

## Working Group to Develop a State Plan for Alzheimer's Disease and Related Disorders

### ACCESS Sub-Group

*First meeting*

October 1, 2012

DEA Conference Room

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Anne LeClerc (RIPTA) and Amy Lapierre (OHHS) were invited to come speak to the sub-group about transportation issues.

1. The meeting began with introductions of everyone in attendance. The following people attended: Maureen Maigret (chair), Catherine Taylor, Lola Okunfolami, Stacy Paterno, Annie Murphy, Dottie Santagata, Cathy Salerno, Marie Carpenter, Laurie Johnson, Donna Desmarais and Lindsay McAllister.
2. Catherine Taylor provided a brief introduction to the State Plan work and explained that a Joint Resolution, passed by the General Assembly last spring, directed the Long Term Care Coordinating Council (LTCCC) to create a Working Group focused on creating a State Plan. Catherine summarized the past two meetings of the full group and mentioned that Lindsay McAllister had emailed the full group to provide a few dementia resources that were mentioned at those meetings, including the National Plan and a link to the federal Alzheimer's website.
3. Anne LeClerc provided the sub-group with an overview of the transportation programs she oversees at RIPTA, including the Flex service, which was the primary topic of conversation at the meeting.
  - a. **Flex Service** – Flex operates in seven zones, indicated as “200” lines on the bus routes, and can go into neighborhoods much like the RIdE service is able to. A Flex bus will bring passengers anywhere within the zone.
  - b. Flex typically drops off and picks up at corners and curbs so it is not necessarily door-to-door. It costs \$2.00 for a one-way trip and \$0.50 for a transfer. Senior discounts do apply. To make a reservation, one must call a 1-800 number and speak to the person who coordinates pick-ups. This must be done 48 hours in advance, however there is interest in someday moving this to a “same day” system. There are two wheelchair securement areas per bus.
  - c. There is currently one person answering these reservation calls and the system is unable to coordinate or interface with the “Trip Planner” function of the RIPTA website.
  - d. Flex buses are painted with dark blue and green paint with only an overhead sign to help differentiate them from the RIdE buses.
  - e. Despite challenges to market the Flex buses, they are used a lot in certain zones, particularly in Woonsocket. Woonsocket and West Warwick were chosen as Flex zones given their historically large RI Works populations.
  - f. Gaps in Service: Kent County was mentioned as one area that is badly in need of Flex. The Tiverton/Portsmouth/Bristol area does not have Flex, however a RIdE pilot program was placed in this area. Riders must be affiliated with a program in order to use this service (such as work,

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- medical appointment, etc.). South County and the western part of the state (Foster/Scituate, Exeter) are also areas without Flex service.
- g. Flex is funded out of general operating funds. DHS provides \$200,000 per year in match – this is one area where the state can use federal dollars as “match” funding to draw down additional funds.
  - h. A family member, personal care assistant or assistant may accompany persons with dementia through the “pass program” at no cost. All RIPTA transit systems allow such assistants to travel free so long as they obtain a pass.
  - i. Another challenge is presented by the vans used for the Flex program in that they do not “kneel” like a bus is able to in order to make the step onto the vehicle level with the sidewalk or ground. A ramp can be deployed at the point of access, however they tend to be a bit jarring when activated and cause some discomfort and uneasiness among those with depth perception issues. One reason for the continued use of these vans is that the state must meet federal “Buy America” standards under purchasing requirements and the options are limited.
    - i. Another issue with the vans is their interior physical appearance. While there are color strips on the stairs, the flooring is entirely black, which causes some riders to pause or freeze once they've reached the top step.
  - j. Drop-offs at a large hospital building can pose the greatest challenge in terms of likelihood the person with dementia will be able to enter the building and find the necessary suite of offices for their appointment.
  - k. RIdE Service** – RIdE will provide services within  $\frac{3}{4}$  of a mile from fixed route service (“as the crow flies”) and operates within the same hours as RIPTA. There is a \$4.00 fare each way and reservations can be made the day before.
  - l. The application process for RIdE causes some confusion. There are two parts to the application; approval that the person in fact needs RIdE's services (a disability is preventing use of fixed route service), and approval of the trip origin and/or destination (must be within the area of service).
  - m.** RIdE only accepts RIPTix or cash. RIPTA is exploring the possibility of accepting non-cash options such as a rechargeable card.
  - n. Elderly Transportation Service** – this service provides trips to individuals over 60 or individuals with a disability. The transport must be for particular purposes such as for a doctor's appointment, adult day services or to a meal site.
  - o. Trips can be made between 10-2 pm, Monday through Friday, and on Saturdays for dialysis trips only.
  - p. The general senior population pays \$2.00 each way, but for the CNOM and Medicaid population there is no cost to the rider.
  - q. There is some confusion over the permissible distance for these trips. An old policy may have imposed a mile limit to certain populations, however

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it appears the mile limit may be a product of budget constraints and not official policy. In other cases the distance may be restricted by a "closest provider" policy. Clarity is needed here.

