

RHODE ISLAND'S STATE PLAN *on Alzheimer's Disease & Related Disorders*



Issued pursuant to a Joint Resolution passed by the Rhode Island General Assembly affirming the need for a State Plan for Alzheimer's Disease & Related Disorders.

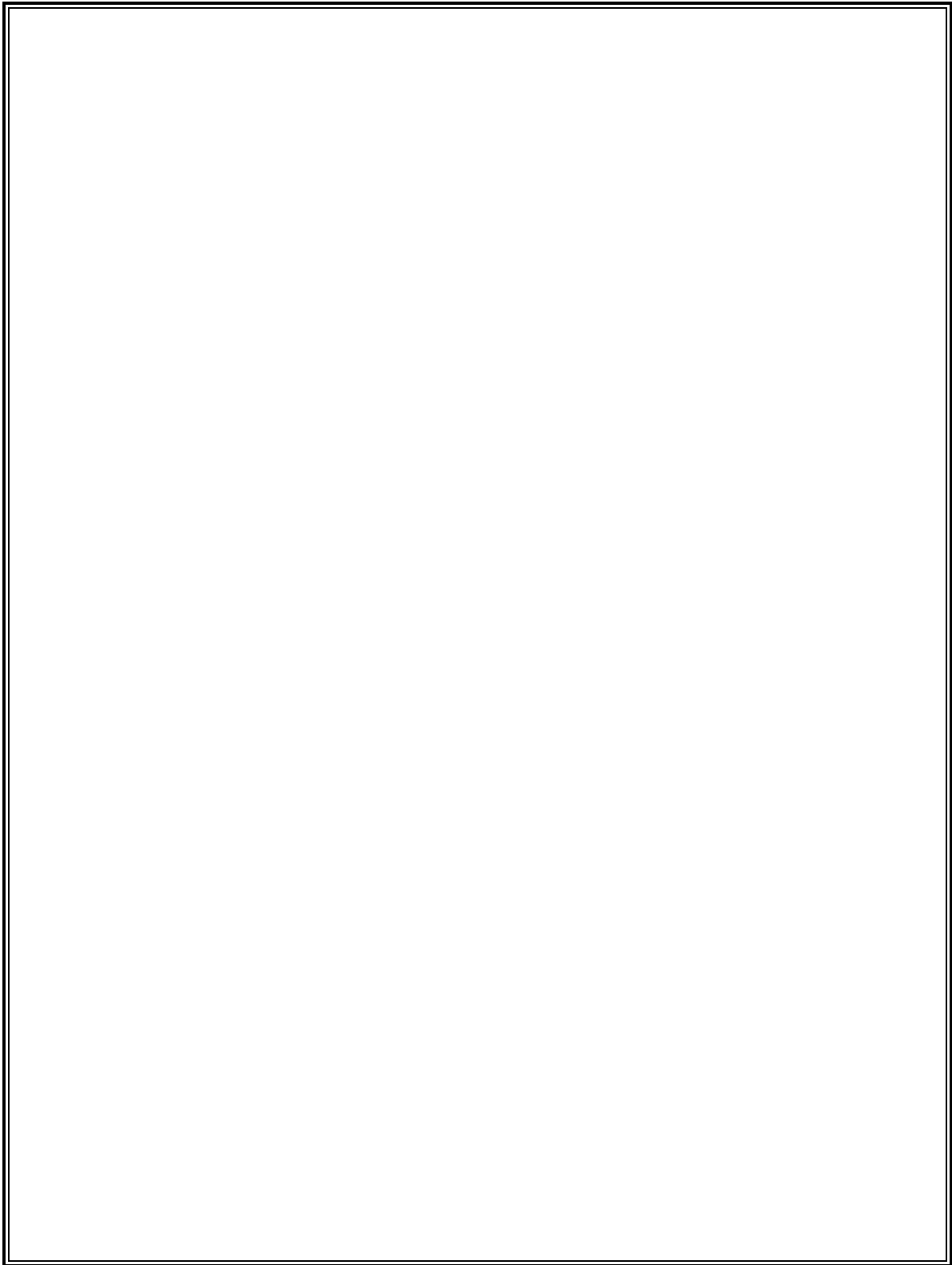


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Executive Summary

The Rhode Island State Plan for Alzheimer's Disease and Related Disorders is the product of a collaborative effort between the Rhode Island chapter of the Alzheimer's Association (AARI), the Division of Elderly Affairs and the Lieutenant Governor's office. The work officially began upon passage by the Rhode Island General Assembly of a Joint Resolution directing the Long Term Care Coordinating Council to serve as the organizational structure for a work group to lead the process. The work group was co-chaired by Lt. Governor Elizabeth Roberts and the Director of the Division of Elderly Affairs, Catherine Taylor.

Meeting over the course of a year, the work group served as a forum for community members to learn about some of Rhode Island's leading Alzheimer's and aging resources. Each of the six subgroups formed to tackle the bulk of the State Plan (Caregiver, Access, Legal, Workforce, Long-Term Care and Care Delivery & Research) provided regular reports on their progress.

Presented in draft form at a public meeting during the summer of 2013 and widely shared across various state-based stakeholder and advocacy groups, the State Plan contains recommendations for specific steps for improvement that were identified by the subgroup participants, with broad public input. The State Plan is organized into the six subgroup topics. The comprehensive list of the recommendations in each topic area is summarized below and can be found in Section IX (Appendix C).

Recommendations from each section of the State Plan

I. CAREGIVERS

This subgroup identified recommendations in six areas including:

Resources & Networking (Develop and strengthen social media networks and newsletters to better serve caregivers and those impacted by ADRD)

Engagement (Increased engagement via creation of certification program, training and education modules, formalized peer mentor network, partnerships with geriatric mental and behavioral health experts to better serve family caregivers)

Respite Care (Increase awareness of existing programs; explore short and mid-term respite as well as mid-to-long-term in-home respite services; explore national models that address who can serve as paid caregiver; explore “fast track” eligibility for Medicaid based on a diagnosis)

Respite Care Training & Education (Improve awareness of CareBreaks program, Department of Elderly Affairs and the POINT, AARI Alzheimer’s Assoc. website; improve utilization rates of respite care among family caregivers; enhance services to include emergency or short-term immediate access; explore long-term respite care service models; expand education and training opportunities for friends and family caregivers, and for those providing respite for caregivers)

Caregivers in the Workplace (Establish and strengthen links with employee assistance programs (EAP) to provide education, materials and online resources, mentoring and real-time support for families; enhance awareness of Rhode Island State Employee Assistance Program; expand EAPs in partnership with all-size employers in Rhode Island)

Additional Caregiver Needs (Identify best practices and future improvements for the support of remote caregivers and caregivers with extensive external demands such as family and job-related responsibilities; expand access to case management/care coordination services in public, private programs; survey for best practices in care and support of elderly parents and adult children with disabilities in a shared living environment; develop/disseminate culturally competent materials to assist with end-of-life-care and planning decisions).

II. ACCESS

This subgroup identified recommendations in six areas, including:

Transportation (Engage RIPTA to develop a phased-in plan to address physical changes, system changes and administrative changes; incorporate State Plan recommendations into services facilitated by the EOHHS Elderly Transportation Services broker; increase distribution of AARP Rider Guide to home care workers, adult day programs and senior centers and online)

Knowing When Driving is No Longer Safe and What to Do (Develop a reference guide for primary care offices to help families/caregivers deal with Alzheimer’s and driving issues)

Telehealth (Expand coverage of telehealth technologies)

The POINT and other resources for individuals and caregivers (Encourage 211/“The POINT” to assist in identifying, quantifying Alzheimer-related inquiries including

information-sharing with AARI; develop a “process map” to guide families with a recent diagnosis to resources, information; increase awareness of The Point resources; encourage Alzheimer’s training for DEA/DHS service providers, etc.)

Emergency Department Care for Individuals with Alzheimer’s Disease (Communicate best practices from emergency departments and incorporate into future recommendations)

Living Rite - A Disruptive Solution for Management of Chronic Care Disease

III. LEGAL

This subgroup identified recommendations in three areas including:

DMV/Safe Driving (Assistance for family members concerned about unsafe driving; development of standards for physical and mental fitness to drive; enhance public awareness of and access to privately offered safe driving courses and assessments)

Law Enforcement, Training and Educational Resources (Allocation additional resources to Attorney General to handle financial elder abuse cases and to Protective Services Unit of Division of Elderly Affairs for annual training programs offered to law enforcement and first responders; identify additional needs such as training, educational and outreach opportunities for law enforcement personnel, including municipal and state police academies, probation, parole officers, senior advocates and the Attorney General’s office)

Legal Tools (Refer to Probate Commission to develop policy recommendations for improving, increasing capacity of Volunteer Guardianship Program and oversight; increase awareness of and account for advance directives, healthcare durable power of attorney durable financial power of attorney in statutory nursing home and assisted living care plan requirements; promote statewide anti-bullying, anti-elder abuse campaign).

IV. WORKFORCE

This subgroup identified recommendations in three areas including:

Workforce Development, Training & Education (Address shortage of outpatient providers; improve communications and care coordination across settings via new educational and training materials; provide incentives for training; identify strategies to avoid staff burn-out; assess awareness among and training for certified nursing assistants)

Training and Education Uniformity (Develop recommendations for required Alzheimer’s and dementia curricula in healthcare education and certification programs for providers; publish uniform definition of terms; explore partnership with universities and AARI to

create PSAs and informational videos for caregivers or anyone interested in basics of caregiving for ADRD)

Additional Opportunities for Growth (Identify additional opportunities for growth via Leadership Institute model, continuing education programs in partnership with hospitals and other organizations for obtaining a higher level of expertise in dementia care—end of life planning, palliative care, aggressive behavior etc.).

V. LONG TERM CARE

This subgroup identified recommendations in seven areas including:

Improving Accessibility of Long Term Care (Outline long term care options, various public and private payment sources on RI Alzheimer’s Disease website; facilitate peer-to-peer mentoring opportunities via web site to pair experienced with inexperienced family members, caregivers)

Best Practices Across Long Term Care Settings (Include dementia training as part of the quality incentive for nursing homes under DHS)

Adult Day Programs as a Component in the Continuum of Long Term Care (Awareness campaign for families of resources offered in Adult Day programs; nationwide survey to inform RI policymakers and stakeholders of potential changes to payment structure to improve long-term sustainability; explore potential for offering night-time hours under existing state regulations in partnership with the RI Department of Health)

Best Practices in Home Care Provision (Explore allowing eligibility for home care services with a primary diagnosis of ADRD; develop recommendations for enactment)

Specific Quality of Care Improvements Applicable Across Settings (Encourage integration of culturally competent elements in long term care settings; assess capacity of existing long-term care providers for specialization in various languages and cultures; develop educational units for inclusion in CME curricula for physicians, nurses on how to guide long term care transitions, advise on advanced planning, palliative care, hospice; standardize Continuity of Care Document; improve medication reconciliation at transitions of care)

Long-Term Goals: Aspects of the Future State of Long Term Care (Use social networking, list-serve, etc, to foster support, create awareness in the local community; develop volunteer, non-professional enrichment programs for individuals living with ADRD)

Adapt to Meet Changing Needs and Desires of Alzheimer’s Population (Potential model living community in urban center; system-wide change of transitioning to private rooms only and eliminating hospital and dormitory-style living; establish statewide accrediting body to serve as adjunct to Rhode Island Department of Health; create innovation center and diverse network of innovators to design future of long term care--new living environments, staffing plans, care delivery).

VI. RESEARCH

This subgroup identified recommendations in five areas including:

Identify Research Priorities and Milestones (Partner with the Rhode Island Advisory Commission on Aging for input on funded research addressing ADRD in RI; communicate importance of increasing participation in research studies and clinical trials on pharmacologic and non-pharmacologic ways to prevent, manage, treat ADRD)

Support collaboration, sharing of research and expertise across institutions, organizations in RI

Expand Research Aimed at Preventing and Treating Alzheimer’s Disease (Publicize, encourage participation in Alzheimer’s Prevention Registry at RI Hospital; support university programs focused on aging and neurodegenerative diseases; support community based behavioral health services treatment and delivery research; support better collaboration with assisted living and nursing care facilities to recruit, track donations to Brown Brain Tissue Repository)

Specific Areas for Improvement to Clinical Trials Participation and Scope (Develop partnerships, outreach for enrolling participants into research studies and clinical trials, including populations at higher risk for ADRD; create partnerships with public health programs to reduce potential environmental factors, health-related problems--obesity, hypertension, diabetes.

Dissemination of Research Findings (Harness existing state resources capable of translating findings into practice; identify partnerships to disseminate research findings to provider networks, researchers; develop proposal for reimbursement formula; propose website resources that will serve all those impacted involved with ADRD; explore website development at URI, partnerships to provide content, maintenance; annual research summit; identify a future “home” or committee to facilitate, support website, research summit, ongoing partner engagement; convene insurance providers to facilitate subscriber service for informational material, training opportunities on ADRD; develop list of geriatric

specialists in medicine, neurology and psychiatry for web site).

Conclusion and Next Steps

Rhode Islanders from around the state shared how they and their loved ones are affected by Alzheimer's disease and related disorders in a series of Listening Sessions held over the winter of 2012-2013. Participants included caregivers, healthcare providers, family members and anyone impacted by Alzheimer's disease or a related disorder who wanted to tell their story. Held in partnership with the Division of Elderly Affairs and the Alzheimer's Association-Rhode Island Chapter, these sessions, free and open to the public, provided invaluable insight into what is now a comprehensive State Plan for Alzheimer's Disease and Related Disorders.

The Working Group to create the State Plan for Alzheimer's Disease, comprising many organizations and individuals in the state, consisted of several sub-groups: Access, Caregivers, Long Term Care, Workforce, Research, and Legal. Each sub-group was tasked with making recommendations for addressing the needs identified in their respective area of focus. After a public comment period, the draft plan was finalized to begin the next step in the process: implementation. The Working Group will reconvene in October 2013 to prioritize the proposed recommendations for implementation. For more information and to become involved, send an email to info@ltgov.state.ri.us (write Alzheimer's in the subject line).

The Alzheimer's Association - Rhode Island Chapter

Formed in 1980, the Alzheimer's Association is a worldwide organization that provides support and education for all people affected by and suffering from Alzheimer's disease. Through its chapters around the country, the Alzheimer's Association is able to tailor their efforts to state and local needs. Here in Rhode Island, the Alzheimer's Association has been a strong advocate for individuals and families impacted by Alzheimer's disease. Most recently, the Rhode Island chapter of the Alzheimer's Association worked very closely with the Work Group co-chairs on the State Plan Joint Resolution and has been a valuable partner throughout the plan development process. The Chapter staff has participated in subgroups, helped to organize listening sessions, and has provided valuable feedback and guidance on throughout the drafting process. This is in addition to the many services provided by the association for those with Alzheimer's and their caregivers, including support groups, educational programs, trainings, workshops, and clinical trial matching services.

A variety of support groups are offered around the state by the Rhode Island chapter of the Alzheimer's Association. The Rhode Island chapter runs many types of support groups, including groups for individuals diagnosed with Alzheimer's, caregivers, and individuals who work in the Alzheimer's field, with the majority of the support groups focusing on caregiver needs. For example, a support group focused on lesbian, gay, bisexual and transgender concerns is offered in Middletown two times every month. These groups are scheduled at various times throughout the day, and can be found all around the state at churches, YMCAs, and libraries. There is also a meeting offered specifically for Spanish speakers twice monthly in Pawtucket. The meetings last two hours and generally occur once a month. The volunteers who run the meetings are trained through the Alzheimer's Association, in a program that lasts for 6 hours. A full listing of support groups can be found on the Rhode Island Chapter's website.

(http://www.alz.org/ri/in_my_community_support.asp - SGList).

The Rhode Island chapter of the Alzheimer's Association also puts on many educational programs, designed to teach interested participants about various topics related to living with Alzheimer's disease. Each program runs for four weeks, with each weekly meeting covering a different aspect of the topic. The array of topics that have been covered in the past include Creating a Family Caregiving Team, Early Detection, and Legal and Financial Aspects of Alzheimer's Disease. All of these programs are free and subsidized by DEA grants.

In order to facilitate participation in clinical trials the Alzheimer's Association also runs a nationwide index of trials and will match interested parties with appropriate trials. The trials look at various aspects of Alzheimer's disease. Some of the trials are testing drugs and dosages, while others look at caregiver techniques and lifestyles. Rhode Island trials are run through local area hospitals. To get involved in a clinical trial or to learn more visit the TrialMatch website at http://www.alz.org/research/clinical_trials/find_clinical_trials_trialmatch.asp.

In addition to the educational programs, the Alzheimer's association also puts on trainings and workshops designed for health care professionals and others who work in the field. Organizations can request such trainings, but they are also available to individuals. Workshops offered specifically through the University of Rhode Island Geriatric Education Center (URI GEC) will award professionals who complete the five-course program a Certificate in Interdisciplinary Practice in Geriatrics.

The Rhode Island Chapter of the Alzheimer's Association continues to be a very active presence in the state with respect to educating the public about living with Alzheimer's disease. Through their support groups, trainings, and educational programs, the organization has become an integral part of the Rhode Island community, and in particular, to those impacted by Alzheimer's disease and related disorders.

Introduction

The process to develop the Rhode Island State Plan for Alzheimer's Disease and Related Disorders began in the spring of 2012 as a collaborative effort between the Rhode Island chapter of the Alzheimer's Association, the Division of Elderly Affairs and the Lieutenant Governor's office. The work officially began upon passage by the Rhode Island General Assembly of a Joint Resolution directing the Long Term Care Coordinating Council to serve as the organizational structure for a Work Group to lead the process. The Joint Resolution, S 2858, can be found in section VI, Appendix A. The Work Group was co-chaired by Lt. Governor Elizabeth Roberts and the Director of the Division of Elderly Affairs, Catherine Taylor.

