

Transportation, Dementia & Caregiving Webinar ~ April 25, 2018



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Webinar Agenda

Overview: NADTC and Dementia Friendly America

- *Virginia Dize, NADTC Co-Director, n4a*
- *Meredith Hanley, Director, Community Capacity Building, n4a*

U.S. Administration for Community Living Overview and Perspective

- *Greg Link, Director, Office of Supportive & Caregiver Services*

The Role of Public Transit and Paratransit

- *Steve Yaffe, Transportation Consultant*

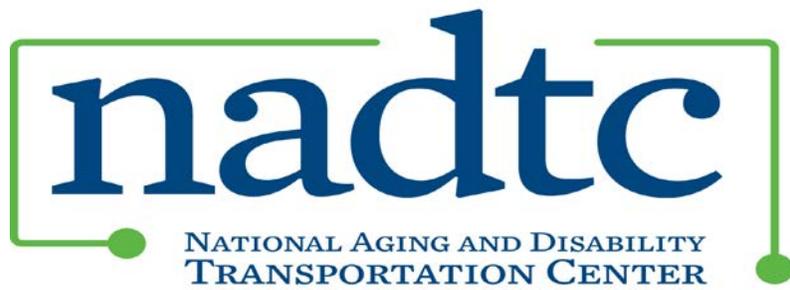
Prince George's County, Maryland: Dementia, Transportation and Caregiving Event

- *Dr. Claudia Thorne, State Coordinator, Dementia Friends Maryland*

Facilitated Discussion/Q&A

Why connect transportation & caregiving?

- Nearly 60% of people with dementia live in their own homes and communities.
- There are 44 million caregivers in the U.S.
- 78% of caregivers provide or arrange transportation
 - Nearly 9 in 10 Asian American caregivers help with transportation, compared to 78% of White caregivers and 72% of African American caregivers
- Only 23% of caregivers have used transportation services.



MISSION: To promote accessible transportation options that serve the needs of **Older Adults, People with Disabilities, Caregivers and Communities.**

MAJOR OBJECTIVES:

- Person-centered technical assistance and information & referral
- Training: webinars, online courses/forums
- Interactive communication and outreach strategy
- Coordination and partnership strategy, including stakeholder engagement
- Investment in community solutions
- Independent program evaluation

KEY STAKEHOLDERS: Transportation providers; human services providers; disability organizations; Area Agencies on Aging; State Departments of Transportation; Tribal Transit and Tribal Elder Services; FTA; ACL; and more....

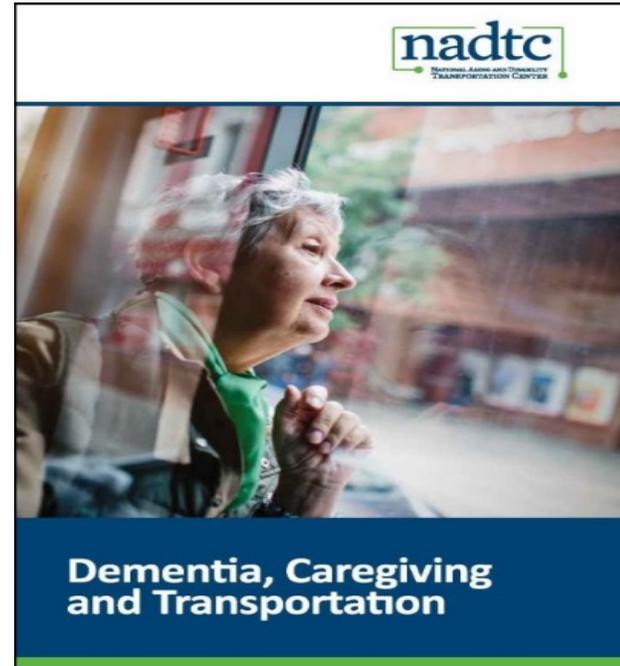
CURRENT OPPORTUNITIES:

- [2nd Annual NADTC Photo Contest](#) Entry deadline: May 18, 2018
- [NADTC Grant Announcement: Getting Ready to Innovate](#). Application due date: May 31, 2017



OBJECTIVES

- Provide an in-depth look at the transportation needs and concerns experienced by family caregivers, particularly caregivers of individuals with dementia.
- Provide guidance on community approaches for connecting transportation and caregiver networks.



