shopping recreation trips. These rides are booked one to seven days in advance. Rides can be subscription, like a group shopping trip each Tuesday with a pick-up at 10:00am to go to the local shopping market. Rides can be scheduled either by the desired pick up or arrival time. Service days and hours will vary between weekday and weekends if available. Personal Care Attendants are welcome, bus attendants are generally not provided. Fares are expected when boarding the vehicle. The exception is for NEMT. Medical transportation rides cannot charge a fare but the rides must be to a medical appointment. Please remember all that I'm describing are shared-ride programs. Not exclusive rides. By picking up and dropping off other riders along the way, more rides can be provided within budget.

Now what is transit's role in transporting people with dementia? Transit services should always train their bus drivers to take notice. Is the rider dressed inappropriately for the weather or the public? Does the rider seem disoriented? Does the rider keep asking the same questions or have difficulty understanding specific directions? Does the rider seem frustrated? Does the rider know his or her destination? If any of these factors pop up, then drivers should notify dispatch to express that concern.

How does that driver respond though? Well, we train drivers to be calm, friendly, provide good customer service. To be clear and concise using short sentences as they calmly respond to questions, and repeat answers as necessary. Most bus systems have announcements that announce that stop before the bus gets there. Some bus systems still don't have that. In either case the bus driver should remind the rider when they are approaching the riders stop. And as always a driver should ensure that seniors and persons with disabilities are seated before leaving the stop.

And I just want to close by emphasizing that transit is accessible and there are many types of transit to meet people's needs and to meet the abilities that they have to continue to travel. And now, I'd like to turn it over to Dr. Thorne.

**Claudia Thorne:** Thank you. Good afternoon everyone. It is an honor and a privilege to be here today to talk about transportation and caregiving in Prince George's County, Maryland. My intention today is to share with you a model that we utilize in Prince George's County in December 2017 to host a convening of stakeholders who were interested in dementia, caregiving, and transportation. The purpose of the convening was to design and replicate a community-based model approach for bringing together all stakeholders. How do we have a meaningful and thoughtful conversation that explores dementia, caregiving, and transportation? And an integrated conversation because areas of the concepts are inter related. Our goal is to raise awareness, have an ongoing dialogue, and to improve and expand transportation options and systems.

As you can see, a flyer we used to advertise this particular conference – the faces are smiling. They're happy. Because we are dementia friends and our goal is to provide hope and support.

I'd like to put Prince George's County in context. We are right outside of Washington, D.C. The land mass is 499 square miles. The population is 912,756. We are 65 percent black African American, 26.5 percent white, and 17.8 percent Latino. There are 12.3 percent of persons in our population living over the age of 65. Once again, our convening of the stakeholders. We provided a forum to explore the current state of transportation for persons living with dementia and their care partners. We were very interested in the lived experience of people living with dementia and their care partners. We wanted to hear first-hand and identify existing resources in the private and public sector so we can continue to dialogue and work with other transportation resources to ensure services provided are more dementia friendly. We want to stimulate interest to improve dementia friendliness of current transportation services.

We in Prince George's County are very proud of what we do. We were one of the first dementia friendly communities. Our county Executive Rashern Baker has a personal interest in this area, and we wanted to share the good work that we are doing with the rest of the country. So looking at our story within the context of best practice, we wanted to look at what we do within the context of the five A's of dementia friendly transportation. Those five A's are, number one: are the services available? And are the services that are offered promoted as supportive transportation? Number two, acceptability. Are they acceptable? Are special needs attended to? With respect towards mainstreaming them into the transportation system. Number three, are accessibility are services accessible? Are they easy to use because we offer supportive assistance? Number four, are services adaptable? Can services adapt to meet the needs of individuals? And number five, are services affordable? To what extent are services affordable for people with dementia and their family members? Are services offered low cost and are they financially sustainable? This is the standard, the Five A's for dementia friendly transportation.

So we started our conference that was attended by a lot of people with panel presentations. These lasted five to seven minutes each and consisted of transportation experts, volunteers, local governments, and the metropolitan area transportation authority. We wanted to really

look at and explore what are the transportation resources for persons living with dementia and their care partners? And also as part of this panel we had one care partner and one person living with dementia to really talk about from their perspective about how transportation as an essential service impacts the quality of their life.

We started our process with the voices of people living with dementia and their care partner because we believe they are the experts. One care partner said “Mom cannot travel by herself. She has to have someone with her. I take her to her doctor appointments and anything else that she wants to do. She wants to stop at the grocery store. She goes to church every week. She goes to the hairdresser. It is important that she maintains her quality of life.” This particular care partner says sometimes transporting her mother is an all-day enterprise. A person who is living with dementia stated that “I have a good support group and I am grateful for that. I get around by Metro Access. If I did not have the Department of Aging helping me I would be in my house. I would not know what was going on. I still feel relevant, which is so important to me. It is really important to emphasize these voices because transportation is just not about medical visits.