The Work Group met for the first time on July 26, 2012 and then on an ongoing basis approximately every two months over the course of the following year. It served as a forum for community members to learn about some of Rhode Island's leading Alzheimer's and aging resources, including the state's Geriatric Education Center at the University of Rhode Island, the Brown University Center for Gerontology and Health Care Research, The Brown Brain Bank, the Norman Prince Neurosciences Institute, and the Alzheimer's Prevention Registry. The Work Group meetings also provided an opportunity for each of the six Subgroups that were formed to tackle the bulk of the State Plan work to report out to the full group. This provided continuity across each of the Subgroups and facilitated a better awareness among the full group participants of the diverse resources, needs, challenges and solutions being discussed at each of the Subgroup meetings.

The Subgroups were designated based upon a survey of other states' Alzheimer's plans and with extensive input from the Work Group participants. Beginning with the first Work Group meeting and over the course of the following month, participants were asked to provide feedback on the proposed subgroups and the suggested jurisdictional areas for each of them to address. Upon approval of their structure, the Subgroups began their work in early October 2012. The Caregiver, Access, Legal, Workforce, Long-Term Care and the Care Delivery & Research Subgroups met every 3-4 weeks throughout the course of the year. For

the outline describing the subject matter addressed by each of them, see section VII (Appendix B).

This State Plan report is organized into six major sections; one for each Subgroup. The narrative contained in each section reflects the many presentations, discussions, concerns and challenges addressed at each meeting of the Subgroups over the course of the last several months. The bulleted recommendations at the end of each subsection outline the solutions and specific steps for improvement that were identified by the Subgroup participants and finalized into recommendations over the course of a month-long editing process. For a comprehensive list of the recommendations put forth by the Subgroups, see Section IX (Appendix C). This State Plan was also presented in draft form at a public meeting on June 6, 2013 for comment and review, posted for a 10-day public comment period on the website of the Lt. Governor, and widely shared across various state-based stakeholder and advocacy email list serves.

It is the intent of the co-chairs that this initial iteration of the State Plan for Alzheimer's Disease and Related Disorders will be the first of many to come. This stage of the process should be viewed not as the conclusion, but rather as the beginning of a critical scope of work. Additional input and commentary is welcome and can be provided by contacting comment@ltgov.state.ri.us.

The co-chairs would like to recognize the work of the Subgroup chairs; Kathy McKeon (Caregivers), Maureen Maigret (Access), Tom Enright (Legal), Gail Patry (Workforce), Kathleen Kelly and Rick Gamache (Long-Term Care) and Peter Snyder (Research). Their leadership was essential to the success of the State Plan development process.

I. Caregivers

Caregivers often must juggle multiple demands at once, including: caregiving responsibilities, families and friends, their own health and wellbeing, as well as job related responsibilities. Meeting these needs is already complicated, but caregivers must also take the lead on processing and coordinating all of the information available to them about Alzheimer’s disease along with the myriad of services, supports, clinical trials and clinical resources aimed at helping people with Alzheimer’s disease and their caregivers. The Caregivers Subgroup took this multitude of challenges into account, seeking to develop recommendations aimed at improving the burden on caregivers and increasing their access to accessible training and supports.

A. Resources & Networking

One important addition to the existing caregiver support structure will be the development of the Rhode Island Alzheimer’s Disease Website— hereafter RIAD website. Throughout the workgroup sessions it became apparent that families – particularly upon initial diagnosis – would benefit the creation of one single place to go to learn about the disease, their options and all available resources. This resource must be available to for caregivers to access in their own time and at their own speed. For more information on the proposed RIAD website see section VI: Research.

This is also an area where the Subgroup participants envisioned the role of social media growing as caregivers in this and future generations become more comfortable using technology to identify resources, access services and communicate with networks of family, friends, other caregivers and providers to provide status updates and even to express their needs and requests for assistance. There already exist a number of national and local caregiving newsletter services (*e.g.*, AgingWellMag.com, Caregiver.com) that play the role of information sharing, however, participants in the Caregivers Subgroup envisioned a “real time”, interactive interface that would enable caregivers to reach out within their communities to connect with services, supports and others’ expertise. Existing newsletter organizations provide a great starting point for the development of such

networks and the development of a RIAD Website will provide an online forum for up-to-date information exchanging and networking.

Recommendations

- Encourage the development of social media networks as resources for people impacted by Alzheimer's disease.
- Build upon existing caregiver newsletters to pool resources and extend outreach to caregivers interested in learning about Rhode Island specific services and supports.

B. Engaging Individuals with Alzheimer's Disease and their Caregivers

Integrating patient and caregiver healthcare and services will also be an important focus area. "Care for the caregiver" often falls to the provider who cares for the individual with Alzheimer's disease (hereinafter AD). Formalizing and enhancing this relationship would optimize the care provided to this population. Caregivers often have very little time to seek out their own care and therefore, building such 'care for the caregiver' into the visit for their loved one would make a significant difference in the long-term health of the state's unpaid caregivers. Specifically, screening for depression, anxiety and "burnout" is crucial for those who care for individuals with AD. An existing example of this model of care in Rhode Island is the Geriatric Psychiatry Program in the Rhode Island and Miriam Hospitals. These programs provide integrated inpatient, outpatient and community-based consultative mental health services for persons with Alzheimer's and their caregivers. The creation of a new educational program for caregivers is imagined as a critical pathway to improve the dissemination and translation of research findings into best practices. This will serve to better prepare the trainee while also enabling them to become a peer mentor for other new caregivers and impacted family members.

Recommendations

- Develop a two-week certification program, offered by a local university or organization with input from the Alzheimer's Association, for family members caring for individuals with dementia.
 - Incorporate ways to address the needs of other family members (in particular young children) in training and education modules to help them better understand the disease.
- Formalize a peer mentor network to connect families and caregivers that are new to the disease with those who have more experience.
- Partner with geriatric mental and behavioral health experts to provide services for caregivers who screen positive for depression, anxiety and burnout, and develop the capacity to offer education and consultation to community providers who work with families and caregivers.

C. Respite Care

Respite services are offered to all caregivers through the CareBreaks program, which is operated by the Diocese of Providence with grants from the Division of Elderly Affairs. The Subgroup participants highlighted the need to improve public outreach to increase awareness of this program. Among the barriers to greater use of the program is the fact that for almost all health care and social service professionals in contact with the family, the focus is on the person with Alzheimer's disease. The Caregiver is often an afterthought. In addition, many caregivers do not think of themselves as "caregivers"; they are simply taking care of family. A concerted effort is underway through CareBreaks to help caregivers self-identify as such despite a commonly held belief that since the care is given to a family member, it doesn't "count." For more information on this program see section X (Appendix D).

Another gap identified by the Caregivers Subgroup concerns family caregiver needs for emergency or short-term respite services. While there is a robust and growing respite network, as established by the CareBreaks program, these services are available to families on a planned basis and for a few hours, or a day at a time. If the primary caregiver becomes ill, another family member has an emergency demanding the primary caregiver's attention, or some other family event calls for the caregiver's attention away from the home, there are very few options for emergency or short-term respite. Often times, nursing homes will offer such services but may require a stay of two weeks or longer and Subgroup participants raised concerns that the application process for such stays can be extensive. Additionally, a mid-length stay in a nursing home is not an ideal scenario for the care of a the person living with Alzheimer's disease as it involves multiple transitions, new schedules, new caregivers, and a complete removal from their "comfort zone."

The state's respite network would benefit greatly from the addition of respite services that could fill the significant gaps between traditional hourly/daily respite care and the longer stretches of residential respite offered by the state's nursing homes. An ideal solution would provide a respite care worker who could stay at the home of the person with Alzheimer's disease and remain with them for the period of time required by the primary caregiver. This approach would enable a greater level of stability not currently provided for in the respite framework.

State policies can also help support respite services. The Shared Living program, for which Alzheimer's disease is an eligible diagnosis, provides an annual budget for the designated caregiver to use respite care services. The existing 1115 Global Medicaid Waiver included a provision for respite services, however, budget restraints made this component impossible to implement. The state is currently working on a renewed 1115 Application in which respite services would be covered for both core and preventive services. An important gap to highlight here, however, is the restriction within the Shared Living program prohibiting spouses and parents from serving as the paid caregiver. Any person with financial responsibility for the care recipient is unable to participate in the program as the compensated caregiver.

The Subgroup participants also discussed the need to consider a diagnosis of AD when implementing the "fast track" eligibility for Medicaid Waiver. This is particularly important for the young onset Alzheimer's disease population that must

rely upon private pay options for care and support. As the disease progresses, this becomes a growing challenge for families and a significant financial burden. The Subgroup therefore identified early, “fast track” eligibility for those with young onset Alzheimer’s disease as a very important addition to the support structure for those impacted by the disease.

Recommendations

- Support and Build upon ongoing public outreach efforts through the Providence Catholic Diocese and Division of Elderly Affairs to increase public awareness of the CareBreaks program.
- Encourage the development of a comprehensive network of respite options across the state, including short and mid-term respite care.
- Explore potential to incorporate mid-to-long-term in-home respite services into the overall network of options.
- Survey national models akin to the Shared Living program that address the prohibition on spouses, parents or other persons financially responsible for the care recipient, from serving as the paid caregiver.
- Explore the possibility for future “fast track” eligibility for Medicaid based on a diagnosis of Alzheimer’s disease or a related disorder.

D. Respite Care Training & Education

Respite care providers should be specifically trained to provide care for the person living with Alzheimer’s disease and understand their needs. The easier the transition between a person’s traditional caregiver and the temporary respite worker, the more likely families are to use respite services. The Subgroup participants highlighted the reality that often times, the caregiving “hand off” can require such intensive preparation and follow-up work that the primary caregiver will not see the value in accessing respite care. Respite care arrangements should strive to set up mid-to-long-term relationships established with an initial meeting set aside for the specific purpose of allowing all parties to become familiar with each

other and to establish an understanding on the part of the respite worker of the care recipient's baseline status.

Again, family caregivers and extended family members would also benefit from the opportunity to attend trainings to help them better understand the disease. This could result in smoother transitions into caregiver roles and easier and more successful use of respite care.

Recommendations

- Increase outreach to improve awareness of respite services through CareBreaks program, the Department of Elderly Affairs (hereinafter DEA) (including the POINT) and the Rhode Island Alzheimer's Disease Website. (For more information on the proposed RIAD Website see Section VI: Research)
 - Improve rate of utilization of respite care among family caregivers.
- Enhance provision of respite care services to include emergency or short-term immediate access.
 - Explore the possibility of shortening average required stay at nursing homes for emergency or short-term respite.
 - Explore the feasibility of simplifying the application process for nursing home respite care.
 - Explore alternative providers of care who could be more readily available to step into a respite need on an immediate basis.
- Seek to develop long-term respite care service modeled around best practices for people with Alzheimer's disease, including keeping the person at home and developing long-term relationships.
- Expand respite care worker education and training opportunities across the state.

- Develop training and education opportunities for friends and family members who will be caregivers and for those who will provide respite to the primary caregiver.

E. Caregivers in the Workplace

The Caregiver Subgroup also considered Alzheimer's disease and caregiving in the context of the workplace. Many large corporations across the country, and in Rhode Island, offer Employee Assistance Programs (hereafter EAPs) to help their employees manage personal issues outside of the workplace that might otherwise impact their work performance and/or personal health and wellbeing. Additionally, the state employee benefits plan currently offers some specific assistance with caregiving for older adults. For example, the state's EAP provides three counseling visits and a phone consultation with a work/life specialist in geriatrics and elder care. Employees may be referred to community resources (for example, support groups).

EAPs typically offer short-term counseling and referral services for both the employee and members of their household. These are a great initial resource for caregivers at the outset of the disease as they struggle to get the services and supports they need in place, and likewise as the demands of caregiving wear on over time. Support groups and brown bag lunch series addressing Alzheimer's disease, caregiving and other relevant long term care issues are an additional resource the Subgroup participants identified as a practical, relatively low-cost benefit for employers to consider offering at their workplaces. This also helps to address concerns about the many demands on a caregiver's time by incorporating services into the workday. The Alzheimer's Association has identified the demand for workplace-based programming and has provided many "Lunch and Learn" programs across the state at various workplaces to help address this need.

In light of the many demands placed on caregiver's time, the Caregiver Subgroup also highlighted less formal supports that can be just as important as the formal caregiver and respite care support structure. For example, caregivers attending the listening sessions expressed an interest in being paired up with caregiver mentors. Each new caregiver would be matched with someone possessing

more experience than they in order to create a peer-to-peer support program that would enable caregivers to reach out and check in with each other as needed. Participants envisioned that this sort of framework would be much more responsive to the realities of a caregiver's day-to-day schedule.

Recommendations

- Establish ongoing links with EAPs and provide educational and informational resources on support for families dealing with Alzheimer's disease.
- Strengthen existing EAP resources for Alzheimer's at large companies currently offering them to employers; include outreach about the State Plan for Alzheimer's disease and Related Disorders and awareness of the Rhode Island Alzheimer's Disease Website (for a discussion of the proposed RIAD Website see section VI: Research)
- Work to ensure that all EAPs receive information about referral resources for employees requiring more intensive or long-term mental health services, such as geriatric mental health programs that include services for caregivers.
- Enhance awareness of the Rhode Island State Employee Assistance Program and make efforts to improve outreach to employees dealing with Alzheimer's disease caregiving responsibilities.
- Support expansion of EAPs across large, mid and small size employers in Rhode Island.
 - Explore possible partnerships across smaller sized companies through building shared resources (e.g. Chambers of Commerce).
- Develop additional partnerships for the provision of workplace-sponsored support groups and educational series focused on Alzheimer's disease.
- Create a peer mentorship program to pair new caregivers with more experienced caregivers.

- Explore the potential to connect peer mentors through online chat function as part of the Rhode Island Alzheimer’s Disease Website (See section VI: Research).
- Incorporate real-time employee-focused supports and resources to the Rhode Island Alzheimer’s Disease Website (See section VI: Research).

F. Additional Caregiver Needs

Remote caregiving also remains a challenge. Secondary and even primary family caregivers may live remotely from the person in need of assistance, yet tools and services to help these caregivers were not immediately apparent to the Subgroup participants. This also remains a challenge for local caregivers whose various job or family-related obligations may require travelling for periods of time away from their loved one. Technological advances, flexible respite care and other services and supports must be identified to help meet this need.

The Caregiver Subgroup also highlighted case management services as one of the greatest potential areas for growth and improved assistance to caregivers. The participants were aware of some commercial insurance plans that offer nurse care managers at no additional cost to the beneficiary for the purposes of helping the family navigate the system of care. This level of one-on-one assistance was identified among Subgroup participants as an invaluable asset to the families under this coverage. To the extent it is feasible, this type of coverage should be expanded across the commercial market. Rhode Island’s 2-1-1 “The POINT” also provides referrals to families in need of case management services. One area identified for growth is the level of counseling on private pay options available through The POINT. This is important in order to assist those families who are above eligibility criteria for public programs yet still require assistance in connecting with the resources available to them.

Another area identified for further development was the planning of assisted living residences capable of supporting intergenerational family arrangements for elderly parents and adult children with disabilities. This model capitalizes upon an existing mutual familiarity with the person’s personal preferences and history, and leverages an already well-developed sphere of natural support within the

community. Keeping a family within a familiar setting would enable the individuals to continue to frequent their local stores, community resources, churches, post office, medical facilities and other area businesses and service providers. The exact legal and regulatory framework for such an arrangement must be further discussed and developed. Furthermore, Rhode Island may benefit from assessing models of intergenerational assisted living in existence across other states.

The Subgroup also sought to develop recommendations for how to improve family caregivers' preparation for and experience of end of life care. Advance planning is key to meeting this goal and efforts must be made to assist caregivers in leading discussions with their loved one about their goals for end of life care. This includes ensuring they have power of attorney documents in place should they lose the ability to make certain decisions on their own, as well as communicating any advance healthcare directives they may have (for a more robust discussion of these issues see Section III: Legal Issues). These materials must also be made available in ways that will effectively reach a mix of Rhode Islanders from an array of different religious and cultural backgrounds. Recognizing that there are many different beliefs, attitudes and norms around end of life care and preparation, materials used to communicate around these issues must be culturally competent and made available in different formats (video, radio, written, in-person meetings, faith-based).

Recommendations

- Identify best practices and future improvements for the support of remote caregivers and caregivers with extensive external demands such as family and job-related responsibilities.
- Expand access to case management and care coordination services in both public and private programs.
- Conduct a survey of existing innovative models in assisted living that may offer best practices in the care and support of elderly parents and adult children with disabilities in a shared living environment.

- Develop and disseminate culturally competent materials to assist families with end-of-life-care and planning decisions.

II. Access

The Access Subgroup approached its work from the perspective of developing a system of care and support that would improve access for people living with Alzheimer's disease – at all stages – and those caring for someone with the disease. The participants cast a wide net to capture as many aspects of our current and desired future landscape, including: how we can support individuals who are no longer able to drive because their dementia has advanced too far and how we can connect individuals and families into the services and supports they will need as they work to create a system of care for the person living with Alzheimer's disease.

A. Transportation

As the Access Subgroup considered the most pressing obstacles to access to care for Rhode Islanders living with Alzheimer's and their caregivers, transportation emerged as one of the foremost concerns. Concerns with public transportation take on enhanced importance, of course, once individuals who have relied upon cars become no longer able to safely drive due to cognitive impairment. The Subgroup sought to gain a baseline understanding of how the Rhode Island Public Transit Authority (hereafter RIPTA) system currently operates and to identify a number of areas where RIPTA could make enhancements to its ongoing operations or seek minor changes in protocol that would vastly improve the experience of a rider with Alzheimer's disease and his or her caregiver(s). It is important to note that in addition to the services outlined below, paratransit and ambulance transportation are available to any Medicaid beneficiary who has attempted to use fixed route services yet is unable to due to physical or mental challenges and so long as they have exhausted all other means of transportation.