ACTIONS

- Partnership with Dementia Friendly America
- Online Course & Toolkit
- Partnership with Dementia Friendly Prince George's County to convene local meeting with caregivers and individuals living with dementia
- Pre-Conference Intensive at n4a Conference: July 29



The *Dementia, Caregiving and Transportation* toolkit was adapted from NADTC's Winter 2017-2018 [online course](#) which provided an in-depth look at transportation needs and concerns experienced by family caregivers, particularly caregivers of individuals with dementia, and offered guidance on community approaches for connecting transportation and caregiver networks.

NADTC recognizes the vital role of caregivers in providing transportation to older adults and people with disabilities, while acknowledging the challenges of providing ongoing care. It is important to help caregivers and individuals learn about how to access information about community transportation services, the range of transportation options that may be available, and important considerations for matching transportation options and specific care needs, particularly for individuals with dementia.

If older adults or people with disabilities don't have access to public transportation or don't know how to use it safely, they risk a loss of independence, isolation, and increased dependence on family and friends for everyday errands and essential medical or personal appointments. Based on the work showcased in the NADTC course, we believe that transportation challenges faced by caregivers of individuals with dementia can be helped by bringing together transportation and caregiving programs to develop community-specific solutions.

The written and video materials in Sections 1 and 2 were developed as a comprehensive review of the issues. However, the individual presentations as well as the two sections may be viewed independently.

KEY FACTS

- Nearly 60% of people with dementia live in their own homes and communities.
- 44 million caregivers in the U.S.
- On average, 78% of caregivers provide or arrange transportation.
- Nearly 9 in 10 Asian American caregivers help with transportation, compared to 78% of White caregivers and 72% of African American caregivers.
- Despite need for support, only 23% of caregivers have used transportation services.

Sources: Dementia Friendly America; AARP & National Alliance for Caregiving; *Caregiving in the U.S.*, 2015

Fostering Dementia Friendly Communities



Dementia
Friendly
America®



Dementia
Friends
USA

A Dementia Friendly America initiative



April 25, 2018 Webinar

Meredith Hanley

**Director, Community Capacity Building,
National Association of Area Agencies on Aging**

mhanley@n4a.org



Dementia Friendly America

- Dementia Friendly America (DFA) launched at 2015 White House Conference on Aging
- DFA goal is to catalyze a movement to more effectively support those living with dementia and their care partners
- Modelled after Minnesota's ACT on Alzheimer's
- National Association of Area Agencies on Aging is fiscal agent and program administrator for DFA.
- Dementia Friends is a program within Dementia Friendly America that focuses on individual-level impact
- www.dfamerica.org and www.dementiafriendsusa.org

What is a Dementia Friendly Community

- A dementia friendly community is informed, safe and respectful of individuals with the disease, their families and caregivers and provides supportive options that foster quality of life.
- Joining DFA means a community is engaging in a process to become more dementia friendly

The Growing Need

Impact on persons with disease and caregivers

By 2025, the number of people age 65 and older with Alzheimer's disease and other dementias is estimated to reach 7.1 million – a 40 percent increase from the 5.1 million age 65 and older affected in 2015¹