- r. This service presents some problems with the timing of the pick-up and drop-offs. RIDE dictates the time and for some, this means a pick-up as early as 6:30 am. This results in arrivals at adult day or other programs between 7:30 am and 7:45. If a program is located at a library or other facility that is not open at this hour, the rider is left outside to wait. This also complicates things for caregivers because drop-offs fall between 2:30 and 3:00 pm, which is too early for many caregivers who are working.
  - i. This is not an issue for ADA services, which run closer to 9 or 9:30.
- s. Caregivers are not receiving warnings from drivers when the vans are running behind schedule. Without this communication, caregivers are left guessing and this causes great frustration and an inability to plan and coordinate with their workplaces.
- t. If an individual has attempted to use fixed route transportation and is unable to do so because of a physical or mental challenge, and has exhausted all other means of transportation, they are able to use para-transit services or an ambulance service. OHHS is in the process of contracting with a vendor under a risk-based capitated model, that will coordinate these services, answer complaints, improve timeliness, negotiate rates and monitor this service. The RFP deadline is late October, 2012.
- u. These services leave out the early-onset Alzheimer's disease population and other individuals with dementia under age 60.
- v. The Sub-group discussed the need to address all of these challenges in a timely way given the state's recent emphasis on aging in place and the growing population of elderly and individuals with dementia living in the state.

### **Takeaways and Recommendations:**

#### **1. Trip Planning:**

- a. Getting from the doorstep to the Flex pick-up location and then back home safely upon drop-off can be challenging for people with dementia. Planning enough time and finding home can be difficult. How can we improve this process?
- b. Drop-offs at a large hospitals could be better coordinated (from drop-off to doctor's office or suite) through use of greeters, provided either by the physician's office as an auxiliary service or through an agreement with a home health agency.

#### **2. Physical Aspects of Transport:**

- a. The physical appearance of the RIDE vans does not differ from the Flex vans. This can cause confusion in those with dementia when the only way

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to discern the two is an overhead sign. Vans could be better differentiated to avoid confusion.

- b. Although there are color strips on the stairs of the Flex and RIdE vans, the interior flooring is entirely black. This causes some riders to pause or freeze once they've reached the top step. Color strips should be added to the interior of the vans to provide an additional visual assist once a person has reached the top of stairs.
  - c. Additional training of drivers to be dementia sensitive is recommended in order that drivers will be better attuned to the particular challenges faced by this population.
3. General Navigation of the System
- a. Only one person is currently available to help someone make a reservation for the Flex van. While the sub-group did not hear complaints about a wait time for service, there was feedback that calls can take as long as 20 minutes when there is a need to help someone plan a trip from door-to-door and multiple stops and connections are involved. In light of the need for additional assistance in planning trips and the lack of any other resources besides the phone line, this may be an area worth further investment.
    - i. Enabling the "Trip Planner" function of the RIPTA website to interface with RIdE and Flex services would be helpful.
  - b. RIPTA is looking into the possibility of using non-cash options to pay for RIdE trips. There was agreement from the sub-group that this would be a helpful option for people with dementia because it might present an easier payment method such as a rechargeable card that a caregiver could set up for the individual with dementia.
4. RIPTA at-large:
- a. Marketing the availability of the Flex program is a real challenge for RIPTA. Funding is not necessarily the issue. The agency needs visioning and need to find a way to reach seniors who did not grow up using public transportation like the younger generations did
    - i. The sub-group discussed the availability of the AARP book on how to take the bus. There was interest in obtaining a few copies to review. AARP also does bus "tours" as part of an education campaign where they bring the bus to locations and help people become more comfortable with them.
    - ii. Maricopa County, AZ was mentioned as a great example as to how to best use land use signage to drive public transportation use.
    - iii. *These two items can be brought back to the sub-group by staff for further discussion*
  - b. There are gaps in South County, the western part of the state (Foster, Scituate and Exeter areas) and the Tiverton/Portsmouth/Bristol area. There are also quality concerns in the Warwick zone. This may require further study.

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- i. Funding is an issue. Flex is funded through \$0.01 tax on gas sales in the state. This amount has not increased since the inception of the tax.
  - c. There is some confusion over the permissible distance for these trips. If trip distance is in fact restricted by mileage or by a "closest provider" policy, some in the sub-group felt strongly that this needs to change to allow for appropriate care and to allow patients to see providers who are beyond the 12 mile limit.
    - i. Clarity is needed on the distance policies under the Elderly Transport program, particularly around the use of "contracted runs."
  - d. The inability of vans to "kneel," combined with the less-than-optimal ramp system fall short of helping people with dementia travel safely and comfortably. Is there a way to improve access to the vans?
  - e. The application for RIDE causes some confusion – is there a better way to communicate the two-part approval process required by this application?
  - f. These services leave out the early-onset Alzheimer's disease population and other individuals with dementia under age 60. What can we do to include or better serve these residents?
5. Timing and Communication:
  - a. RIPTA should consider shifting the time of pick-ups and drop-offs for the elderly transport program to a later hour.
    - i. Anne LeClerc, Amy Lapierre and Dottie Santigata will set up a meeting to discuss these logistics.
  - b. RIPTA should consider improve the communication between drivers who are running behind schedule and the rider and/or their caregiver(s). The vans are equipped with radios so this should be feasible.
6. Miscellaneous:
  - a. If individuals with dementia are expected to give up their licenses when they are no longer able to safely drive, they need real and workable alternative transportation options.
    - i. The sub-group discussed the availability of an article (potentially a few studies) from Dr. Ott concerning driving and dementia. There was interest in inviting Dr. Ott to attend a meeting of the sub-group to discuss his research.
    - ii. *Staff will explore this option for a future meeting.*
  - b. Families may not be aware that the DMV is willing to play a role in helping take licenses out of the hands of people with dementia. More awareness of this assistance may be beneficial.