Existing Services

Flex Service

The Flex services operates in seven zones, indicated on the RIPTA bus routes as the "200" lines. Flex service will go into neighborhoods much like the Ride services do and will bring passengers anywhere within the zone of services. Flex typically drops off and picks up passengers at street corners alongside the curb. It is

not, therefore, necessarily a door-to-door service. A one-way trip costs passengers \$2.00; and transfers cost an additional \$0.50. Senior discounts are offered. There are two wheelchair securement areas per van.

Any traveller requiring a personal care assistant or other type of companion to travel with them may do so at no additional cost by obtaining a specific pass through the Pass Program operated by RIPTA. Reservations must be made 48 hours in advance and are made by calling the Flex reservation line. RIPTA may explore the possibility of making this a “same day” system at some point in the future.

Flex buses are painted much the same as the larger RIPTA fixed route buses, but have overhead signage to differentiate them from the Ride buses. Flex buses are not equipped with ramps, however they do have lifts. According to participants in the Access Subgroup, the lifts can be physically jarring when activated and can cause some discomfort and uneasiness among those with depth perception issues. Another concern raised by Subgroup participants is the physical appearance of the interior of the vans, which have black flooring on the steps and down the aisles. Again, according to some participants with experience, this causes some riders with depth perception or visual impairments uneasiness when boarding the vehicle.

Woonsocket and West Warwick are the highest utilization areas in the state. Gaps in Flex van service occur in across areas of Kent county and in the Tiverton/Portsmouth/Bristol area, which has no Flex service at all (Flex was attempted in this area in the past but ridership was very low).

ADA service

ADA service is one of the services provided by The Ride Program. The Americans with Disabilities Act mandates that public transit agencies provide equivalent paratransit service to people with disabilities that prevent use of the fixed route system. ADA service is available within three-quarters of a mile (defined as “as the crow flies”) from a pre-defined fixed route and is available during the same operating hours as RIPTA services in the area. Due to this mileage corridor requirement, there are Rhode Islanders who do not use the ADA service because their transportation needs do not fall within the allowable corridor

Fares cost \$4.00 each way. RIdE only accepts RIPTix or cash payment, however as mentioned above, RIPTA is exploring the possibility of accepting non-cash payment options such as a rechargeable card. Reservations must be made at least a day in advance.

The RIdE application contains two parts; an eligibility determination for RIdE services (defined as a person whose disability prevents the use of fixed route service as provided by the regular RIPTA transit system), and approval of the trip origin and destination as within the defined area of RIdE service.

Elderly Transportation Services

Elderly Transportation services are currently provided by The Ride, however this may be changing under the model discussed below. Elderly Transportation provides trips to individuals over the age of sixty or individuals with a disability. There are five statutory purposes for elder transportation; adult day, senior meal sites, medical appointments, dialysis and services for the blind. Travel arrangements can be made between the hours of 10:00 am - 2:00 pm, Monday through Friday, and on Saturdays for dialysis appointments only. The cost of participation is \$2.00 each way. There is no cost for Medicaid beneficiaries. Trips must be reserved 7 days in advance.

The Subgroup participants identified some challenges presented by the timing of the pick-up and drop-off times of elderly transportation services. For example, for some riders pick-up times may be as early at 6:30 am, posing challenges for the rider and their caregiver alike. This also results in drop-off times at destinations that may not yet be open (approximately 7:30 – 7:45 am). For example, some adult day programs or other activities offered to older adults do not open until 8:00 am or 9:00 am. Drop-off times are also a challenge for caregivers as they typically fall between 2:30 pm and 3:00 pm when caregivers may not yet be home from work nor able to meet the person at home. Participants also noted that the practice or policy of requiring that clients be transported to the closest adult day program or congregate meal site are not as responsive to client needs as they could be. For example, there are only two dementia-specific adult day programs in the state. Although all adult day programs can serve clients with dementia, an Alzheimer's specific program may be more appropriate for some clients.

Additional Considerations

Rhode Island's Executive Office of Health & Human Services is in the midst of rebidding their transportation services to change to a risk-based capitated model that will negotiate rates, monitor service, improve coordination of these services, answer complaints and improve timeliness. This presents an exciting opportunity for the state to work with the selected broker to improve all non-emergency elderly transportation services and tailor the system to the needs of the population. Furthermore, the adoption of a broker model also provides the state with a chance to consider ways of improving its transportation services in underserved communities such as Little Compton and Tiverton.

The current network of special transit services as described above does not serve the early-onset Alzheimer's population under the age of sixty and other individuals with dementia-related disorders that do not qualify them under the ADA. Additionally, Rhode Islanders living outside the state's urban centers where RIPTA transit is most robust experience significant gaps in coverage. While some municipalities offer their own senior transportation services for travel to and from senior centers (a list of towns with senior centers can be found in Appendix E), this is a narrower purpose than the more broadly defined needs described in this Plan.

As the state works to improve its public transportation network, the needs of the Alzheimer's disease population – particularly in light of its increasing numbers – must be a major consideration. Mobility can be key to an individual's ability to remain living within the community and also effects one's ability to socialize and avoid isolation, two important factors in the wellbeing of Alzheimer's patients. As the state's emphasis on aging in place progresses and the population of individuals with Alzheimer's disease increases a renewed effort to address this gap in service will be required.

Opportunities for Enhancements

Riders who have Alzheimer's disease need additional supports to help them plan and navigate their trips. Similarly, caregivers who are trying to assist a rider with Alzheimer's disease in accessing RIPTA's services, and who may be greatly impacted by any unpredictability in an already complicated schedule, need help planning transportation in advance and would benefit from increased reliability and predictability across the system. For example, the 1-800 number for Flex service

trip planning is typically staffed by one person. While the Subgroup heard no complaints about a wait time for the use of this service, there was input that calls to plan out transportation needs can take as long as twenty minutes or more, especially when a trip involving multiple transfers or connections must be arranged. Additionally, the online “trip planner” function of the RIPTA website does not currently permit someone arranging for transportation to use the online trip planner tool while accessing assistance over the phone.

The Subgroup participants envision an ideal system that would enable a person to log onto the RIPTA website to arrange transportation through the traditional transit system, RIde and Flex vans. It would also enable the call-in service to interface with the trip planner website if additional help was required. This way, individuals, caregivers and other assistors would be better empowered to understand the transportation options available to them and, if possible, plan ahead if an appointment, errand or other transportation need could be done using public transportation. Online planning would also reduce the burden on RIPTA’s existing call-in trip planning, and in doing so free up resources for more complicated transportation needs requiring one-on-one assistance.

The Access Subgroup also addressed a number of timing and logistics concerns raised by the existing system. One important improvement to address caregiver’s complex care coordination needs would be a more timely notification if RIde vans get behind schedule. Current practice is reportedly inconsistent, leaving caregivers unaware if a pick-up time will be drastically later than planned for. Additionally, caregivers and individual’s alike would benefit from a more flexible system that would enable a “real time” response to changes in transportation needs if, for example, a medical appointment is delayed, cancelled or rescheduled. Currently, rides arranged through the RIPTA RIde or Flex van system need to be made well in advance. A transportation system with the ability to respond to urgent or important “last minute” transportation needs would also improve services for the Alzheimer’s population.

There has been an ongoing effort to train RIPTA drivers in the needs of special populations. This is a critical effort that should continue into the future. Having a basic level of understanding of some of the particular challenges that can arise for a person with Alzheimer’s disease using public transportation can make a

significant difference in maintaining the safety and wellbeing of that individual as well as the other riders. The Access Subgroup supports RIPTA's initiative to have its drivers trained and, in particular, applauds and encourages ongoing efforts to provide them with dementia-specific training and education.

There are also a few dementia-friendly physical changes that could be made to RIDE and Flex vans and RIPTA buses that would improve service to this population. Enhancing the differences in physical appearance between a RIDE van and Flex van would assist individuals with cognitive impairment as they wait for and seek to get aboard the appropriate transportation vehicle. Additionally, all buses should have "kneeling" capability to help individuals with depth perception issues or visual impairment as they ascend into the vehicle. Adding a non-cash payment option for RIDE would also be a significant improvement that would simplify the system for both caregivers and riders.

A few additional observations made by the Subgroup participants also lend themselves to possible improvements to the public transportation system in Rhode Island. Any efforts to make ridership as simple and as seamless as possible would be welcomed by the Alzheimer's community. A great example is the AARP's Bus Riders Guide, which can help new riders become familiar with the bus system and learn how to use it safely. Additional tools to improve the population's comfort level with using public transportation would be useful to individuals and families as they seek to prepare for a future that relies less and less upon driving. For example, the application for ADA service program could be simplified and provided in additional languages to be more accessible across various communities.

Another augmentation concerns the complex navigation of medical buildings, doctor's suites, and hospitals once an individual with Alzheimer's is dropped off by public transportation. This can vastly complicate and in some cases prevent an individual's ability to get from "curbside to counter." The Subgroup recognized that some medical complexes are already offering concierge services to aid individuals in getting to their destination and encourage this as a best practice. To the extent possible, these services should be encouraged and additional partnerships forged to offer "curbside to counter" services to offer safe and successful transportation for all Rhode Islanders with Alzheimer's disease.

Recommendations

- Engage RIPTA to develop a phased-in plan to address the following concerns raised by the Access Subgroup:
 - **Physical Changes**
 - Share information with community partners that Ride vehicles and Flex vehicles have distinct physical appearances and that any remaining outliers will be phased out.
 - Ensure all RIPTA buses have “kneeling” capability to ease rider’s ascent to the vehicles
 - Consider adding bright colored safety strips to the center aisles and top of entry stairs of all buses to aid riders with compromised depth perception and visual impairment.
 - Develop communication plan and materials to educate community partners about non-cash payment options for Ride and Flex vans.
 - **System Changes**
 - Development of online trip planning capability for Flex services.
 - Development of an interface between the call-in trip planning service and the online trip planning capabilities for RIPTA buses and to the extent feasible, Ride and Flex vans.
 - Addition of same day services within Ride and Flex Van system to accommodate riders when important appointments are delayed cancelled or rescheduled.
 - Consider potential back-up or “on call” transportation option for urgent or important “last minute” cases.
 - Review policy of the Elderly Transportation program that requires clients to go to nearest adult day program.

- Consider the development of a new policy allowing exceptions based on individual client need.
- **Administrative Changes**
 - Implement mandatory ongoing and consistent driver training on dementia for RIPTA employees
 - Encourage and facilitate “curb to counter” assistance for riders, particularly when dropped off at large office buildings or campuses.
 - Continue to pursue improvements and aids to simplify ridership and ease navigation of the public transit system.
 - Simplify the ADA application and explore whether there is a way to communicate the two-part approval process required by the existing application.
 - Make the ADA application available in multiple languages
 - Explore the expansion of lines of service available to individuals under the age of 60 who are not eligible under the ADA for service but who would benefit from access to special services given their Alzheimer’s diagnosis.
 - Continually reassess geographic distribution of RIPTA transit service
- Incorporate the recommendations of the State Plan into new work streams and services facilitated by the EOHHS Elderly Transportation Services broker.
 - Consider creation of a Mobility Manager position within the Elderly Transportation Services system to work closely with the EOHHS broker to augment case management services offered by The POINT and its regional POINT offices.

- A Mobility Manager would develop an extensive list of transportation options available across all communities, including public and private services, volunteer driver programs and any other possible means of transport.
- This position could offer an individualized assessment to each person in whichever community they live.
- This position could also serve as a resource to the Rhode Island Department of Motor Vehicles (DMV) as it works to improve the informational resources and alternatives to driving it offers individuals once their licenses are revoked.
- Consider addition of online real-time chat function through the trip planner function of the RIPTA website as an additional tool for individuals and families to coordinate their transportation needs.
- Improve dissemination of the AARP Rider Guide among home care workers, adult day programs and senior centers.
 - Explore opportunities for wide dissemination of The Guide, including posting it to the Rhode Island Alzheimer's Disease Website (see Section VI: Research for more discussion of the website).

B. Knowing When Driving is No Longer Safe and What to Do

The Access Subgroup raised concerns around families' ability to assess the proper time to ensure that unsafe driving does not occur, and their comfort level with doing so. The Subgroup sought to identify what resources are available to families as they are going through this process, spanning primary care providers, the DMV, and privately-offered driving courses and assessments options that are discussed at length in Section III: Legal Issues.

The Subgroup participants benefitted from the input of Dr. Brian Ott, the Director of the Alzheimer's Disease and Memory Disorders Center at Rhode Island

Hospital, the largest memory assessment program in the state, who helped define the scope of concerns related to cognitively impaired drivers. Dr. Ott also assisted the Subgroup in understanding the recommendations around continuous performance-based assessment of their risk as a driver every 6 months or, at a minimum, yearly. These assessments are offered by a number of instructors and companies and can cost between \$150-400 per assessment (a list of companies offering driver tests can be found in section XII: Appendix F). There is also a program named DriveCam, which families may wish to consider. This program provides weekly video feedback of a drivers experience on the road. This service requires an initial equipment purchase of \$495.00 (plus an additional \$50.00 for installation) and operates on a monthly subscription basis (\$30.00 per month). Drivers can also be assessed at the Rhode Island DMV, however the evaluators are not guaranteed to be trained to assess individuals with Alzheimer's disease.

Another concern raised by participants related to the comfort level of primary care providers in assessing an individual's ability to remain on the road. While physicians are often comfortable with the role of assessing a level of cognitive function, they are less confident in playing a role in the translation of that level of impairment to an assessment of the patient's ability to continue driving. Given this concern, it is imperative that primary care providers are aware of the resources available to deal with driving issues and subsequently connect concerned caregivers, friends or family members with those options.

Recommendations

- Develop a quick reference guide for primary care offices to use in referring concerned caregivers, friends, or family members to options available to help them deal with Alzheimer's and driving issues.
 - Upload this resource onto the RIAD Website (see section VI: Research)
- Explore ways to make privately offered safe driver courses and assessments more affordable to Rhode Islanders.

C. Telehealth

The Access Subgroup also explored the potential for telehealth to bring innovation and improved access and outcomes to people living with Alzheimer's disease and in particular, for those with other chronic conditions such as heart or respiratory disease and diabetes. People living with Alzheimer's disease often receive much of their care on an acute basis at an urgent care, emergency department, or other hospital setting. In addition to being among the most costly care delivery settings, individuals with Alzheimer's disease are particularly at risk of acquiring infection or injury in these settings. All efforts should be made to provide better access to care for these individuals in their normal community-based care settings. Technology-enabled care models, such as remote care and telemedicine, have the ability to connect community-based caregivers with higher-licensed clinicians at the time and location of need, which can significantly improve health outcomes and quality of life while reducing the overall cost of caring for this population.

A telehealth platform equipped with video conferencing, phone, chat, clinical data and tools, audio conferencing, and a payment portal presents the possibility of providing hospital or specialist-level care while allowing the person with Alzheimer's to remain in their familiar home setting. Caregivers, both paid and unpaid, could telepresent with the individual living with Alzheimer's disease from their home or nursing home residence in order to more easily, safely, and efficiently consult with nurses, physicians, and specialists at off-site locations.

Medication reconciliation may also be aided by the telehealth portal as the clinical data tool could serve as a single access point for all providers. This tool also addresses concerns raised by the Access Subgroup (and the Caregiver Subgroup) participants about the care coordination burden placed on caregivers by offering a single platform for all health and wellness related data relevant to the person with Alzheimer's disease. This would reduce redundancies in paperwork, patient history, and other important background information gathered each time a patient interacts with a new provider or must update information with an ongoing provider.

Commercial insurance covers telehealth to varying degrees. Psychological visits and to a greater extent, rural healthcare, is typically covered, however it is not yet covered for primary and specialty care. Medicare and Medicaid have begun approaching telehealth from the pilot project angle, but infiltration of the market

remains slow. Telehealth represents a promising technological innovation that is capable of greatly improving care, access, and care coordination for people with Alzheimer's disease and their caregivers.

Recommendations

- Expand public and commercial coverage of telehealth technologies to assist in managing chronic illness diagnoses such as Alzheimer's disease.
- Research grant opportunities to implement telehealth demonstration programs for families caring for persons with Alzheimer's or other dementia in home situations.

D. The POINT and other resources for individuals and caregivers

The Access and Caregivers Subgroups each had particular interests in assessing the extent to which information for individuals with Alzheimer's disease and their families and caregivers is central, complete, and sensitive to their needs. In an effort to understand the scope of services offered by 211 and "The POINT", Rhode Island's two primary sources of information and referrals, the two subgroups met jointly. In light of those two information-gathering sessions, each of the subgroups had suggestions for how "The POINT" could continue to improve its services and resources for the Alzheimer's disease population.

211/"The POINT" is offered at all hours of every day of the year and is provided in 175 languages and dialects. It is a free service that assists Rhode Islanders in connecting to health and human service providers, government agencies, and community-based organizations. Subgroup participants were interested in learning about how 211/"The POINT" might already be serving individuals with Alzheimer's disease and their families and caregivers, and also sharing some information about what sort of supports and services that population is looking for.