Nearly 60% of people with dementia live in their own community homes



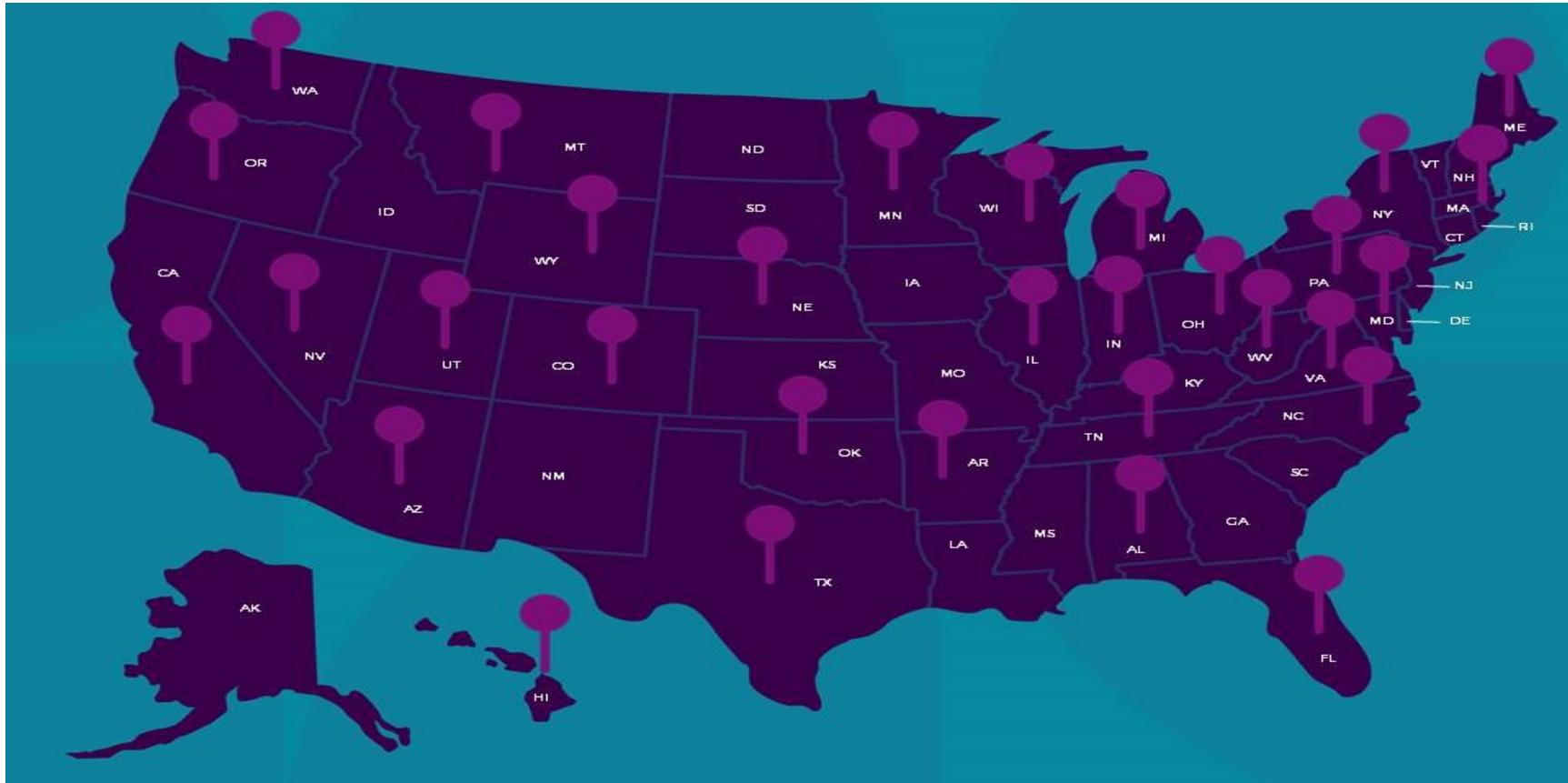
1 in 7 live alone



Dementia Friendly America is all About Community Impact



In Communities Across the Country



Goal is to have a DFA community in each state across the country and expand relationships with existing states/communities.

Online Tools and Resources

**Communities where all people
can live, age and thrive**

[LEARN MORE](#)



The Dementia Friendly America tools and resources help communities work toward dementia friendliness.

[Access Our Tools & Resources](#)



The Dementia Friendly America initiative is on a mission to catalyze a nationwide movement to foster dementia friendliness.

[Discover More About This Initiative](#)



Communities across the country are working to support those with cognitive impairment and their care partners. Is yours ready?