So our transportation experts that presented included a person who led volunteer transportation programs. The volunteer sector is very important because it is local volunteer-led, grassroots neighbor helping neighbor. Transportation information helplines are also provided as a part of this. Sarah Fawt helped talk about the village network. There are over 200 village networks across the United States. The Department of Public Works and Transportation in Prince George’s County described the services that they provide. They provide public transportation to seniors and disabled persons, and senior transportation to nutrition services, medical programs, and program-specific transportation as well. The county also offers a call-a-cab and call-a-bus service.

The largest transportation resources within the Prince George’s County area is the Washington Metropolitan Area Transportation Authority. WMATA. And WMATA provides Metro Access. The cost was described, the procedure for making appointments, and the other services that are offered through WMATA which include travel training to help people understand independent

travel. And also safety and training requirements for Metro Access drivers, which include background checks. WMATA also offers a door-to-door service. So to move on to our focus groups.

Our focus groups asked five separate questions. Focus group question number one: where are persons with dementia and their care partners traveling to? Question number two: what types of transportation are utilized? Question number three: to what extent are transportation services dementia friendly? Question number four: what kind of supportive services are needed? And number five: How can the current system be improved? The focus group, if you are going to do this at the local level, it is really important to establish and set the tone for the focus group to have very open and honest conversations. And to make sure listening is respectful and everyone can share their voices. We also wanted to keep the focus on transportation, since the focus of this particular group was on transportation. The focus group leaders set the foundation and told people what would happen next over the next hour. We also provided notebooks and tablets to record the session.

So the destination, the most popular destination for caregivers and persons with dementia are medical appointments. People do spend a lot of time going on doctor visits. Going shopping, grocery shopping. Church, not just on Sunday but there are weekly church activities, there is daily mass. The other destinations were social, leisure, and recreation activities, exercise, going to medical day care, banking, going to the hair dresser or the barber, and other social destinations. People with dementia may have very different priorities than their care partners.

The persons living with dementia are very interested in visiting their friends and having social interaction. Their priority is staying active, relevant, and staying connected to the community. For care partners, the focus is on the business aspect of getting people where they need to go. So that's the destination. So people living with dementia and their care partners are going to many different places.

Transportation like every other aspect of caregiving, families provide more here than any other resource. Families and extended families are the most important resources in transporting people with dementia. And there are many individuals living with early stages of dementia who

are still driving. As people move more deeply into caregiving, the demands for transportation grow, and many individuals who are caregivers find themselves adjusting their work lives to either ensure an early retirement, or they move into consulting so they have the flexibility that is required to take their family members where they need to go. There are challenges in utilizing related systems related to cost, crossing jurisdictional boundaries, and the limits of what is available in certain parts of the county.

So what about supportive service? As I mentioned earlier, family and friends are providing back-up driving support. And when they aren't available, a backup option is needed to support their loved one with dementia getting to where they need to go. And while people do know about the transportation resources that are available, the information needs to be more centralized and broadly disseminated. There is also the need for a person to have a non-medical companion or aide who is going along to provide care and to support travel. If the caregiver needs to take a break, what does one do? Caregiving is very complex. It involves multiple persons, it is inter-generational, and there are certain risks to caregivers and it is important to caregiving because caregiving is very stressful, to get involved in self-care opportunities.

So the dementia friendliness of the system is that we found that some transportation workers are knowledgeable and compassionate, and transportation can be improved by providing training to staff. Recommendations for improvement include providing financial support, affordable transportation options, and more information on services that are available. For metro access, we wanted to expand scheduling and access to reduce trip time and to have frequent communication updates. And also in this very fluid geographical area, we wanted to make sure that there were fluid boundaries to improve access.

We also wanted to look at expanding our call-a-bus program. For information dissemination, because there are so many different organizations that are involved with transportation, we really wanted to look at centralizing and distributing transportation resource information to various support groups and senior centers. And more information is needed on available transportation resources and services. And customer service becomes really important. We



want to be able to provide van rides to assist drivers in providing door-to-door and curbside services. We want to also train transportation workers on dementia to develop their capacity to provide dementia friendly services. So it was a very rich conversation and some work has already started prior to the conference and has been ongoing since the conference.

In the City of Greenbelt in Prince George's County, they just recently hired a Mobility Manager, part time to assist with transportation for seniors and people with disabilities. And the Prince George's County government is beginning conversations with Dementia Friends on exploring Dementia awareness and sensitivity training for its workers.

And then to support you, should you want to and we hope that you do, want to convene a similar conference, here is a list of tasks that we engaged in. One of the greatest incentives we had is that we provided lunch and also provided on-site respite care. So that caregivers who don't have a way of coming out without someone providing care of their loved ones, we were able to provide respite care on site, as well as transportation vouchers were provided by the county for this. So I thank you, and moving forward.