Recommendations

- Encourage 211/“The POINT” to develop capacity to sort call-in data and geographical break-down of needs in order to better inform the state’s awareness of Alzheimer-related inquiries, including: needs of caregivers, areas in need of improvement, and gaps in services and support.
- Forge connections between the Regional POINT offices (the DEA network of local agencies linked to 211/“The Point”) and the Alzheimer’s Association to encourage information-sharing regarding identified needs, questions, requests for service, and to disseminate local information about Alzheimer’s Association programming.
 - Develop a “process map” as a joint project between “The POINT” and the Alzheimer’s Association to guide families with a recent diagnosis to address the following:
 1. What are the stages of the disease and what should you expect in each of them?
 2. What are the important planning needs our family should consider?
 3. What are the commonly used services (adult day programs, senior centers, transportation, meals, caregiver supports, etc.)?
 4. How can this information be available in a manner that is accessible and culturally appropriate for various cultures?
- Seek out a way to connect individuals and their families dealing with a recent diagnosis of Alzheimer’s disease or a related disorder with a package of information that includes the “process map” and the basic information that will help them become familiar with the available resources.
- Explore ways to increase public awareness of the importance of early access, through “The POINT”, to options counseling.

- Encourage ongoing Alzheimer's training, including awareness of caregiver resources and needs, for the full network for DEA/DHS service providers.
- Ensure that adequate training and resources are provided to "The POINT" and the DEA partner agencies to ensure Options Counseling adequately addresses both publicly and privately funded services.

E. Emergency Department Care for Individuals with Alzheimer's Disease

Sudden changes to the environment, foreign smells and sounds or other disruptions in routine can all cause anxiety and confusion to someone living with Alzheimer's disease. There are many specific process improvements that can be made to emergency department (ED) protocols that will improve the care and safety provided to individuals with Alzheimer's disease seeking emergency care in the ED. Primary among them are the training of ED staff in best practices for treating individuals with Alzheimer's and the prioritization of early screening among ED patients for individuals with cognitive impairment. In many cases, patients with Alzheimer's disease or a related dementia will require a geriatric psychiatry consult or a consult with a pharmaceutical doctor (Pharm. D.) or geriatrician to assist ED staff in understanding and reconciling patient medications. The Subgroup identified some existing practices within the state's emergency room departments that have recognized these particular needs and have built partnerships to ensure the proper consultative services are available to their ED physicians and staff. A forum for sharing these practices and innovative changes to ED care would ensure that other providers could benefit from others learned best practices.

Recommendations

- Disseminate best practices from ongoing changes being made in the state's emergency departments and incorporate into future recommendations.

F. Living RIte - A Disruptive Solution for Management of Chronic Care Disease

In July 2012, the University of Rhode Island was awarded a 3-year \$14 million grant by the Centers for Medicare & Medicaid Services (CMS) to provide comprehensive chronic care management and preventive care for intellectually and

developmentally challenged adults and/or individuals with Alzheimer’s disease or a related disorder – with two or more chronic conditions who receive Medicare and Medicaid benefits. The project, entitled *Living RItE- A Disruptive Solution for Management of Chronic Care Disease*, is part of CMS’s Healthcare Innovation Challenge, a highly competitive initiative that seeks to identify and support innovative opportunities to improve care delivery and achieve its three-part aim of “improving the individual experience of care, improving the health of populations, and reducing the per capita costs of care for populations.”

The Living RItE initiative's goal is to deliver seamless and comprehensive care in an efficient manner, improving the health, well-being and employment opportunities for its target population, and at the same time lowering costs for both the Medicare and Medicaid programs. All patients are enrolled in an electronic health record system which allows all of their individual interdisciplinary team members to access and share information. Members include not only traditional health providers but also two new community health workers who are people with disabilities, a Developmental Disability peer specialist and a Living Rite Life Coach. The first services offered to each of the enrollees are prescription medication reconciliation and a complete physical exam with state of the art accessible equipment. Within two weeks of enrollment participants are also given assessments, which include but are not limited to, health, employment, quality of life and a test for severe impairment. Assessment results assist the client in setting realistic goals that will have a positive impact on their potential to pursue the least restrictive lifestyle possible. Furthermore, individual care plans for participants are then developed and managed based upon assessment results.

As the Centers head into the second year of the grant, they will be conducting targeted outreach to Alzheimer’s disease day center clients and providing healthy lifestyle and behavior modification services to the developmentally disabled clients that will assist them in better managing their chronic conditions. Future work on the State Plan recommendations will need to incorporate the best practices and lessons learned from this ongoing project. More information on the Living RItE program can be found in Appendix G.

III. LEGAL ISSUES

Individuals, families and communities impacted by Alzheimer's disease face an array of very challenging decisions related to their loved one's healthcare, safety and living environments. Over the past several years, a number of initiatives and resources have become available to Rhode Islanders to help protect the health and safety of people living with Alzheimer's disease. The Legal Subgroup sought to define these programs and tools, assess them for any necessary updates, and develop recommendations regarding any additional resources that would be beneficial to those impacted by Alzheimer's disease.

A. DMV/Safe Driving

1. Assistance for Family Members Concerned About Unsafe Driving

One of the primary concerns for individuals and families dealing with an Alzheimer's diagnosis is driving. Everyone's situation will be unique, however at some point, a person with Alzheimer's will have to stop driving. Driving requires quick reflexes and decision-making abilities that will falter as the disease progresses, impairing a person's ability to drive competently and safely. Losing the independence to drive can be an extremely difficult development for everyone involved in the decision and it is never too early to begin planning ahead for this transition. For families looking for assistance in this stage of the disease, there are national resources available as well as state-based resources and tools.

Under Rhode Island law (R.I.G.L. § 31-10-44(d)), any physician or optician of a person diagnosed with a physical or mental condition that will significantly impair their ability to safely operate a vehicle may voluntarily report their concerns to the Rhode Island Department of Motor Vehicles (DMV). Additionally, any family member or police officer with concerns about an individual's ability to drive may also report their concerns to the DMV's Operator Control Department and request for that person's license to be suspended.

Operator Control will then contact the person in writing to request that they come into the DMV for an interview. The interview will be used to assess what additional information may be needed from the medical community, potentially including: an assessment by a physician, optometrist, neurologist, or other doctor. If the medical information is sufficient to warrant it, the person will be asked to complete a medical road exam. All of the collected information will then be used to inform the DMV's decision to revoke or reinstate the person's license. Finally, starting at age 75, drivers must renew their licenses every other year (rather than every five). This is one additional way that drivers with cognitive impairments, that should prohibit them from driving, may be screened..

Many families are not aware of this process at the DMV, nor do they realize that physicians and law enforcement officers can be used as partners in these difficult decisions. Furthermore, every city and town in Rhode Island has a senior advocate who serves as a designated officer liaison for families and communities dealing with concerns relevant to the senior population. These officers are another excellent resource for families with questions or concerns related to safe driving practices. They also play a critical role in providing Alzheimer's training and increasing the awareness of the available Alzheimer's resources among other officers within their police force.

Recommendations

- Engage community partners (senior centers, assisted living residences, adult day programs, police departments, etc.) to educate families about the resources available to assist them with concerns about safe driving.
 - Develop a one-page handout describing an overview of the laws, processes, and partners available to assist families with driving concerns.
 - Engage Roger Williams University School of Law (RWU) Elder Law Society to assist in development of one-page handout and implement educational presentation for use at senior centers and other potential partners.

- Work with the RI DMV's Operator Control to clearly define license suspension and revocation steps for families on the Operator Control Website (<http://www.dmv.ri.gov/locations/index.php#2>) and ensure that these families are being provided with sufficient information concerning alternate modes of transportation.
- Solicit white paper from RWU Elder Law Society containing a proposal for best practices in conducting a medical road test (as employed by the RI DMV), including: proper processes, dementia-sensitive training or education modules for Operator Control personnel, and any relevant definitions.

2. Development of Standards for Physical and Mental Fitness to Drive

In addition to enhancing awareness of the resources available to help families deal with seeking to have a license revoked, the Legal Subgroup also discussed the importance of having clear guidance for how individuals will be assessed. R.I.G.L. § 31-10-44 creates a Medical Advisory Board at the RI DMV to serve as an advisory panel regarding physical and mental fitness standards for licensure to operate a vehicle. This Board, made up of various specialist members, is meant to assist the DMV Administrator in determining the qualifications of any person reported to the DMV for their questionable physical or mental fitness to drive. These functional standards for physical and mental fitness, while referenced in statute, have not yet been issued. Participants in the Legal Subgroup raised serious concerns that without such standards in place families and individuals are left without clear criteria. This lack of guidance raises due process concerns for any individual being reassessed for fitness to drive and also means that physicians, families and law enforcement have no clear standard to reference when assessing whether or not to report a person to the DMV.

Recommendations

- Engage a temporary work group of legal professionals, disability advocates, DMV personnel, and other critical community partners to submit proposed regulations (as defined by R.I.G.L. § 31-10-44(b)) for functional standards for

determining physical and mental fitness to maintain motor vehicle licensure to the DMV for promulgation.

3. Utilization of Privately Offered Driving Courses and Assessments

External to the state resources and processes described above, the Legal Subgroup also considered the various organizations and companies available to assist families with dementia and driving concerns. As was also discovered by the Access Subgroup, there are several programs available in Rhode Island to provide safe driving courses that can help refresh individuals' driving skills as well other programs that will assess whether an individual with Alzheimer's disease should retain driving privileges. These programs can be instrumental in providing important information to individuals and families as they navigate driving decisions. They may also be attractive to concerned family members looking to provide some distance between themselves and the ultimate decision that the person with Alzheimer's disease must stop driving.

The cost of safe driving courses and driving assessments can vary. Some require a small refundable deposit in order to reserve a place in the course and others, particularly assessments, can be very expensive. According to anecdotal evidence, some assessments offered in the state can cost between \$300 and \$1,800.

Recommendations

- Enhance public awareness of independent safe driving courses and assessments by providing basic information on the Rhode Island Alzheimer's Disease Website (see section VI: Research) and including a reference to the existence of such services on the RI DMV website.
- Improve accessibility of these programs by encouraging commercial insurance coverage of driving courses and assessments, and enhancing public awareness of Medicare and VA policies covering safe driving courses and assessments.

B. Law Enforcement, Training and Educational Resources

1. Rhode Island Attorney General

Among the Legal Subgroup participants, there was a strong consensus that elder abuse crimes demand the utmost attention and require dedicated resources for criminal investigation and prosecution. It is difficult to estimate the number of elder abuse crimes – either of a physical or financial nature – that occur versus those that are reported, investigated, and ultimately successfully prosecuted. However, the Legal Subgroup expressed an interest in seeing additional resources allocated to the Office of the Attorney General to expand the state’s capacity to investigate reports of elder abuse and, where appropriate, prosecute such crimes. As the population of aging Rhode Islanders increases over the coming decades, an increasing proportion of residents will be among those elderly vulnerable to physical and financial abuse. Legal Subgroup participants felt that this increasing threat must be met with additional law enforcement resources to ensure that the state’s investigatory and prosecutorial capacity is sufficient. It is the hope that such a step would serve as a deterrent by boosting oversight, investigation, and prosecution of crimes against senior citizens, particularly those with Alzheimer’s disease.

Additionally, the provision of high-quality training sessions offered by the Attorney General for law enforcement officers statewide is a valued service. The Legal Subgroup recognized this program as a critical part of the state’s overall efforts to improve awareness of Alzheimer’s disease, train community law enforcement officers on elder abuse laws and dementia, and improve the uniformity of training across the state. There are few other state resources in the position to provide this essential training. The Legal Subgroup highlighted this program as an important asset in preparing Rhode Island to best serve and protect residents with Alzheimer’s disease and their families.

Recommendations

- Allocation of additional resources to support investigatory and prosecutorial personnel in the Office of the Attorney General in light of the complexity of financial elder abuse cases.

2. Identification of resources to support ongoing efforts within the Division of Elderly Affairs

The Division of Elderly Affairs (DEA), a division of the Executive Office of Health and Human Services, is the state's dedicated agency for the service and protection of senior citizens, adults with disabilities, and their families and caregivers. DEA's Protective Services Unit is responsible for investigating complaints of elder abuse of Rhode Islanders over the age of sixty by a family member, caregiver or person with a duty of care. Abuse may include physical, emotional, sexual, or financial exploitation or abandonment. In addition to the unit's resources, DEA currently has a contract with Family Services for a twenty-four hour call-in number to report concerns that an elder is in danger. Once the DEA's Protective Services Unit becomes aware of a case, will conduct an initial level of investigation and then hand off the case to the Office of the Attorney General. The Protective Services Unit must also develop a care plan to prevent additional abuse and to address the elder person's social service needs. Subgroup participants acknowledged the critical role the Protective Services Unit plays as a partner to law enforcement in the investigation and prosecution of crimes against elders and in serving those seniors who are in need of social services and case management assistance. In light of the critical investigatory assistance and need for regular and ongoing coordination with the Office of the Attorney General, the Subgroup participants felt this was an area of state government greatly in need of additional resources. This is particularly important given the anticipated increase in age of the average Rhode Islander, and the enhanced vulnerabilities of those living with Alzheimer's disease.

Additionally, the DEA has historically offered community trainings focused on educating law enforcement, family, and other community members on how to recognize signs of elder abuse and what to do if one suspects that elder abuse has occurred. Through its Commission for the Care and Safety of the Elderly, the DEA also offers annual training for law enforcement and firefighters on the statutory duty to report. This is a critical resource that should continue and potentially expand to include training aimed at improving dementia awareness among these professionals. The Legal Subgroup was unanimous in its support for continuing the DEA's training programs and expanding them in the near future. This remains a

concern for the Alzheimer's population given their particular vulnerabilities and frequent inability to serve as competent witnesses to their own abuse.

Recommendations

- Identify a strategy for increasing resources available to the Protective Services Unit of the Division of Elderly Affairs.
- Support the annual training programs offered to police and fire advocates through DEA as an ongoing opportunity for law enforcement and first responders.
 - Supplement the existing platform to incorporate dementia awareness training.

C. Identification of Additional Needs

Despite the high quality of training opportunities offered in Rhode Island for law enforcement and other community personnel, the Legal Subgroup observed that there is a lack of uniformity across local departments. The role of the Senior Advocate (a designated police officer) was observed to be of critical importance, particularly as a single point of contact within police departments for communication about elder abuse and dementia training and education. Senior Advocates were also identified as a great starting point for departments to improve the dissemination of lessons learned through training throughout all levels of staff.

An additional area of need identified by the Legal Subgroup was a training and education opportunity developed for first responders, and specifically Emergency Medical Technicians (EMTs), focused on the identification of signs of elder abuse and specific skills for interacting with individuals with Alzheimer's disease. Given the often-complicated nature of elder abuse cases and the potential for a complaining witness to lack the capacity to testify, the experience of first responders upon reaching a scene of purported abuse is critical to the ability of law enforcement to adequately investigate and if appropriate, prosecute the incident of abuse.

An exemplary training initiative underway in the state that should be noted is the collaboration between the DEA, the Rhode Island Alzheimer's Association and the Department of Corrections to provide Alzheimer's disease education and training to prison wardens and clinicians. This is a particularly timely and responsive initiative that will assist prison personnel in recognizing the disease and its symptoms enabling them to provide appropriate responses within the prison environment. The Subgroup recognized the importance of this work and would like to see its scope expand to consider other long-term care settings that house people living with Alzheimer's disease who have spent time in prison and to consider the challenges of finding housing placements for this population.

Recommendations

- Maintain provision of training and educational opportunities as a priority for law enforcement personnel, including municipal and state police academies, probation, parole officers, and the Attorney General's office.
 - Particular outreach efforts must be directed at patrol-level police officers who, though they are not their department's designated senior advocate, are those most likely to respond to the scene of a reported elder abuse crime.
 - Existing training curricula should consider integrating "train the trainer" modules to assist in the dissemination of the teaching elements offered by each course.
- Encourage long-term appointments of Senior Advocate personnel across all police departments in the state and make dementia training a requirement.
- Develop an elder abuse and dementia course for all first responders to be made available on a bi-annual basis.
 - Online courses will be particularly effective here.
- Encourage the ongoing collaboration to address needs and challenges associated with the prison population living with Alzheimer's disease.

- Incorporate work to address similar challenges within long-term care settings housing residents who were previously incarcerated.
- Address difficulties associated with finding housing placements for formerly incarcerated individuals with Alzheimer’s disease.

D. Legal Tools

1. Guardianship

The Legal Subgroup dedicated multiple meetings to Rhode Island’s guardianship system. Guardianship is a legal tool by which the Probate Court assigns to an individual the legal power to make decisions for another individual, or “ward”, who is unable to make decisions for him or herself. Decisions made under a guardianship may concern arrangements for the individual’s care, comfort, and maintenance – including medical and healthcare decisions – as well as decisions about where the individual may live. Some guardianships also involve the management of money and property, including bill-paying on behalf of the ward.

Rhode Island General Laws § 33-15-1, *et seq.* provides for three types of guardianship: (1) limited guardian or guardian, (2) Good Samaritan guardianship, and (3) temporary guardianship for a specific purpose. Limited guardians assist incapacitated individuals in the way that “least interferes with the legal capacity” of an individual to act on his or her own behalf. A guardian assists the individual in meeting essential requirements for physical health and safety, managing financial resources, and protecting the individual’s rights. Good Samaritan guardians are volunteer guardians who serve on behalf of individuals who might otherwise be unable to have a guardianship due to a lack of financial resources. Temporary guardianship for a specific purpose is limited to a specific and defined area of need. Petitions for guardianship are to be filed in accordance with statutory requirements and are heard before the Probate Court of appropriate jurisdiction.

As described above, Rhode Island’s laws enable a guardianship to be tailored to fit the level of need required by a “ward”. The law favors the use of less restrictive alternatives to guardianship where the circumstances allow for it. The discussions of the Legal Subgroup recognized the statutory structure of the guardianship system

in Rhode Island to be intact. There are some areas of the system overall, however, that were identified as potential areas for improvement.