[Learn How To Join Us On The Map](#)

www.dfamerica.org



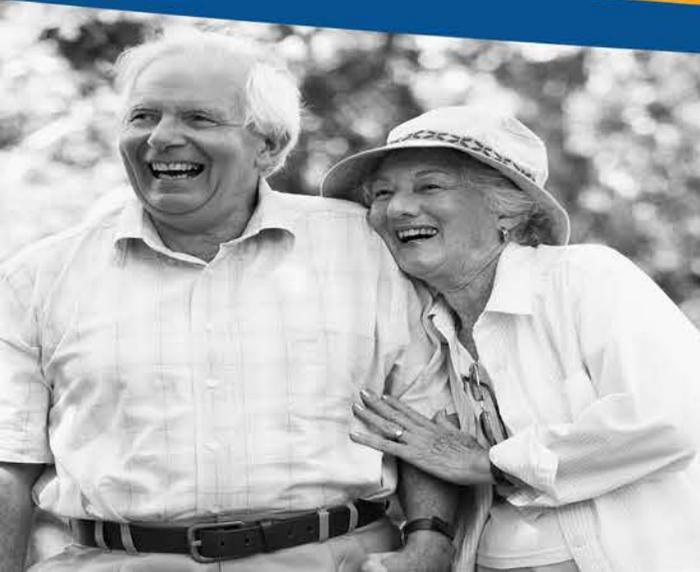
Addressing Transportation, Dementia and Caregiving

April 25, 2018

Greg Link, MA

Office of Supportive and Caregiver Services

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Family Caregiving Is.....

- Regularly looking in on or calling a friend or loved one to see how they are doing or if they need assistance
- Helping with, or doing, routine tasks for someone, such as grocery shopping, bill paying, household chores, or transportation
- Assisting someone with medications or personal care tasks
- Communicating with health care professionals or other providers, services and agencies
- Performing complex medical/nursing tasks like wound care or operating medical devices

A Profile of the “Typical Caregiver”

- **Who they are**
 - 49 year old female
 - Caring for 69 year-old female relative that needs help with a long-term physical condition
- **What they do**
 - Provide care for 4 years
 - 24.4 hours per week
 - Helps with 2 ADLs/4 IADLS
 - Do medical/nursing tasks
 - Have no assistance or formal training
- **Work and Career**
 - Is a H.S. grad/some college
 - Employed and working full time
 - Average household income: \$54,700
- **Care Receivers**
 - Live with the caregiver or close by
 - Hospitalized once in the past year

Family Caregivers of Adults Age 50+: The Numbers

- 34.2 million adults (14.3%) in the U.S. provided care to an adult age 50 and older
- 60% of caregivers are female
- Caregivers of someone age 50 and older are 50+ years old themselves
- Nearly 8% of caregivers are 75 years of age or older
 - 24% provide care for 5 years or more
- Nearly 30% say the care recipient needs help because of a memory problem

Source: National Alliance for Caregiving/AARP, 2015

Caregivers and Transportation

- On average, caregivers of someone age 50+ help with 4.2 out of seven IADLs, including transportation (78%)
- When dementia becomes a factor....
 - Caregivers assist with an average of 4.6 IADLs
 - Are more likely to help with transportation (83%)
 - Those caring for someone age 75+ are more likely to have helped arrange transportation (82%)*
- In 2016, 21% of calls to the Eldercare Locator were about transportation

*Source: National Alliance for Caregiving/AARP 2015

ACL Programs to Support Persons with Dementia and their Family Caregivers

- National Alzheimer's Disease Call Center
- Eldercare Locator
- Older Americans Act (OAA)
 - Title III-B – Supportive Services
 - Title III E - National Family Caregiver Support Program (NFCSP)
 - Title VI – Native American Programs
- Alzheimer's Disease Supportive Services Programs (ADSSP)
- Alzheimer's Disease Initiative/Specialized Supportive Services (ADI/SSS) Programs
- Lifespan Respite Care Program

www.acl.gov



Select ACL Program Data Summary/Findings

2017 National Survey of OAA Participants – Transportation Services

- 5.2% of transportation clients report a diagnosis of memory-related disease
 - 58% of those clients live alone
- Of the transportation clients with dementia
 - 64% use the service to get to a doctor or health care provider appointment
 - 16% use transportation to go shopping (vs. 35% without dementia)
 - 51% reported having family/friends who help arrange services (vs. 23% without)