**Virginia Dize:** Well thank you Claudia. This is Virginia gain. Our partnership with Prince George's County just been really exciting, and we look forward to continue to work in partnership with and support them. Because we recognize that a community meeting, which takes a lot of work and time, can just be the beginning, as they say in Casablanca, the beginning of a beautiful friendship. But it does take time. Lots of time. In Prince George's County, a lot of the people who were involved in this effort are either volunteers, or caregivers, or both. And not everyone has the luxury to take off a day to plan a meeting. So it is going to take some time, it's going to take some hard work. And it takes persistence to keep things going. I also think it's important for everyone engaged in this work to really have a clear sense of how they want to see their community improved.

So if there are opportunities like grant funding opportunities such as the NADTC grant opportunity, or regular funding cycles you can become a part of, like for example at the local level, it is essential for drawing down some federal funds. And are there opportunities to bring in new supporters who can work on this effort? We do also include links to all the resources we

mentioned. I do want to say that the dementia, caregiving, and transportation toolkit includes a link to a report that Dr. Thorne did on the meeting in Prince George's County. It's a tremendously important resource. And finally, we are now finally at the point where we can talk with you all and open it up for questions. And I know that we have a couple of questions already.

**Greg Link:** The question I received was, how many ACL participant surveys were there, and can you provide a link to more details on the data? So we have different sample sizes in each of the groups, I don't know how large the transportation sample is, but I imagine it will be in the neighborhood of 1100 to 1200, and all of the survey results are publicly available on the ACL website, at [agid.acl.gov](http://agid.acl.gov) and that takes you to our data warehouse and it has a lot more than just the national survey data. It's pretty comprehensive and it's all publicly available.

**Virginia Dize:** Thanks Greg. I think we also have a question that was directed to Steve. So I'm going to move the phone.

**Meredith Hanley:** The question for Steve was "you mentioned things that bus drivers should look out for when people have dementia. Have you trained transit staff on interacting with people with disabilities?"

**Steve Yaffe:** I have reviewed programs, and training programs generally include a trainer in the program with a disability to sensitize new bus drivers as to the mobility needs of people with physical, sensory, and invisible disabilities, some of which may be cognitive. Within that, there is a second component of any good bus operator training program, and that's behavior management. The bus driver should think of themselves as a Loveboat Captain – captain of the ship, but a calming influence. So they need to be trained not to escalate, speak calm, slowly and to the point. And repeat if necessary. This is in addition to all the other training drivers receive. I

should have mentioned there is priority seating behind the driver on every bus, that's federal law. And then the third component is something I learned from Houston Metro. And that's to have monthly all hands on-deck training for everyone. We would bring in riders with different types of disabilities. And the usual format is, they start speaking thank you for what you do every day – it is so important for me to get around. Thank you for kneeling the bus, for deploying the ramp, and so on. And they get into Q and A. And some of the questions and answers are pretty interesting, especially since the labor force I last worked with was primarily foreign-born. It gets to a meeting of the minds so it gets to a mutual understanding of the importance of what I do.

**Virginia Dize:** This is Virginia again. We have another question. It is a question about partnership and how the partnership with the NCMM and/or travel trainers been explored to help address the objectives listed as well as assist with this project?

And I can say that the NADTC is one of four national training and technical assistance centers funded by the Federal Transit Administration, as well as the National Center for Mobility Management, and the National Rural Transit Assistance Program, and also the Shared Use Mobility Center. So we are in constant communication with one another. We share notices about what's going on in our different newsletters. And the FTA periodically convenes all of us to talk with one another to ensure that our work is complementary. That where there are opportunities where we can work together, that we are well aware of it.

We have funded projects that are focused at the local level on travel training, and we have utilized the resources that are available through our – NADTC we are a partnership between n4a and Easterseals, which is where Julie works. And we work together very intimately and closely. And actually Julie Dupree is a nationally recognized expert on travel training, and Easterseals has a curriculum that lots of local communities have adopted on travel training. So yes, partnerships is something that we try to ensure always happen at the state, local, and national levels.

With that, we are just about at 3:30. Amazingly enough. I think that's the last question we have that has popped up in the chat box. I do want to remind everyone that we want to hear from you.

Did you learn something, did you find that this webinar met your needs? Do you have suggestions from other webinars or ways we could improve this webinar? We would really like to hear from you. It's a simple multiple-choice questionnaire, so we hope you will seize the opportunity to tell us what you think. And if you have additional questions, we welcome those. Those should come to [contact@nadtc.org](mailto:contact@nadtc.org), and we thank you for your time and attendance this afternoon and I especially want to acknowledge our wonderful speakers. And with that, we'll sign off. Good night. Good afternoon.

### **Conclusion of Webinar**