One of the Legal Subgroup's primary concerns with the existing guardianship program lies in the system's inability to adequately serve those who are in need of a volunteer guardian because they lack the financial resources to compensate a guardian. Under current state law and policy, a Volunteer Guardianship Program (VGP) is administered through the state's Division of Elderly Affairs by contract with an outside vendor. The VGP serves low-income seniors over the age of sixty who are living in a long-term care residence and whose impairment is due to dementia. Those assisted under the VGP must have no other options for guardianship other than reliance upon an appointment through the Volunteer program. The VGP is reliant upon finding geographically appropriate volunteers to serve those who are referred to them. Volunteers can be difficult to find in a consistent and reliable way, particularly given the geographic challenges of finding someone willing to serve at the right time and in the right place. Given this framework, the program often struggles to find a sufficient number of volunteers in the area of need, which in some circumstances leaves the probate court tasked with finding an appropriate attorney willing to serve as guardian on an ad hoc basis.

A primary concern of the Legal Subgroup participants is that the state's Volunteer Guardianship Program does not serve hospital patients with no available guardians and who lack the capacity to be discharged following a hospital stay for an acute need. This is due to the risk that program resources will be expended only to discover that there are adequate assets available for the person to obtain a traditional guardian. The Good Samaritan Law applying to all Volunteer Guardianship Program cases will not apply if the potential ward has the financial resources to hire a private guardian. Consequently, hospital patients often remain without guardians given that probate courts may not be willing to appoint a guardian for the specific purpose of discharging the patient to a nursing home because patients will then be left without a permanent guardianship in place. This leaves certain patients and hospitals without adequate remedy when the patient is medically ready to be discharged, yet lacks a guardian to legally discharge them to a more appropriate care setting. The Subgroup spent significant time on this issue in particular, given its relevance to those living with Alzheimer's who may find

themselves in this situation and strongly recommended that the VGP be expanded and provided sufficient resources to do so.

Another concern raised by some participants of the Subgroup is the lack of resources dedicated to ongoing and consistent oversight of the guardianship system on the whole. The Subgroup expressed interest in seeing increased oversight. Among probate judges, there was also interest in seeing enhanced capacity and authority for probate judges to hold guardians accountable for their mandatory reporting requirements. This concern was also raised with respect to individuals holding powers of attorney who abused such authority, yet, were often able to escape legal consequences given the lack of consistent oversight and subsequent lack of legal tools available to the probate courts to hold those individuals accountable.

Recommendations

- Refer the concerns regarding guardianship to the Legislative Commission to Study the Feasibility of Modernizing Probate Law and Procedure (hereinafter the Probate Commission) as established by R.I.G.L. § 33-26-1 for further study and to develop recommendations for submission to state policymakers with respect to the following items:
 1. Increasing the jurisdiction, resources, and thus capacity of the Volunteer Guardianship Program to provide their services to more Rhode Islanders in need.
 2. Modifying the existing Guardianship for a Specific Purpose to better respond to long-term stay residents at hospitals in need of a volunteer guardian for discharge purposes.
 3. Pursue federal funding (i.e., the Administration for Community Living/Administration model program) to support a volunteer guardianship oversight program in the state.
 4. Explore enhancements to existing probate court authority and resources.

2. Advance Directives; Healthcare Durable Power of Attorney, Durable Financial Power of Attorney

The importance of early planning is of particular concern to for those caring for and assisting individuals with Alzheimer’s disease. Advance Directives are a very important part of an individual’s planning for their physical and financial wellbeing should they become unable to communicate decisions on their own. In particular, a Health Care Durable Power of Attorney, allows an individual to designate an alternate decision maker to make health care decisions when the individual is unable to. An alternate can also be designated to serve as a financial agent to handle decisions about money and property through another kind of construct called a Durable Financial Power of Attorney. In Rhode Island, there are specific “state approved” forms that should be used to designate an agent to serve under a Health Care Durable Power of Attorney or Durable Financial Power of Attorney. Many Rhode Islanders may be unaware that while these forms are legally binding, they do not require consultation with an attorney in order to be effective.

The Legal Subgroup discussed the importance of improving public awareness of how these tools can be used in a timely manner in order to help someone with Alzheimer’s and their families be prepared for the future. Discussions among friends and family regarding advance planning should occur as early as possible in order to prevent a situation where they must learn to navigate these legal tools in a time of crisis. Additionally, many participants expressed concern that Durable Healthcare Powers of Attorney should continuously be updated throughout the course of an individual’s life and, in particular, once they have entered a long-term care residence.

For example, pursuant to Rhode Island Department of Health Regulations for Nursing Home Facilities § 25.1(a), resident care plans “shall be reviewed, evaluated and revised by professional staff no less than every three months, or when there is a significant change in the resident's health status.” Additionally, under R.I.G.L. §23-17.4-15.7, assisted living facilities must have a “service plan” for each resident, developed by a qualified person within a reasonable amount of time after move-in and based upon initial assessment. Plans must be updated when a resident’s condition changes significantly. Both requirements offer a commonsense

opportunity for long-term care facilities to initiate and/or update Durable Healthcare Power of Attorney designations with residents and their family members or representatives . Subgroup participants raised an interest in finding ways to increase awareness and resources for assistance in supporting individuals and families in using these legal tools to best prepare for their long-term needs.

Recommendations

- Include healthcare power of attorney designation and ongoing review provisions in statutory nursing home and assisted living care plan requirements.
- Engage existing community networks and healthcare partners in order to increase awareness of advance planning issues and to improve Rhode Islanders' awareness of and comfort level with Durable Healthcare Powers of Attorney.
 - Promote dissemination of state-approved power of attorney form at senior centers and adult day programs.
 - Solicit participation of RWU Elder Law Society to develop and deliver educational presentations and materials to various community partners, including senior centers.
 - Encourage primary care offices to upload health care power of attorney forms to their online portals.
 - Develop CME course material for medical professionals on the importance of advanced planning and the availability of educational materials for patient referrals.
 - Conduct specific outreach to faith-based organizations to augment or initiate educational programs that aid families with advanced planning for end of life care.

- Initiate potential partnership with DMV to make materials and forms available online and in hard copy at DMV locations across the state.
- Improve awareness of the Rhode Island Bar Association’s handbook, “A Guide For Getting Your Affairs In Order” on advance planning, and the “Ask a Lawyer” program as an additional conduit for encouraging advance planning.

3. Senior Bullying

Several Subgroup participants raised concerns about anecdotal evidence of senior bullying and elder abuse in the state’s publicly-supported housing developments for seniors and the disabled. Some participants also mentioned incidents of seniors with Alzheimer’s disease in particular being treated poorly by other residents at long-term care residences due to the persistence of misplaced fears about the disease. These concerns served as a reminder that bullying is not solely a vice of the younger generations and that efforts need to be taken to address bullying and abuse later in life, particularly with respect to the Alzheimer’s population.

Recommendations

- Promote a statewide anti-bullying, anti-elder abuse campaign among seniors across all settings and programming including nursing homes, assisted living residences, senior centers and adult day programs. These programs will be targeted at reducing incidences of bullying and dispelling misconceptions about Alzheimer’s disease.
- Recruit state and community partners to work in concert with one another in order to reach a diversity of settings across the state.

IV. Workforce

The diagnosis, treatment and care management of persons with Alzheimer's disease requires specific training in the needs of those living with the disease as well as their caregivers. Developing a dementia-capable workforce is a critical building block for many other pieces of the overall State Plan. The Workforce Subgroup began its work by assessing the current training and training gaps within hospitals, nursing homes, and home health care agencies. However, the need for community-based providers and primary care providers with skills and training in dementia sensitivity will be equally as critical. This is particularly true in light of the recent shift in both consumer preference and state policy away from facility-based care toward home and community-based care.

A. Workforce Development, Training & Education

While the demand for a dementia-specific workforce is not precisely known, what is true for the healthcare workforce generally can also be applied to a dementia-competent workforce. Greater numbers of personal care attendants and licensed nurse's aides who work in long-term care facilities as well as home and community-based settings will be needed to provide high quality care across all care settings as the population ages and the number of Rhode Islanders living with some form of dementia rises. A particular focus on staff training and retention will be required in order to stem the rates of burn-out and high turn-over often experienced in this field. This is a particular concern for the often low-paying yet high-intensity positions demanded by the needs of individuals with Alzheimer's and related dementias. Efforts to retain staff should be supplemented by high-quality training and preparation for working with this population, including mentorship programs that pair more experienced staff with newer staff just entering the field.

Although most training programs are targeted at the personal care attendant and nursing levels of care, activity program staff, administrators, dietary staff, maintenance staff, and other team members should also be incentivized to seek out dementia training and educational opportunities. As the state trends towards a more individual-centered model of care, all long-term care residences and programs

should consider whole-staff training to be standard practice. That said, cost and time concerns continue to be barriers to higher rates of training participation. The more streamlined the training modules can be, the more likely they will be to reach the desired level of participation. Options such as integrated on-site training, short off-hours trainings, and condensed 15-20 minute training modules inserted into daily staff meetings were highlighted by the Subgroup as the best approach.

It is widely accepted that primary care providers would greatly benefit from better and more frequent access to education and training in the effective care of patients with Alzheimer's disease. However, it is not so widely acknowledged that subspecialties, such as neurologists and geriatric psychiatrists, will also require such training. Equal efforts must be made to make training available to primary care, nursing home staff, and specialists. Great efforts to encourage training among specialists are currently underway through the Rhode Island Geriatric Education Center and the Brown University Geriatric Psychiatry and Geriatric Medicine Fellowships. These initiatives and others like it must continue to grow and improve participation within across a targeted audience.

A key component of this training must also be an emphasis on communication and continuity of care. Subgroup participants raised concerns about the level of access to geriatric psychiatrists for seniors in general, but with particular concern for residents of nursing homes where it can be very challenging to get such specialty care arranged. Furthermore, physicians and nursing home staff must aim to improve the quality and frequency of communication across the care setting, from primary care to specialty care, and between nursing homes and the physicians' offices.

Recommendations

- Develop statewide strategy to address the shortage of outpatient providers (with specific emphasis on the shortage of geriatric psychiatry) and difficulty in connecting nursing homes with geriatric psychiatrists for patient consults.
- Foster improved communications and care coordination across settings for individuals living with Alzheimer's disease through new educational and training materials.

- Encourage participation in Alzheimer’s training and education programs:
 - Promote participation among all staff members, including non-professional staff, within long-term care facilities and programs serving adults with Alzheimer’s disease.
 - Develop incentives for administrator and management-level staff to participate in programs.
- Include strategies for addressing staff support to avoid burn-out, including mentorship structure and/or coaching among experienced staff and newer staff.
- Assess current status of Certified Nurses Assistant (CNA), nursing and physician training to determine the extent to which Alzheimer’s disease awareness and capability are currently included in any curriculum.
 - Determine the feasibility of making this training a requirement for licensure.

B. Training and Education Uniformity

The Workforce Subgroup participants also found the lack of uniformity and standardization across the various training and certificate programs concerning. Based on an informal survey of multiple long term care settings, including nursing homes, assisted living residences, adult day programs, home and hospice care providers and hospital inpatient units conducted by the Workforce Subgroup, training is offered frequently, yet the required level of training and curriculum resources varied widely. Over 90% of the nearly fifty respondents offered their staff training, with nearly 70% of those making it mandatory (primarily for nurses and CNAs). Approximately half of those offering training used a nationally recognized program, which in most cases was identified to be the program provided by the Alzheimer’s Association. That said, the remaining half of those who responded that they offer training ranged widely in their curricula, trainers and experts.

Families would benefit from knowing the staff caring for their loved one has undergone the basic level of dementia-capable training. They currently have no way of easily determining what program, certification, or in-service trainings the staff have participated in and how that might translate into care improvements. Furthermore, a curriculum that could be portable across the long-term care spectrum as staff change jobs or move into different care settings would improve the value proposition of a training program for staff and help increase the number of dementia trained providers in the Rhode Island workforce.

The Rhode Island Department of Health Regulations for Licensing of CNAs and CNA Training Programs require one hundred hours of training for CNAs, including no less than twenty hours of practical clinical training under supervision. The required curriculum for a “state-approved” training program provides education on caring for patients with cognitive impairment, including: techniques for addressing the unique needs and behaviors of individuals with dementia and related diseases. The curriculum also includes strategies for communicating with patients, understanding patients’ behavior, appropriate responses to behavior, and methods for reducing the effects of cognitive impairment. The Workforce and Long Term Care Subgroups discussed the potential for additions to this curriculum that would focus on person-centered care best practices, strength based activity programming, and approaches to creating therapeutic environments to decrease stress and over-stimulation to avoid or decrease difficult behaviors.

CNAs applying for licensure from out-of-state shall “possess a current registration as a nursing assistant in good standing in an alternate jurisdiction” and provide documentation of good standing and employer verification that they have worked the equivalent of three months full-time as a nursing assistant. In the absence of work experience, an out-of-state applicant must provide documentation of successful completion of a one hundred hour state-approved training program in another jurisdiction, including twenty hours of practical clinical training and successful completion of a nursing assistant examination. These regulations establish a strong base for work developing and focusing future efforts to educate and train nursing assistants in Alzheimer’s-specific best practices.

Recommendations

- Develop a statewide stakeholder group with input from state agencies, professional medical associations, long term care providers, and other stakeholders to develop a recommendation for inclusion of specific required dementia elements in healthcare education and certification programs.
 1. Assess status quo of existing Alzheimer's curricula for physicians and nurses and develop recommendations for future augmentations if advisable.
 2. Examine CNAs training programs statewide to assess whether additional augmentations or standardization is recommended.
 - Conduct a national search for best practices in primary, continuing education, and ongoing trainings.
 3. Publish uniform definitions of the following to assist families in discerning what level of training staff have across facilities:
 - Dementia-capable
 - Alzheimer's trained
 - Certified in Alzheimer's Disease Care
- Explore a partnership between state college and university resources and the Alzheimer's Association to develop series of Rhode Island-specific online videos to upload to the RIAD Website (see section VI: Research) with two targets:
 1. A focus on introducing families and caregivers to Alzheimer's disease and Alzheimer's disease resources across the state.
 2. A series of short training modules for anyone interested in learning the basics of caring for someone with Alzheimer's disease (as long as people don't confuse viewing a video with training).

C. Additional Opportunities for Growth

Half of survey respondents cited a need for additional training for frontline staff on prevention of aggressive or disruptive behaviors often associated with Alzheimer's and related dementias, as well as in the individualized approaches needed to manage these issues when they escalate. This concern echoes a theme identified within the Workforce Subgroup as well as the Long Term Care Subgroup that mid-level staff often are not provided with the tools nor expertise that would help them avoid provoking disruptive or aggressive behaviors. This issue requires additional attention as long-term care facilities, regulators, and state policy makers continue to make progress in the culture change initiative and work to improve person-centered care across all settings. Furthermore, the state's local hospitals with geriatric subspecialty programs should be looked to for additional knowledge and expertise as providers across all settings seek to provide high quality care and interventions. Local hospitals should be encouraged to provide both more support and their own expertise to existing training and education programs.

Interestingly, respondents also expressed an interest in the availability of some higher-level training opportunities to take staff education and specialization to the "next level" of practice. Some Workforce Subgroup participants discussed this interest in the context of developing a year-long leadership institute for management-level staff seeking mentorship, workshops on best practices, and training on the medical, psychological and social care of older adults.

Fortunately, Rhode Island benefits from having one of the country's forty-five Geriatric Education Centers located within the University of Rhode Island. The Rhode Island Geriatric Education Center (RIGEC) is funded through a Title VII health professions program out of the Health Resources and Services Administration (HRSA) to provide support for healthcare workforce development and education. The GEC offers continuing education for currently practicing health professionals, develops and disseminates curricula relating to the care of older adults, supports the training and retraining of faculty to provide instruction in geriatrics, and provides clinical geriatric training opportunities for health professions students. The GEC is also driving interdisciplinary education as a best practice for all disciplines involved in the care of older adults.

The RIGEC currently collaborates with a number of partners including URI's Colleges of Nursing, Pharmacy and Human Science and Services (Allied Health and Gerontology). It also works with the Rhode Island College of Nursing and College of Social Work, Roger Williams Medical Center, the Program of All Inclusive Care the Elderly (PACE) of Rhode Island and Memorial Hospital of Rhode Island (MHRI) Department of Family Medicine, Division of Geriatrics. Through these collaborations, the Center offers a series of five workshops directed towards health care professionals who work with older adults, many of which pertain to dementia issues specifically. Participants have a year to complete the workshops. Upon completion participants may earn a Certificate in Interdisciplinary Practice in Geriatrics. The most recent array of covered topics are as follows:

- 1) Fundamental concepts in interdisciplinary geriatric practice.
- 2) Interdisciplinary geriatric assessment and teamwork.
- 3) Common geriatric assessment and teamwork.
- 4) Common geriatric syndromes and clinical management.
- 5) Patient care transition issues and strategies with older adults.

The Brown University Department of Psychiatry and Human Behavior, in collaboration with Butler Hospital, The Miriam Hospital, Rhode Island Hospital, Providence Veterans Administration Hospital, and the Brown University Center for Gerontology and Health Care Research, offers a one or two year clinical Fellowship in geriatric psychiatry. This program provides clinical experience intended to equip future practitioners with the required skills for practicing geriatric psychiatry, as well as to establish a foundation of research to educate the future leaders in geriatric psychiatry. Residents who choose to attend a second year are required to launch an independent research project and develop a foundation in research methodology. This program will allow residents to become knowledgeable clinicians, administrators, and researchers in the geriatric psychiatry field.