2017 National Survey of OAA Participants – Caregiver Support

- 62% of caregivers caring for someone with a memory-related disease
- Fewer than 15% of care recipients received transportation

Charting your Path to Success: Tools & Resources

National Alzheimer's and Dementia Resource Center ([NADRC](#))

- Report: [Identifying and Meeting the Needs of Individuals with Dementia Who Live Alone](#)
- Report: [Tools for Screening, Identification, Referral, and Care Planning for People With Alzheimer's Disease and Their Caregivers](#)

National Aging and Disability Transportation Center ([NADTC](#))

- Training and Webinars
- Resources and Publications

The Role of Transit & Paratransit



Steve Yaffe

Transportation Consultant

Transit Services Manager Department of
Environmental Services – Transportation
Division (Recently Retired)

Arlington County, Virginia

The Transit Spectrum is Wide (1)

Fixed Route Transit



Transit is Accessible

Bus



Streetcar



Neighborhood, small city or rural circulator

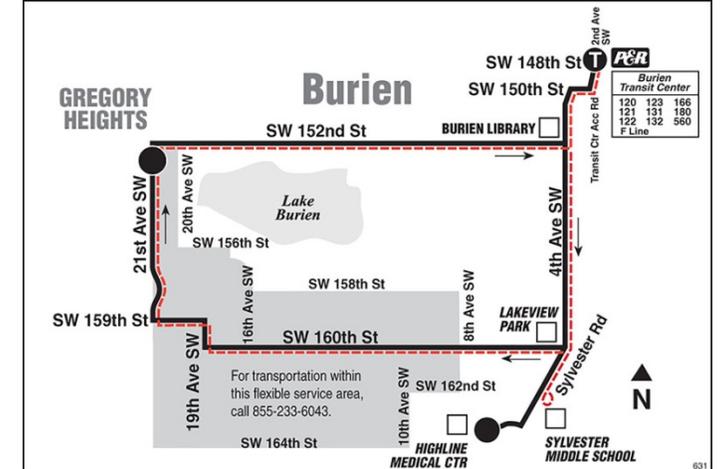


Light Rail



Heavy Rail

Flexible Transit



MAP LEGEND

- Makes all regular stops.
- - - SNOW route. Ruta para casos de nieve. Alternative/flexible service area.
- TIME POINT/INTERMEDIAS: Street intersection used for time schedule reference point listed at the top of time columns to estimate bus arrival and trip times.
- Ⓣ TIME POINT/TRANSFER POINT. INTERMEDIAS/LUGAR DE TRASBORDO.
- P&R PARK & RIDE: Designated free parking area with direct bus service to major commercial centers.
- LANDMARK: A significant geographical reference point.



OmniLink buses can serve locations up to ¾ mile off the route



The Transit Spectrum is Wide (2)

Paratransit

Dial-a-Ride
& Adult Day
Health Care
Transport

Group
Grocery
Trips

Shared-
Ride Taxi,
ADA &
NEMT



Flex Zone Transit



Volunteer-Based
(and agency
transportation) can
be curb-to-curb,
door-to-door or
door-through-door

MicroTransit

Denver RTD Call-n-
Ride connects those in
defined zones with a
light rail station



Taxis, Lyft & Uber
are partnering with
municipalities to
provide rides in
defined zones.