The RI Alzheimer's Association also plays an important role in training the state's workforce. For over a decade, the Alzheimer's Association has offered professional development for people who work in Alzheimer's disease and related fields. These trainings are led by full-time staff or offered by one of the organization's three consultants. For convenience the trainings are held in the offices or facilities of the organization requesting the trainings. For individual

professionals or caregivers who wish to be trained, there are also “stand alone” trainings, which occur at the request of facilities across the state. Trainings of this nature are offered every month in six-hour segments. On a given month, the Alzheimer’s Association provides approximately four trainings in total, including organization visits and stand-alone trainings. Exit surveys are administered to the participants to assess effectiveness and emerging areas of interest.

Training and education must also take account of the importance of delivering culturally competent care across an array of cultures and languages represented in Rhode Island. Trainers and educators must take this need into account and find efficient ways of working cultural practices and awareness into their curricula. Furthermore, there are many existing community organizations that should be viewed as partners in this work to ensure that it is done with high quality and accuracy.

A final area for training and education discussed by the Subgroup participants focused on palliative care and hospice care. Given that Alzheimer’s disease has vast variability in median survival rates and an often-complicated trajectory, practitioners struggle to predict serious declines in status, including the end of life stage of the disease. This often prevents families from having a timely discussion of goals for end of life care and presents equally challenging circumstances for clinicians seeking the appropriate time to raise the issue to their attention.

Further complicating this equation can be the varying levels of palliative care education and training among clinicians, which can impact their own comfort level in discussing it with patients. Lessons can and should be taken from the training and education offered by some hospice agencies to their own staff in this area. Improving education and training for clinicians about end of life planning, palliative care, and hospice is a critical step toward improving quality of care for Alzheimer’s patients and their families. A specific step discussed by the Subgroup to improve communications around end of life planning and care choices would be to train clinicians to discuss health crises in the greater context of the disease trajectory. For example, discussing an acute illness, such as pneumonia, within the context of Alzheimer’s disease or related dementias on its own trajectory will better assist

individuals and their families in making informed and timely decisions about care plans at the end of life.

Recommendations

- Assess interest level in, and identify resources for, developing a Leadership Institute for staff interested in obtaining a higher level of expertise in dementia care.
- Develop Continuing Medical Education Modules on relevant dementia topics.
 - Encourage inclusion of end of life planning segments in Continuing Medical Education.
 - Encourage development of CME track on Alzheimer's disease and palliative care.
- Engage RIGEC resources to develop and offer trainings on avoiding, diverting and managing aggressive behaviors among individuals' with Alzheimer's disease.
 - Incorporate lessons and best practices from Healthcentric Advisors nursing home quality improvement collaborative.
- Engage the behavioral health expertise of the Geriatric Psychiatry Program at Rhode Island and Miriam Hospitals for training on pharmacologic and non-pharmacologic approaches to managing aggressive behaviors.
 - Incorporate training into the development of CME track on Alzheimer's disease.
 - Work to disseminate best practices across providers, using the Rhode Island Alzheimer's Disease Website and Research Summits. For a discussion of both of these resources see section VI: Research.
- Encourage local hospitals with geriatric subspecialty programs to provide support to existing programs in the areas of medical care for individuals with AD.

- Explore potential supplemental funding through the RIGEC to provide trainings for frontline staff on older adults and, particularly, dementia care.
- Develop partnerships across communities and with a diverse range of partners to integrate existing training and education programs with best practices for the delivery of culturally competent care, including language skills where possible.

V. Long Term Care

The Long Term Care Subgroup sought to understand the role of long-term care in lives of people with Alzheimer's disease and their families – both in recent history and with respect to how the participants see the landscape changing in the future. The participants began by assessing quality improvement across the existing long-term care framework as well as non-residential long-term care services. Transitions between care settings also emerged as an area of particular importance in ensuring high quality continuity of care for a person living with Alzheimer's disease. The Subgroup then turned to a discussion of how existing long term care settings might be forced to evolve in the coming years as Rhode Islanders age and seek alternative long-term care arrangements. Finally, the Subgroup addressed questions of how payment and delivery reform may serve this sector of the healthcare industry by presenting new opportunities for thinking beyond the confines of the existing system.

A. Improving Accessibility of Long Term Care

Rhode Island's Alzheimer's population is served to a large extent by the network of nursing homes, assisted living residences, home care agencies and adult day programs operating across the state. Many of these facilities offer a specific dementia care unit or program. Senior centers also play a critical role in Rhode Island's communities, providing a location for seniors to access educational and social programming, physical activities, and meals throughout the week. This array of options can be daunting for families to navigate and compare. However, these resources prove critical to enabling families to maintain the independence of an individual living with Alzheimer's disease and to ensuring they have the right level of supports and services as the disease progresses. The Subgroup participants therefore quickly recognized the importance of a community resource that could help support families in making these decisions. Participants shared an interest with other Subgroups that had identified the need for a Rhode Island Alzheimer's Disease Website that would contain comprehensive and timely information about Alzheimer's disease and each of the long term care settings and/or programs available to Rhode Islanders as they age (For an in depth discussion of the RIAD

Website see section IV: Research). The Website was also envisioned as a source for caregivers and families seeking advanced expertise and knowledge from families who have been through the experience before them.

Another area of confusion identified by Subgroup participants for clarification was the designation of some facilities as having specific “dementia units” or noting that they offer “specialized dementia care.” Despite the use of these types of designations, Rhode Island has no specific requirement that employees exhibit a uniform level of competency in dementia-capable skills. Therefore, these designations could lead families to make misinformed decisions that would not necessarily be the best for their loved one with AD. Depending upon their accreditation requirements, organizations, and staff must be licensed, registered, or certified, however none of these include specific dementia-capable standards. Families would greatly benefit from knowing there is a state standard for training prior to entrusting a staff and facility with the care of their loved one with Alzheimer’s disease. This information could subsequently be posted to the Rhode Island Alzheimer’s Disease Website to empower families to easily understand and compare their long term care options. Subgroup participants also expressed a hope that standardizing the training requirements and qualification terminology for dementia care would serve to increase the quality of dementia care currently provided across a number of long-term care residences and services. The Subgroup paid significant attention to existing practices across the state’s nursing homes, assisted living residences, adult day programs and home care services, recognizing the level of high quality care already being provided today in many of them.

Recommendations

- Develop content for Rhode Island Alzheimer’s Disease Website in order to outline the spectrum of long term care options in the state and describe the various public and private payment sources. For more information on the RIAD Website see section VI: Research.
- Facilitate peer-to-peer mentoring opportunities through Rhode Island Alzheimer’s Disease Website in order to pair experienced caregivers and family members with less experienced families and caregivers.

- Develop a statewide stakeholder group with input from state agencies, professional medical associations, long term care providers, and other stakeholders to develop a recommendation for specific dementia elements to be required in healthcare education and certification programs (*as recommended in section IV: Workforce*)
 - Form a recommendation, regarding standardized education and training requirements, for use of terms and phrases such as “dementia unit” and “specialized dementia care.”

B. Best Practices Across Long Term Care Settings

The Subgroup interviewed representatives from nursing homes and assisted living residences, both with and without specific dementia care units. Best practices from their settings centered on the provision of person-centered care as opposed to the historical focus on task-based care. Staff culture often enabled and even prioritized building flexibility into the daily schedule in order to focus on meeting at the resident’s location. The Subgroup also discussed the importance of consistent staffing to provide continuity for the person living with Alzheimer’s disease and to foster a relationship of trust. In this context, trust was often developed by staff members taking the time to learn a resident’s personal history, including their personal needs and preferences, individual concerns or insecurities, and past experiences that may impact a resident’s personality and how they communicate or express their needs. The Subgroup also discussed the value of structuring staff work and allocating responsibilities in a way that allowed for the development of personal connections and empathy among the staff providing direct care and services. This was highlighted as particularly important for those caring for individuals with Alzheimer’s disease given the difficult nature of the disease.

Best practices with respect to challenging behaviors among those living with Alzheimer’s disease were woven into every aspect of the Subgroup’s deliberations. In particular, the Subgroup intends for the state to benefit from ongoing work lead by Healthcentric Advisors. This effort aims to reduce the use of anti-psychotic medications within nursing homes by focusing on environmental factors that contribute to challenging behaviors. This Nursing Home Quality Improvement Collaborative is being offered primarily in a “train the trainer” model to encourage

dissemination of best practices across nursing home staff. This initiative will offer value to the profession as it continuously seeks to provide person-centered care to those living with dementia.

Recommendations

- Include dementia training as part of the quality incentive for nursing homes under DHS.
- Track dementia-specific work conducted out of Healthcentric Advisors and the disseminated best practice learned from the Nursing Home Collaborative to reduce use of medications and to improve transitions.

C. Adult Day Programs as a Component in the Continuum of Long Term Care

Adult Day programs emerged as an underutilized resource for individuals and families wishing to keep a person with Alzheimer's living at home. Participants in many adult day programs benefit from a variety of engaging and therapeutic activities designed for enjoyment and to preserve independence. Comprehensive personal and nursing care services, nutritional supports and care planning and care management services may also be offered. Individual care plans are tailored to best contribute to participant health and comfort, and to support their highest level of function. Adult Day centers across the state serve a high percentage of individuals with Alzheimer's disease or a related disorder and two of them serve solely persons with memory impairment.

As more Rhode Islanders seek to remain at home later into their lives, this model of care will become all the more critical given its range of available nursing care, medication management, care coordination, physical and social engagement opportunities, and the array of support and educational services offered to families and caregivers. In anticipation of a growing number of residents seeking to remain at home later into their lives, the state will need to consider vehicles to help support the programs and to make them more affordable for participants and their families. Furthermore, the state is currently exploring the possibility of allowing individuals with an Alzheimer's diagnosis under the age of sixty to qualify for the co-pay

program (currently a program under the state's Global Medicaid Waiver) for adult day services. This would be a significant benefit for the young onset population and those who help care for them. The Subgroup strongly supports this provision in the current Global Waiver renewal request.

While Medicaid and the state's co-pay program support the individual's or caregiver's cost for income-eligible adult day participants, private daily rates for many families paying out-of-pocket can average well over \$50. Moreover, the state reimbursement rate of \$52.98 per person/per day falls short of covering most providers' cost of care, causing many programs to operate at a significant deficit and/or to rely upon fundraising. The state's Medicaid rate has remained stagnant for the past five years, with the most recent increase occurring simultaneously with the elimination of offsetting legislative grants. Recognizing the funding and reimbursement challenges for adult day programs, the Subgroup participants raised expressed serious concern for the sustainability of the programs into the future. Yet, these programs will continue to play an increasingly important role as elderly Rhode Islanders and people living with Alzheimer's seek alternative long-term care arrangements while continuing to live within the community. Developing a more sustainable financial model for these programs will be critical to ensuring that they remain an available option.

The Subgroup also identified a currently unmet need in the form of programs and services akin to what is offered by a traditional adult day program, but instead held during the night time hours. This gap was also discussed by the Caregivers Subgroup in the context of how caregivers needs are not being addressed. People with Alzheimer's disease may become restless at night, struggle to fall asleep or remain sleeping and require supervision and engagement during the night hours, caregivers often lack the sleep they need to remain healthy themselves and to keep up with their job-related obligations. An adult program during the night hours could merely be an extension of the services offered by existing adult day programs, yet this is a service not currently offered in Rhode Island.

Recommendations

- Develop an awareness campaign to educate families about the resources offered through Adult Day programs.

- Conduct a national survey to inform policymakers and stakeholders in Rhode Island of potential changes to the payment structure for adult day programs to improve their long-term sustainability.
- Explore potential for licensure of adult day programs to offer night-time hours under existing state regulations in partnership with the RI Department of Health.

D. Best Practices in Home Care Provision

Home Care is another area in need of additional examination. There is a growing demand for home and community-based services. Alzheimer's disease and other memory disorders do not qualify a person for home care services under Medicare, however, for those who do qualify it is often a primary, or at very least significant, underlying diagnosis complicating the clinical diagnosis for which they are receiving care through a home health agency. Alzheimer's often complicates the situation of home care patients with Alzheimer's disease who are not technically receiving care for their dementia, yet need significant clinical care and other services to ensure their well-being in the home. Additionally, the Subgroup participants raised concerns that home care providers often feel there are insufficient options for their patients with Alzheimer's disease if they are in need of wrap-around services, yet not receiving them in their current care plan.

Recommendations

- Explore the possibility of allowing eligibility for home care services with a primary diagnosis of Alzheimer's disease or a related disorder.
 - Develop recommendations for enacting this policy change at the state level.

E. Specific Quality of Care Improvements Applicable Across Settings

The work of the Long Term Care Subgroup and the Alzheimer's disease listening sessions raised a concern critical to a state as diverse and ever-changing as Rhode Island: the provision of culturally competent care. The Subgroup paid particular attention to the language skills necessary to provide responsive and appropriate care to a diverse population. Participants also stressed that culturally competent care means providing meaningful opportunities for social interaction and engagement, offering culturally sensitive food and recognizing that "person-centered" care includes allowing ample flexibility to observe religious or cultural events and practices. Based on the anecdotal evidence heard by participants in the State Plan process, this is an area with room for vast improvement.

Transitions are another area for which families and caregivers are in need of additional assistance as they seek to understand the spectrum of services available across different long term care settings and the complex payment structures associated with each of them. The non-linear nature of Alzheimer's disease and its complicated symptoms exacerbates this struggle. Often times, individuals with Alzheimer's disease are able to live at home and receive care through various outpatient and home care providers. That said, many people living with Alzheimer's disease and their caregivers make the choice to use assisted living residences and nursing homes as the disease progresses.

As described in other sections, families often need significant guidance from healthcare professionals as they struggle to make decisions about living arrangements for individuals with Alzheimer's disease. Health care providers – specifically primary care physicians and long-term care providers – must be prepared to discuss these options and their implications with those who seek additional advice and guidance. This is also another area where the long-term care system must work to improve the level of communication between healthcare professionals, and individuals, along with their families, around advance planning, palliative care, and hospice care. These are difficult conversations to have and even harder decisions to make, but a system of high quality care demands that they be made by well-informed consumers in a timely manner. Case management services and agencies such as hospice care providers should be able to play a significant role here.

Transitions are also an area of focus for an ongoing initiative at Healthcentric Advisors. This is a project from which the state will benefit in the coming years. This initiative spans all acute care hospitals, home care programs, many participating nursing homes, and five distinct community coalitions to focus on the individuals at the highest risk for burdensome transitions—defined as multiple admissions to the hospital over the following three months or near the end of life—to reduce the rate of readmissions. The primary objectives will be to highlight medication reconciliation, especially for those with Alzheimer’s disease, and to enhance coordination through the Aging and Disability Resource Centers and community care transitions teams. This project will serve both to reduce readmissions numbers and to disseminate best practices across the relevant care settings.

The Long Term Care and Access Subgroups also raised concerns specific to the Continuity of Care document. This document is used to transmit specific code status and other semantics of a patient summaries across care settings during a transition of care. In particular, a renewed effort at the state level is needed to standardize the content of this document and unify the technological specifications for transmission to ensure the entirety of the patient’s summary is sent. This is particularly crucial for the cognitive assessment done for people with Alzheimer’s disease given the complex and time-consuming nature of assessing cognitive function.

Recommendations

- Forge community partnerships to encourage integration of culturally competent elements appropriate to patient diversity within each long term care setting, including: food and nutrition needs, skilled language needs, space and time for observation of religious or cultural practices and other accommodations as the need or desire is expressed. One proposed solution is to make training videos available in multiple languages.
- Assess capacity within the network of Rhode Island’s existing long-term care providers for specialization in various languages and cultures.
 - Identify specific resources available to providers interested in and capable of moving towards such specialization.

- Develop recommendations for the designation of any provider offering language and/or cultural specialty.
- Develop educational units targeted at physician and nurse-level staff for incorporation into CME curricula to instruct healthcare professionals how to guide individuals and families through long term care transitions and to advise them on advanced planning, including discussions about palliative care and hospice.
- Standardize the Continuity of Care Document used to transmit patient summaries between hospitals and nursing homes and other care providers.
 - Set and communicate standards for electronic submission to ensure uniform transmission.
 - Improve medication reconciliation for dementia patients at transitions of care.

F. Long-Term Goals: Aspects of the Future State of Long Term Care

Understanding that to a great extent, the future of eldercare will be provided in the home and community-based sector, and acknowledging that public funding will not be able to sustain the level of services rendered under current models, the Committee recommends building community support networks to keep people with dementia living in their homes for as long as possible. This would mean relying on members of church groups, civic organizations, and neighbors to help look after, transport, and run errands for community-based elders living with the early stages of dementia. This type of volunteer and non-professional support network will be a critical part of moving towards a future prepared to keep individuals at home and in the community for as long as possible.

One example of a volunteer-run service available in Rhode Island today is Al's Moving Minds, a non-profit organization that runs social groups and activities for people living with early and moderate memory loss. With programs in Warwick, Pawtucket, and other Rhode Island areas, Al's Moving Minds provides a place to

have fun and socialize while giving caregivers a chance to have some time for themselves. Past programs have included movie nights, walking, book club, gardening and bowling. This program depends entirely upon on donated time, goods and funding.

Recommendations

- Use social networking in order to foster neighborhood support and create awareness in the local community to help facilitate network support.
- Establish a list-serve or scheduling service that can be used on a voluntary basis by virtually every neighborhood across the state.
- Support the development of volunteer and non-professional programs across the state aimed at enriching the lives of individuals living with Alzheimer's disease.

The Subgroup also spent time envisioning how the long term care system might adapt to meet the changing needs and desires of the Alzheimer's population. They developed three items: a potential model living community, a system-wide change, and a regulatory change as outlined below:

- 1. Model Long-Term Care Setting Within an Urban Center** – Develop a self-contained, safe, residential setting offering permanent housing for people living with Alzheimer's and their caregiver(s). Include day and night-time care and activities. Establish an indoor/outdoor memory garden with plants, fountains, handicapped-accessible walkways, park benches and picnic tables, birdhouses and other wildlife. Foster a holistic care culture that highlights community, family, nutrition, wellbeing, and safe enriching activities.
 - a. Encourage development to be a partnership among like-minded organizations and/or corporations willing to provide sponsorship.
 - b. Identify grant funding from a variety of sources.

2. **Transition to Private Rooms only** – Reduce and ultimately eliminate the practice of hospital and dormitory-style living accommodations for elders living in long-term care settings. Single rooms provide residents with the dignity and privacy they need and deserve. This transition will also improve health and wellbeing, and reduce disruptions to individuals' sleep and care.
 - a. Track increase in private living with reductions in medical error rates and infections.
 - b. Measure hospitalizations and readmissions of people living with Alzheimer's disease who are in private rooms versus the traditional model of multi-resident rooms.
3. **Establish a Statewide Accrediting Body to Serve as Adjunct to the Rhode Island Department of Health** – Employ this new entity to offer accreditation to all dementia care settings across the state. Move towards an incentive-based accreditation system that will encourage all dementia care providers to voluntarily obtain and maintain accreditation in lieu of the traditional regulatory compliance process and Department of Health survey system.
4. **Create an Innovation Center** – Develop a diverse network of innovators thinking and collaborating together to design the future of long term care, including new living environments, staffing plans and care delivery.

VI. Research

Research continues to expand our understanding of the causes of, treatments for, and possible prevention of Alzheimer's disease. Goals set by researchers locally and nationally are seeking to identify preventive interventions, and to develop innovative new treatments to slow disease progression as early as possible. The Research Subgroup recognizes that any future ability to delay the onset of Alzheimer's disease, to minimize its symptoms, and to delay its progression is entirely dependent on support for both ongoing, and an acceleration of, biomedical research and clinical inquiry. To that end, the Research Subgroup advocates for statewide support of important, local scientific research efforts. This support will ensure that, as evidence-based solutions are identified, such information is rapidly disseminated, put into practice, and brought to scale so that individuals with Alzheimer's disease can benefit from increases in scientific knowledge.

The discussion of Research goals in Rhode Island should not fail to acknowledge the Obama administration's investment of \$50 million in fiscal year 2012 and \$80 million for fiscal year 2013 in new Alzheimer's disease research funding. These investments will increase support for Alzheimer's disease research across the country and in Rhode Island. Participants in the Research Subgroup, however, sought to keep a local focus at the center of their work to develop recommendations for the State Plan and, thus, largely leave questions of funding to the national stage.

A. Identifying Research Priorities and Milestones

Input and feedback must be continuously solicited from the public on ongoing research to prevent and treat Alzheimer's disease across the state. This research must be coordinated and expanded where necessary. Specifically, actions must be taken that will build on ongoing research focused on the identification of genetic, molecular and cellular targets for interventions. To this end, there may be numerous public, private, and non-profit partners in Rhode Island with a focus on health that are capable of assisting in efforts to promote greater awareness of ongoing research, outreach and education on Alzheimer's disease (AD).

Recommendations

- Partner with the Rhode Island Advisory Commission On Aging to issue a Request for Information (RFI) to individual researchers and their institutions for input on funded research addressing Alzheimer's disease and related dementias across the state.
 - Disseminate this information across the Rhode Island research community and inform the state's policy makers of funded projects already underway, areas ripe for potential collaboration, and any concerns regarding gaps in research or participant engagement.
 - This catalog of current pre-clinical and clinical research efforts should be updated on a biannual basis, and disseminated widely.
- Communicate statewide about the importance of increasing participation in research studies and clinical trials while also identifying ways to enhance recruitment of participants for clinical trials on pharmacologic and non-pharmacologic ways to prevent Alzheimer's disease, and manage and treat its symptoms.
 - Develop new efforts aimed at communicating on an ongoing and targeted basis with primary care providers around the state about the importance of discussing participation in research studies and clinical trials.
- Support the collaboration and sharing of research and expertise across institutions and research organizations in Rhode Island.

B. Expanding Research Aimed at Preventing and Treating Alzheimer's Disease

Academic institutions across Rhode Island should work to expand epidemiologic research to identify the risk and protective factors for Alzheimer's disease. Non-pharmacologic treatments and behavioral interventions to help caregivers deal with Alzheimer's disease and related dementias must remain a priority. Stakeholders statewide expressed strong interest in developing a new initiative aimed at encouraging and inviting researchers in epidemiology to explore databases funded by the state and federal government for the purposes of assessing

quality of healthcare for AD patients as well as to identify increased risk (risk factors) or decreased risk (protective factors) of AD.

Research must also be aimed at better understanding how to deliver high quality pharmacologic and behavioral interventions in the diverse range of settings in which clients live and receive care, including evaluating the effectiveness of new models of care delivery. The rapidly changing health care system will see treatment and support for Alzheimer's disease take place in a variety of home and community-based settings. There will be a growing need for community-based health services and inventions research. Future initiatives should encourage research in this arena and increase awareness of these activities among the public and community care settings.

Once again, the importance of increased enrollment in research studies and clinical trials is also crucial for the development of better treatments, and ultimately, a cure for AD. Participating in clinical trials and other research studies often offers volunteers access to the latest experimental approaches available and provides them with added care by clinical research staff. These benefits, as well as the contributions one makes by participating in research, are not widely understood among individuals and families impacted by Alzheimer's disease. These issues must be more widely communicated.

There are also complications to the ongoing success of state-based research that are important areas for improvement. For example, maintaining contact and ongoing clinical feedback from participants in clinical trials who have entered a nursing home is critical to ensuring the value of the data collected through these projects. Participants in the Subgroup highlighted the challenge for researchers to know when research subjects enter long-term care facilities and subsequently follow up with them in the later stages of the disease. Furthermore, additional education and awareness about how to make brain donations to Brown University's Brain Tissue Repository, as well as blood and spinal fluid donations, was identified by participants as another initiative in need of greater public education.

The Research Subgroup envisions a future collaboration of representatives from across the federal government, state and local governments, academic medical research institutions, and the private sector to create an action plan for increasing enrollment in research studies and clinical trials. This would include building

patient/family registries and improving awareness of the benefits of participating in research studies and clinical trials here in Rhode Island. The Subgroup also stressed the need to implement a better tracking or notification system for research centers for when their participants enter long-term care facilities.

Recommendations

- Publicize and encourage participation in the Alzheimer’s Prevention Registry (managed by Rhode Island Hospital) that is currently in place to enhance future recruitment of currently healthy “at-risk” participants into Alzheimer’s prevention trials.
 - This registry should be expanded, to include participation by all stakeholders across the State of Rhode Island, incorporating the work of the following partners;
 - Brown University’s Center for Gerontology
 - Butler Hospital Memory Disorders Program
 - Butler Hospital Geriatrics/Geriatric Psychiatry
 - Memorial Hospital Geriatrics
 - The Providence VA Medical Center RIH Division of Geriatrics
 - The Rhode Island Hospital and Miriam Hospital Geriatric Psychiatry Program
 - RIH Memory Clinic
 - Roger Williams Medical Center
 - The University of Rhode Island’s Geriatric Education Center
- Support efforts of the Norman Prince Neurosciences Institute and Aging Brain Center as well as the efforts of the Interdisciplinary Neuroscience Program (INP) at URI and other URI and Brown University programs focused on aging and neurodegenerative diseases.
- Support community based behavioral health services treatment and delivery research.

- Collaborate with the state's Assisted Living and Nursing Care facilities to work towards enhancing how brain donations to the Brown Brain Tissue Repository are recruited and tracked, as well as blood and spinal fluid donations.
- Improve the tracking of clinical trial participants throughout the lifecycle, particularly once they have entered a long-term care residence.

C. Specific Areas for Improvement to Clinical Trials Participation and Scope

Racial and ethnic factors have an impact on the prevalence of Alzheimer's disease. There is a higher prevalence of disease burden across the African-American and Latino population, as compared to the Caucasian population, and the former two racial groups live longer with the disease than the latter. The specific genetic and environmental/lifestyle factors that play a role in increasing risk of disease, for certain racial and ethnic groups, are not fully understood. Hence, enrollment of participants across various racial and ethnic minorities, in Alzheimer's disease studies, must become a specific priority within the larger goal of increasing overall participation across the population. The state must consider how to most effectively reach out to various racial and ethnic groups in Rhode Island (e.g. African-American, Latino, Spanish, Hmong, Portuguese, etc.) through senior centers, community centers, churches and other organizations and agencies to educate their communities on the importance and benefits of participation in clinical trials.

The Research Subgroup participants also discussed the importance of underscoring the benefits of participation in clinical trials on the most promising pharmaceuticals and lifestyle interventions for the prevention and treatment of Alzheimer's disease. A concerted effort must be made to identify grant funding opportunities to explore these areas in particular as yet another essential piece to the overall research picture.

Recommendations

- Develop new partnerships and initiate strategic outreach to address the challenge of enrolling sufficient and diverse numbers of people into research

studies and clinical trials, including ethnic and racial populations that are at a higher risk for Alzheimer's disease.

- Forge partnerships among the state's existing public health programs aimed at reducing potential environmental factors and other health-related problems such as obesity, hypertension, and diabetes.
 - Identify grant funding opportunities from the state, other local agencies and foundations.
 - Disseminate grant funding across various researchers in the state and their respective institutions.

D. Dissemination of Research Findings

Research findings must be more efficiently and effectively disseminated among the general public, medical practitioners, the pharmaceutical industry, and public health systems. Under the existing structures, promising research and interventions are published in specialized research literature and presented at scientific meetings. Additional steps are needed to make this information more widely accessible in Rhode Island in a meaningful and timely way. To that end, the Subgroup participants discussed the need to create additional opportunities in the state to inform Rhode Islanders of the latest in research findings and foster collaboration among institutions.

One important step in that direction identified by the Subgroup is the creation of a centralized location for communications about all Rhode Island Alzheimer's disease-related efforts. Participants designed two ways of achieving this goal; the development of a "one-stop-shop" website and the convening of a yearly Alzheimer's disease research summit. Such a resource (*referred to throughout this document generically as the Rhode Island Alzheimer's Disease Website*) is envisioned as providing easy access to information about services and supports for those affected by dementia, highlighting dementia-capable providers and support staff, best practices, new research, and other relevant news and updates that would be helpful to this population. URI, as the state's public university, was proposed by the Subgroup to be the host of the website with content and resources provided by all

involved stakeholders. The research summit would be a call to all involved in Alzheimer's disease research to join together to discuss ongoing and new projects, data needs, efforts at recruitment, and any timely findings ripe for dissemination.

One example of the type of research summit imagined by Subgroup members is the Community Program on Aging, Brain Health, and Alzheimer's Disease, which was hosted by The Norman Prince Neurosciences Institute at Rhode Island Hospital in partnership with Bradley Hospital, Brown Alpert Medical School, Brown Institute for Brain Science, Butler Hospital, Hasbro Children's Hospital, and the Department of Veterans Affairs. This summit was held in October 2012 in Newport, RI and provided an array of presentations on aging, dementia, and the current state of the science by experts from the Norman Prince Neurosciences Institute. Topics spanned healthy aging vs. dementia, how Alzheimer's disease starts and spreads, how Alzheimer's disease is diagnosed and treated, the latest advances in early detection and clinical treatments, and where caregivers can get help. This work should be recognized and incorporated into any future research summit called to address ongoing projects and data.

A state-wide committee, viewed as a "neutral" facilitator, could help coordinate these efforts across the various research teams, hospital systems, universities, and providers. More work will need to be done to identify the staffing resources, participation, and ongoing facilitators needed for this committee. Sustainability will also be a key consideration to the success of such a centralized resource. Keeping the goals identified here moving forward and maintaining some of the suggested efforts (e.g. the registry, website, summit) will be immensely important to ensuring that all parties remain invested and engaged.

There are a few other specific needs that are intended to be addressed through the development of these resources. Evidence shows that many providers do not have the most appropriate toolset to best care for older adults with dementia, and that consequently, practices and standards currently in use across the state are not always considered best practices. The efforts mentioned in this section are important steps in making this information more available. Furthermore, they will improve provider education and support use of best practices. Part of these efforts must be a focus on helping older adults maintain their health and independence in the community. Existing public health and aging services in the state must be used

to better disseminate relevant findings through their own networks, but must also make use of partnerships with other interested stakeholder groups across the state to better disseminate their findings. Furthermore, a comprehensive list of geriatric specialists in medicine, neurology and psychiatry should be collected and maintained on the Website to make this information widely available to individuals and families.

Recommendations

- Harness existing resources in the state such as the RIGEC at URI and the Gerontology Center at Brown that are capable of translating findings into practice.
- Identify partnerships among local agencies and institutions to disseminate research findings to networks of providers and researchers.
 - Incorporate annual geriatric psychiatry seminar offered by Butler Hospital and open to the public.
 - Explore potential to build upon monthly conference offered to Lifespan staff members interested in geriatrics and make selected conferences available to the public.
- Develop proposal for reimbursement formula reflective of high-quality care based on best practices and reflective of the necessity for increased provider education.
- Propose website resources that will serve individuals living with AD and related dementias, their families and caregivers, providers, long-term care residences and other impacted community service providers.
 - Explore the development and hosting of the website at URI and identify partners in state government to assist with ongoing community outreach and engagement to generate, develop, and drive website content.

- Develop a sustainability model for the website's lifespan.
- Propose annual research summit goals, identify attendees, and potential sponsors.
- Identify a future "home" or committee to facilitate and support the Rhode Island Alzheimer's Disease Website, research summit, and the ongoing engagement of all partners involved in this work.
- Convene insurance providers to facilitate the dissemination of informational material on dementia to subscribers on a yearly basis. This communication could also include information for on-going training.
- Develop a list of geriatric specialists in medicine, neurology and psychiatry and make it widely available on the RIAD Website.
 - Work to ensure the ongoing accuracy of the list.

VII. Conclusion

The State Plan for Alzheimer's Disease and Related Disorders should serve as a work plan aimed at encouraging collaboration across all stakeholders and driving improvements to the care and services provided to individuals with Alzheimer's disease and their caregivers. There are some recurring themes to this Plan, including faster and more organized dissemination of research findings and best practices, standardized training and education programs across all staff and providers, and the development of an online resource (the RIAD Website) to facilitate coordination among researchers and clinicians and to provide local and timely information to those living with Alzheimer's disease or serving as a caregiver.

These will be excellent starting points for the ongoing work of carrying out the recommendations contained in this document. That said, the co-chairs of this effort, as well as the energy and engagement of the Work Group participants and other stakeholders, communicate a clear intention that this work should be an ongoing effort over the coming years to continuously improve the health and wellbeing of all Rhode Islanders impacted by Alzheimer's disease and related disorders.

VIII. Appendix A

Joint Resolution

LC02415

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2012 -- S 2858

STATE OF RHODE ISLAND

IN GENERAL ASSEMBLY JANUARY SESSION, A.D. 2012

JOINT RESOLUTION

AFFIRMING THE NEED FOR A STATE PLAN FOR ALZHEIMER'S DISEASE AND
RELATED DISORDERS

Introduced By: Senators Jabour, Ruggerio, Paiva Weed, Walaska, and Gallo Date

Introduced: April 10, 2012

Referred To: Recommended for Immediate Consideration

WHEREAS, Alzheimer's disease is a fatal, degenerative disease of the brain that
impairs cognitive function, memory and behavior; and

WHEREAS, Alzheimer's disease is not part of the normal aging process; and

WHEREAS, Alzheimer's disease is the sixth leading cause of death in the United States and the fifth leading cause of death for those over 65 years of age; and

WHEREAS, Alzheimer's disease is the only leading cause of death that cannot be prevented, cured or even slowed; and

WHEREAS, An estimated 5.4 million people nationwide have Alzheimer's disease, including 200,000 individuals under the age of 65; and

WHEREAS, In 2010, approximately 24,000 Rhode Island residents were living with Alzheimer's disease; and

WHEREAS, Alzheimer's disease is the most common type of dementia, accounting for an estimated sixty to eighty percent of incidence; and

WHEREAS, People living with Alzheimer's disease and related disorders use hospital, nursing home and other health and long-term care services at a high rate, resulting in high costs to Medicare, Medicaid and other payers; and

WHEREAS, Medicaid payments for beneficiaries over the age of 65 with Alzheimer's disease are nine times higher than payments for those without the disease; and

WHEREAS, By the year 2050, the total cost of care nationally for individuals with Alzheimer's disease is expected to soar from \$172 billion in 2010 to more than \$1 trillion (in today's dollars); and

WHEREAS, Medicaid's share of that spending will increase over 400 percent during that time; and

WHEREAS, These costs do not reflect the value of unpaid care provided to those living with Alzheimer's disease by family members and friends; and

WHEREAS, There are over 50,000 unpaid caregivers providing an estimated 60 million hours of uncompensated care for people living with Alzheimer's disease; and

WHEREAS, Alzheimer's disease takes a tremendous emotional toll on all whose lives it touches, including family members, friends, and especially the caregivers of those living with Alzheimer's disease; and

WHEREAS, Caregiving has negative effects on the caregiver's own employment, income, financial security, and health; and

WHEREAS, The projected growth in the aging population of Rhode Island, combined with the particular needs of the Alzheimer's disease population, present a substantial and unique challenge to the state; and

WHEREAS, On January 4, 2011, President Obama signed into law the National Alzheimer's Project Act (NAPA), requiring the Secretary of the U.S.