Paratransit's Role in Meeting the Transportation Needs of Persons with Dementia and Their Caregivers

Adult Day Health Care Transportation



- **Hand to Hand Transport**
 - **Arrange with caregivers to meet the driver and rider at the building entrance**
- **Can the rider return to an empty house?**
 - **Check to see if Rider Has the house key**
 - **Client file should have an emergency drop-off option**
- **Does the rider have conflicts with other riders or have a best friend riding too?**
 - **Use a seating chart to keep people apart or together**
- **Does the rider resist using seatbelts or behave unsafely when riding?**
 - **Assign that rider to a bus with an attendant**

Paratransit's Role in Meeting the Transportation Needs of Persons with Dementia and Their Caregivers

Program for All-inclusive Care for the Elderly (PACE)



- Every bus has an attendant
 - Attendant goes into the house to assist the rider put on a coat and observe conditions inside.
- Bus Attendant is part of the care team
 - Team has weekly meetings to discuss each client
- Rides are provided to all supportive services
 - Medical appointments, therapy and adult day health care
- Clients must be eligible for nursing home placement, but have the supports necessary to live safely in the community.
 - <https://www.medicaid.gov/medicaid/ltss/pace/index.html>

Paratransit's Role in Meeting the Transportation Needs of Persons with Dementia and Their Caregivers

ADA Paratransit



- ADA Paratransit is for those traveling within the transit service area who cannot ride transit due to a disability.
 - **No restrictions on the purpose of the trip**
- Everyone must go through the local ADA certification process
 - **Those who don't know when to board, alight or how to transfer qualify.**
- Riders are expected to travel independently, either curb-to-curb or if necessary, door-to-door
 - **ADA paratransit services are not door-through-door. No hand-offs.**
- Every rider can bring a Personal Care Attendant (PCA)
 - **ADA paratransit services do not have bus attendants**
- Fare is expected when boarding, usually double the regular bus fare
 - **Some systems have a pre-payment program**

Paratransit's Role in Meeting the Transportation Needs of Persons with Dementia and Their Caregivers

Dial-a-Ride, Non-Emergency Medical Transportation (NEMT) & Group Shopping/Recreational Trips



- Rides generally must be booked 1-7 Days in Advance
 - Rides can be subscription (regular standing order)
 - Rides can be booked by preferred pickup or arrival time
 - Service days and hours vary
- Service may be curb-to-curb or door-to-door
 - PCAs may ride. Attendants generally not provided.
- Fares expected when boarding the vehicle
 - Some systems may have a pre-payment option. No charge for NEMT trips, but rides must be to an NEMT-paid service.

Transit's Role in Meeting the Transportation Needs of Persons with Dementia and Their Caregivers

Using Public Transit



Train Bus Drivers to Take Notice:

- Is the rider dressed inappropriately for the weather or for the public?
- Does the rider seem disoriented to surroundings?
- Does the rider keep asking the same questions?
- Does the rider have difficulty understanding simple directions?
- Does the rider seem frustrated?
- Does the rider know his/her destination?

Transit's Role in Meeting the Transportation Needs of Persons with Dementia and Their Caregivers

Using Public Transit



Train Bus Drivers to Respond:

- Be Calm, Friendly & provide good customer service
- **Be clear and concise. Short sentences.**
- Calmly respond to questions (and repeat answers)
- **Remind the rider of the upcoming stops**
 - Assure the rider that you will remind him/her when approaching the stop
- Be patient & reassuring
- **Notify a supervisor of the rider and where you drop him/her off**

Thanks for your interest

Steve Yaffe

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Dementia, Caregiving, and Transportation in Prince George's County, MD: A Model for Replication

Dr. Claudia Thorne

Dementia Friends Maryland

April 25, 2018

drclaudiathorne@gmail.com

2022367543

Convening Purpose

The purpose of the convening is to provide a replicable community-based model approach for bringing together persons with dementia, care partners, and transportation networks to raise awareness about the transportation needs and to improve and expand transportation systems for this population.

Dementia Friendly America - Prince George's County
presents:
Dementia, Caregiving & Transportation

Challenges & Opportunities for Addressing the Mobility Needs of Individuals with Dementia and Their Caregivers

December 4, 2017, 9:30 am -1:00 pm
Prince George's Ballroom
2411 Pinebrook Avenue
Landover, Maryland 20785



Please note: This event will be videotaped.

- Lunch will be provided.
- Respite care is available on a first come basis.
- A Thank-You gift of \$20 in Call-a-Cab coupons will be available to all attendees 60+ attending the conference and care recipients transported by caregivers.
- For more information, please contact atillery@pickettfences.org or call 301.358.2066



Transportation & Dementia Convening

- u This convening provided a forum for stakeholders to explore the current state of transportation for persons living with dementia and their care partners.
- u Presentations on the lived experience of care partners and persons living with dementia in navigating transportation systems.
- u Opportunity to identify existing resources and to continue to develop transportation resources.
- u Stimulate interest to improve the dementia friendliness of the transportation system.
- u Highlight efforts within Prince George's County, MD at a national level.



5 A's of Dementia Friendly Transportation

- u Availability: Services are available to people with dementia and to their family members. Services are offered and promoted as supportive transportation.
- u Acceptability: Services are acceptable to people with dementia and to their family members. Special needs are attended to with respect to mainstreaming them into the transit system.
- u Accessibility: Services are easy to use because they offer supportive assistance and get people where they need to go.
- u Adaptability: Services can be adapted to meet needs. Services accommodate needs for schedule reminders and help at destinations.
- u Affordability: Transportation services are affordable for people with dementia and their family members. Offer low cost financially sustainable services.

Beverly Foundation, 2001

Panel Presentations

- u 5-7 Minutes
- u **Transportation Experts:** What are the transportation resources in the community for persons living with dementia and their care partners?
 - Volunteer Sector
 - Local Government
 - Metropolitan Area Transit Authority
- u **Care Partners and Persons Living with Dementia:** How does transportation, as essential service, impact the quality of life?

Voices of Persons Living With Dementia and Care Partners

- u Mom can't travel by herself...She has to have someone with her. I take her to 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...

Care Partner

- u 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...

Person Living With Dementia

Transportation Resources (con't)

Volunteer Transportation Programs.

- u Local Volunteer Led. Grass Roots. Neighbor helping neighbor.
- u Community Orientated and Geographically Focused.
- u Transportation Information Helpline

Prince George's County

- u Trips to seniors and disabled persons.
- u Senior Transportation Service
 - u Nutrition
 - u Medical Program Service
 - u Program Specific
- u Call-A-Cab
- u Call-A-Bus

Transportation Resources

Washington Metropolitan Transportation Authority (WMATA)

- u Metro Access
- u ADA Compliant Public Transportation
- u Cost
- u Appointments
- u Travel Training to help people to understand the existing system
- u Training Requirements for Metro Access drivers, Background Checks
- u Offer Door-to-Door Service
- u Allows Personal Care Assistant and Companion Care

Focus Group Questions:

- 1: Where are persons with dementia and their care partners traveling to?
- 2: What types of transportation are utilized?
- 3: To what extent are transportation services "Dementia Friendly?"
- 4: What kind of supportive services are needed?
- 5: How can the current system be improved?



Focus Group Findings: Destination

- u Medical Appointments (Doctor, Physical & Occupational Therapy, Hospital, Dialysis)
- u Shopping - Grocery and other shopping
- u Church every Sunday and church activities during the week
- u Social, Leisure, and Recreation Activities - Family Outings, Walks in Park,
- u Exercise
- u Medical Day Care
- u Banking
- u Hairdresser and Barber
- u Destinations are regional and include a multi-county, tri state-area.

Focus Group Findings: Utilization

- u Personal Vehicle Use: Care partners are transporting family members along with friends and extended family members. Some individuals with dementia are still driving.
- u Metro Access: Sometimes it takes 14 days to schedule. Schedule is often filled.
- u Call-A-Bus, Call-A-Cab, Veterans Transportation, Private Cab Services, Wheelchair accessible cabs, ambulance, volunteers, PATHS (Peers Available to Help Seniors)
- u Challenges in utilizing Metro Access, Call-A Bus, and Call-A-Cab related to scheduling, costs, crossing geographical boundaries, and limits of availability in certain regions of the county. There are also concerns about safety.
- u Some municipalities have transportation systems with varying costs .

Focus Group Findings: Support

- u Conference participants report that they know about transportation resources. Information needs to be centralized and more broadly disseminated.
- u Family and friends are providing driving support. When family and friends are not available a backup transportation system is needed.
- u Families need to have a consistent nonmedical companion or aide for ongoing care and to travel with persons with dementia.
- u Logistical and Personal Management Support is needed to transport persons with dementia. Logistical support includes scheduling appointments, arranging transportation, paying fares, driving to appointments, navigating routes, and communicating with drivers. Personal management support includes orientating persons to prepare for travel, preparing travel kits, managing incontinence, managing personal belongings when out, and managing agitation.
- u Caregiving and providing transportation support is demanding and stressful.

Recommendations for Improvement

- u **Financial:** Provide financial support, affordable transportation options, and more information on services available.
- u **Metro Access:** Expand scheduling and access, reduce trip time in scheduling clients, have frequent communication updates, and establish fluid boundaries to improve access.
- u **Call-A-Bus:** Expand. Charge small fee. Extend the hours of Call-A-Bus. Shorten length of ride with multiple passengers. Prompt pick up and drop off.
- u **Information Dissemination:** Centralize and distribute transportation resource information to support groups, senior buildings and senior centers. Provide more information on available transportation resources and services.
- u **Customer Service:** Provide van aides to assist drivers in providing door-to-door vs. curbside service. Provide support at the drop off sites when care partner parks car and cannot leave person with dementia unattended. Train transportation workers on dementia to develop their capacity to provide dementia friendly services.

Focus Group Findings: Dementia Friendliness

- u Some transportation workers are knowledgeable and compassionate. Transportation can be improved by providing training on how to work with persons with dementia to can enhance the dementia friendliness of the transportation system.
- u Transportation affordability is an issue.

Program Development Tasks

- Develop convening purpose, theme, content
- Develop focus group questions and guidelines
- Identify focus group facilitators
- Develop program schedule
- Identify and secure panelists and moderator
- Develop speakers
- Secure space
- Design & Distribute Invitations
- Develop process for handling RSVP's/conference registration/confirming respite care/release for filming
- Secure funding to support conference coordinators and facilitators
- Securing interpreter(s)
- Secure on-site respite care
- Secure transportation incentives for participation
- Identify and contract with caterer
- Identify administrative support
- Develop conference signage
- Conduct PreEvent Site Visit
- Confirm AV Needs
- Expressions of Gratitude

Thank You

Planning Committee

- u Jeanne Anthony, National Association of Area Agencies on Aging
- u Christal Batey, Dementia Friendly North County Area Lead
- u Shaunda Bellamy, Pickett Fences Senior Services, Inc.
- u Virginia Dize, National Aging and Disability Transportation Center/National Association of Area Agencies on Aging
- u Gloria Lawlah, Senior Family Supports, LLC
- u Donna Crocker Mason, Dementia Friendly Mid County Area Lead
- u Karen Sylvester, Prince George's County Department of Family Services
- u Claudia Thorne, PhD, MSW, Dementia Friends Maryland, Coppin State University
- u Flavia Walton, PhD, South County Area Lead
- u Vikki Kalitsi, Visiting Angels of Prince George's County

Panelists

- u Bonita Spikes, Person Living with Dementia
- u Gwendolyn Graves, Care Partner
- u Sara Fought, Jewish Council of Aging of Greater Washington, VillageRides
- u D'Andrea Walker, Prince Georges County Department of Public Works and Transportation
- u Malcom Augustine, Board Member, Washington Metropolitan Area Transit Authority

Holding a community meeting is just the beginning....

- It takes time to find workable solutions to identified problems
- It takes hard work and persistence to make change happen
- It's important to have a clear sense of what you want to see happen in your community
- Seize the day! Are there opportunities...grant funding, regular funding cycles, new funding, new supporters....that you can use to move forward?

Resources

- [*Dementia Caregiving and Transportation Brochure*](#)
- [*Dementia, Caregiving and Transportation Toolkit*](#)
- [*Transportation Options for Older Adults and People with Disabilities*](#)
- [*Dementia Friendly America Website*](#)



Q&A

To ask a question, type it into the chat box to the left of your screen. We look forward to your questions!

Webinar Evaluation

surveymonkey.com/r/nadtccaregiverwebinar





NATIONAL AGING AND DISABILITY
TRANSPORTATION CENTER

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