Department of Health and Human Services to establish a national Alzheimer's Project; and

WHEREAS, On February 22, 2012, the Department of Health and Human Services released a Draft National Plan to Address Alzheimer's Disease, which includes the goal of preventing or treating Alzheimer's disease by 2025; and

WHEREAS, Rhode Island has a significant opportunity to build upon this national momentum as well as to identify and address the distinct needs and unique challenges to the State posed by Alzheimer's disease and related disorders; and

RESOLVED, That the state of Rhode Island shall develop a State Plan for Alzheimer's Disease and Related Disorders, which shall be a comprehensive state strategy for educating the public about Alzheimer's disease, collecting and analyzing statewide data related to the current and future needs of Alzheimer's patients and their caregivers, and recommending ways to improve the provision of care and availability of community supports for those living with Alzheimer's disease and their caregivers; and

RESOLVED, That the Long Term Care Coordinating Council, as established in R.I.G.L. 23-17.3, shall convene an Alzheimer's Disease and Related Disorders working group (hereinafter "working group"), to be chaired by the Chair of the Long Term Care Coordinating Council, the Lieutenant Governor, or the Lieutenant Governor's designee, and co-chaired by the director of the Division of Elderly Affairs, for the purposes of developing such a state plan; and

RESOLVED, The working group shall consist of a comprehensive array of community stakeholders, including but not limited to members of the Long Term Care Coordinating Council; and

RESOLVED, The working group shall transmit to the Governor and to the General Assembly, a State Plan for Alzheimer's Disease and Related Disorders on or before July 1, 2013.

LC02415

IX. Appendix B

Rhode Island State Plan on Alzheimer's Disease and Related Disorders

Charge to Subgroups

1. Family Caregiver Needs: Supports and Services ["Caregivers"]

- a. Adult Day care
- b. Respite care
- c. Employee support services
 - i. Adult Day programs at the work site
- d. Informal community supports
 - i. Support groups and counseling
 - ii. Intergenerational assisted living
- e. Remote caregiving (out-of-state caregivers)
- f. Crisis prevention and management
- g. End of Life resources
 - i. "burdensome transitions" at end of life
- h. Cultural differences around attitudes towards dementia end of life care

2. Access to Services ["Access"]

- a. Transportation and mobility challenges
- b. Telemedicine
- c. How can we improve care and access for disproportionately affected communities?
 - i. Minority outreach
- d. Clinical Care coordination
- e. Discharge planning and coordination
- f. Non-residential care services
- g. Funding
- h. Cultural competency and service availability (geographically, linguistically)

3. Workforce Development [“Workforce”]

- a. Meeting RI’s future needs for health care professionals and support personnel
- b. Assuring sufficient and appropriate educational capacity
- c. Provision of training and career ladders for health care professionals and assistive personnel
- d. Education and Training improvements:
 - i. Increasing awareness across all providers and specialties of particular needs or concerns for people with Alzheimer’s disease or related dementias
 - ii. Adequate training around cognitive screenings

4. Protecting the Legal Rights of Individuals and Families [“Legal”]

- a. Privacy rights vs. community supports
- b. Public safety and law enforcement coordination
- c. Conversations about “taking the keys away”
- d. Elder abuse/neglect
- e. Financial protection
- f. Legal Tools
 - i. Public Guardianship
 - ii. Power of Attorney
 - iii. Advance directives

5. Residential Care [“LTC”]

- a. Quality improvement across the spectrum of facility-based care
- b. Non-residential services
 - i. Adult day care and night care programs
- c. Home Care in residential settings and in the home
- d. Are there concerns around capacity of the state to meet the need?
- e. Do we have appropriate care settings in the state?
- f. Transitions

- g. Payment & Delivery reform

6. Care Delivery & Research ["Research"]

- a. Coordinating existing clinical resources and social services
 - i. Centers of Excellence
 - ii. Norman Prince Institute for Neuroscience
- b. Broadening of knowledge across the healthcare spectrum
 - i. Best care choices considering individualized patient goals and needs
- c. Informed consent: competency and community consent

X. Appendix C

A comprehensive list of the Recommendations from each section of the State Plan

I. Caregivers

A. Resources & Networking

- Encourage the development of social media networks as resources for people impacted by Alzheimer's disease.
- Build upon existing caregiver newsletters to pool resources and extend outreach to caregivers interested in learning about Rhode Island specific services and supports.

B. Engaging Individuals with Alzheimer's Disease and their Caregivers

- Develop a two-week certification program, offered by a local university or organization with input from the Alzheimer's Association, for family members caring for individuals with dementia.
 - Incorporate ways to address the needs of other family members (in particular young children) in training and education modules to help them better understand the disease.
- Formalize a peer mentor network to connect families and caregivers that are new to the disease with those who have more experience.
- Partner with geriatric mental and behavioral health experts to provide services for caregivers who screen positive for depression, anxiety and burnout, and develop the capacity to offer education and consultation to community providers who work with families and caregivers.

C. Respite Care

- Support and Build upon ongoing public outreach efforts through the Providence Catholic Diocese and Division of Elderly Affairs to increase public awareness of the CareBreaks program.

- Encourage the development of a comprehensive network of respite options across the state, including short and mid-term respite care.
- Explore potential to incorporate mid-to-long-term in-home respite services into the overall network of options.
- Survey national models akin to the Shared Living program that address the prohibition on spouses, parents or other persons financially responsible for the care recipient, from serving as the paid caregiver.
- Explore the possibility for future “fast track” eligibility for Medicaid based on a diagnosis of Alzheimer’s disease or a related disorder.

D. Respite Care Training & Education

- Increase outreach to improve awareness of respite services through CareBreaks program, the Department of Elderly Affairs (hereinafter DEA) (including the POINT) and the Rhode Island Alzheimer’s Disease Website. (For more information on the proposed RIAD Website see Section VI: Research)
 - Improve rate of utilization of respite care among family caregivers.
- Enhance provision of respite care services to include emergency or short-term immediate access.
 - Explore the possibility of shortening average required stay at nursing homes for emergency or short-term respite.
 - Explore the feasibility of simplifying the application process for nursing home respite care.
 - Explore alternative providers of care who could be more readily available to step into a respite need on an immediate basis.
- Seek to develop long-term respite care service modeled around best practices for people with Alzheimer’s disease, including keeping the person at home and developing long-term relationships.

- Expand respite care worker education and training opportunities across the state.
- Develop training and education opportunities for friends and family members who will be caregivers and for those who will provide respite to the primary caregiver.

E. Caregivers in the Workplace

- Establish ongoing links with EAPs and provide educational and informational resources on support for families dealing with Alzheimer's disease.
- Strengthen existing EAP resources for Alzheimer's at large companies currently offering them to employers; include outreach about the State Plan for Alzheimer's disease and Related Disorders and awareness of the Rhode Island Alzheimer's Disease Website (for a discussion of the proposed RIAD Website see section VI: Research)
- Work to ensure that all EAPs receive information about referral resources for employees requiring more intensive or long-term mental health services, such as geriatric mental health programs that include services for caregivers.
- Enhance awareness of the Rhode Island State Employee Assistance Program and make efforts to improve outreach to employees dealing with Alzheimer's disease caregiving responsibilities.
- Support expansion of EAPs across large, mid and small size employers in Rhode Island.
 - Explore possible partnerships across smaller sized companies through building shared resources (e.g. Chambers of Commerce).
- Develop additional partnerships for the provision of workplace-sponsored support groups and educational series focused on Alzheimer's disease.

- Create a peer mentorship program to pair new caregivers with more experienced caregivers.
 - Explore the potential to connect peer mentors through online chat function as part of the Rhode Island Alzheimer’s Disease Website (See section VI: Research).
- Incorporate real-time employee-focused supports and resources to the Rhode Island Alzheimer’s Disease Website (See section VI: Research).

F. Additional Caregiver Needs

- Identify best practices and future improvements for the support of remote caregivers and caregivers with extensive external demands such as family and job-related responsibilities.
- Expand access to case management and care coordination services in both public and private programs.
- Conduct a survey of existing innovative models in assisted living that may offer best practices in the care and support of elderly parents and adult children with disabilities in a shared living environment.
- Develop and disseminate culturally competent materials to assist families with end-of-life-care and planning decisions.

II. Access

A. Transportation

- Engage RIPTA to develop a phased-in plan to address the following concerns raised by the Access Subgroup:
 - **Physical Changes**
 - Share information with community partners that Ride vehicles and Flex vehicles have distinct physical appearances and that any remaining outliers will be phased out.
 - Ensure all RIPTA buses have “kneeling” capability to ease rider’s ascent to the vehicles

- Consider adding bright colored safety strips to the center aisles and top of entry stairs of all buses to aid riders with compromised depth perception and visual impairment.
- Develop communication plan and materials to educate community partners about non-cash payment options for RId and Flex vans.
- ***System Changes***
 - Development of online trip planning capability for Flex services.
 - Development of an interface between the call-in trip planning service and the online trip planning capabilities for RIPTA buses and to the extent feasible, RId and Flex vans.
 - Addition of same day services within RId and Flex Van system to accommodate riders when important appointments are delayed cancelled or rescheduled.
 - Consider potential back-up or “on call” transportation option for urgent or important “last minute” cases.
 - Review policy of the Elderly Transportation program that requires clients to go to nearest adult day program.
 - Consider the development of a new policy allowing exceptions based on individual client need.
- ***Administrative Changes***
 - Implement mandatory ongoing and consistent driver training on dementia for RIPTA employees

- Encourage and facilitate “curb to counter” assistance for riders, particularly when dropped off at large office buildings or campuses.
 - Continue to pursue improvements and aids to simplify ridership and ease navigation of the public transit system.
 - Simplify the ADA application and explore whether there is a way to communicate the two-part approval process required by the existing application.
 - Make the ADA application available in multiple languages
 - Explore the expansion of lines of service available to individuals under the age of 60 who are not eligible under the ADA for service but who would benefit from access to special services given their Alzheimer’s diagnosis.
 - Continually reassess geographic distribution of RIPTA transit service
- Incorporate the recommendations of the State Plan into new work streams and services facilitated by the EOHHS Elderly Transportation Services broker.
- Consider creation of a Mobility Manager position within the Elderly Transportation Services system to work closely with the EOHHS broker to augment case management services offered by The POINT and its regional POINT offices.
 - A Mobility Manager would develop an extensive list of transportation options available across all communities, including public and private services, volunteer driver programs and any other possible means of transport.

- This position could offer an individualized assessment to each person in whichever community they live.
 - This position could also serve as a resource to the Rhode Island Department of Motor Vehicles (DMV) as it works to improve the informational resources and alternatives to driving it offers individuals once their licenses are revoked.
- Consider addition of online real-time chat function through the trip planner function of the RIPTA website as an additional tool for individuals and families to coordinate their transportation needs.
- Improve dissemination of the AARP Rider Guide among home care workers, adult day programs and senior centers.
- Explore opportunities for wide dissemination of The Guide, including posting it to the Rhode Island Alzheimer's Disease Website (see Section VI: Research for more discussion of the website).
- B. Knowing When Driving is No Longer Safe and What to Do
 - Develop a quick reference guide for primary care offices to use in referring concerned caregivers, friends, or family members to options available to help them deal with Alzheimer's and driving issues.
 - Upload this resource onto the RIAD Website (see section VI: Research)
 - Explore ways to make privately offered safe driver courses and assessments more affordable to Rhode Islanders.
- C. Telehealth
 - Expand public and commercial coverage of telehealth technologies to assist in managing chronic illness diagnoses such as Alzheimer's disease.
 - Research grant opportunities to implement telehealth demonstration programs for families caring for persons with Alzheimer's or other dementia in home situations.

D. The POINT and other resources for individuals and caregivers

- Encourage 211/“The POINT” to develop capacity to sort call-in data and geographical break-down of needs in order to better inform the state’s awareness of Alzheimer-related inquiries, including: needs of caregivers, areas in need of improvement, and gaps in services and support.
- Forge connections between the Regional POINT offices (the DEA network of local agencies linked to 211/“The Point”) and the Alzheimer’s Association to encourage information-sharing regarding identified needs, questions, requests for service, and to disseminate local information about Alzheimer’s Association programming.
- Develop a “process map” as a joint project between “The POINT” and the Alzheimer’s Association to guide families with a recent diagnosis to address the following:
 - i. What are the stages of the disease and what should you expect in each of them?
 - ii. What are the important planning needs our family should consider?
- What are the commonly used services (adult day programs, senior centers, transportation, meals, caregiver supports, etc.)?
- How can this information be available in a manner that is accessible and culturally appropriate for various cultures?
- Seek out a way to connect individuals and their families dealing with a recent diagnosis of Alzheimer’s disease or a related disorder with a package of information that includes the “process map” and the basic information that will help them become familiar with the available resources.
- Explore ways to increase public awareness of the importance of early access, through “The POINT”, to options counseling.

- Encourage ongoing Alzheimer’s training, including awareness of caregiver resources and needs, for the full network for DEA/DHS service providers.
- Ensure that adequate training and resources are provided to “The POINT” and the DEA partner agencies to ensure Options Counseling adequately addresses both publicly and privately funded services.
- D. Emergency Department Care for Individuals with Alzheimer’s Disease
 - Disseminate best practices from ongoing changes being made in the state’s emergency departments and incorporate into future recommendations.
- E. Living Rite - A Disruptive Solution for Management of Chronic Care Disease

III. Legal

A. DMV/Safe Driving

i. **Assistance for Family Members Concerned About Unsafe Driving**

- Engage community partners (senior centers, assisted living residences, adult day programs, police departments, etc.) to educate families about the resources available to assist them with concerns about safe driving.
 - Develop a one-page handout describing an overview of the laws, processes, and partners available to assist families with driving concerns.
 - Engage Roger Williams University School of Law (RWU) Elder Law Society to assist in development of one-page handout and implement educational presentation for use at senior centers and other potential partners.
- Work with the RI DMV’s Operator Control to clearly define license suspension and revocation steps for families on the Operator Control Website (<http://www.dmv.ri.gov/locations/index.php#2>) and

ensure that these families are being provided with sufficient information concerning alternate modes of transportation.

- Solicit white paper from RWU Elder Law Society containing a proposal for best practices in conducting a medical road test (as employed by the RI DMV), including: proper processes, dementia-sensitive training or education modules for Operator Control personnel, and any relevant definitions.

ii. Development of Standards for Physical and Mental Fitness to Drive

- Engage a temporary work group of legal professionals, disability advocates, DMV personnel, and other critical community partners to submit proposed regulations (as defined by R.I.G.L. § 31-10-44(b)) for functional standards for determining physical and mental fitness to maintain motor vehicle licensure to the DMV for promulgation.

iii. Utilization of Privately Offered Driving Courses and Assessments

- Enhance public awareness of independent safe driving courses and assessments by providing basic information on the Rhode Island Alzheimer's Disease Website (see section VI: Research) and including a reference to the existence of such services on the RI DMV website.
- Improve accessibility of these programs by encouraging commercial insurance coverage of driving courses and assessments, and enhancing public awareness of Medicare and VA policies covering safe driving courses and assessments.

B. Law Enforcement, Training and Educational Resources

i. Rhode Island Attorney General

- Allocation of additional resources to support investigatory and prosecutorial personnel in the Office of the Attorney General in light of the complexity of financial elder abuse cases.

ii. Identification of resources to support ongoing efforts within the Division of Elderly Affairs

- Identify a strategy for increasing resources available to the Protective Services Unit of the Division of Elderly Affairs.
- Support the annual training programs offered to police and fire advocates through DEA as an ongoing opportunity for law enforcement and first responders.
 - a. Supplement the existing platform to incorporate dementia awareness training.

iii. Identification of Additional Needs

- Maintain provision of training and educational opportunities as a priority for law enforcement personnel, including municipal and state police academies, probation, parole officers, and the Attorney General's office.
 - Particular outreach efforts must be directed at patrol-level police officers who, though they are not their department's designated senior advocate, are those most likely to respond to the scene of a reported elder abuse crime.
 - Existing training curricula should consider integrating "train the trainer" modules to assist in the dissemination of the teaching elements offered by each course.
- Encourage long-term appointments of Senior Advocate personnel across all police departments in the state and make dementia training a requirement.
- Develop an elder abuse and dementia course for all first responders to be made available on a bi-annual basis.
 - Online courses will be particularly effective here.

- Encourage the ongoing collaboration to address needs and challenges associated with the prison population living with Alzheimer’s disease.
 - Incorporate work to address similar challenges within long-term care settings housing residents who were previously incarcerated.
 - Address difficulties associated with finding housing placements for formerly incarcerated individuals with Alzheimer’s disease.

C. Legal Tools

i. **Guardianship**

- Refer the concerns regarding guardianship to the Legislative Commission to Study the Feasibility of Modernizing Probate Law and Procedure (hereinafter the Probate Commission) as established by R.I.G.L. § 33-26-1 for further study and to develop recommendations for submission to state policymakers with respect to the following items:
 1. Increasing the jurisdiction, resources, and thus capacity of the Volunteer Guardianship Program to provide their services to more Rhode Islanders in need.
 2. Modifying the existing Guardianship for a Specific Purpose to better respond to long-term stay residents at hospitals in need of a volunteer guardian for discharge purposes.
 3. Pursue federal funding (i.e., the Administration for Community Living/Administration model program) to support a volunteer guardianship oversight program in the state.
 4. Explore enhancements to existing probate court authority and resources.

ii. Advance Directives; Healthcare Durable Power of Attorney, Durable Financial Power of Attorney

- Include healthcare power of attorney designation and ongoing review provisions in statutory nursing home and assisted living care plan requirements.
- Engage existing community networks and healthcare partners in order to increase awareness of advance planning issues and to improve Rhode Islanders' awareness of and comfort level with Durable Healthcare Powers of Attorney.
 - Promote dissemination of state-approved power of attorney form at senior centers and adult day programs.
 - Solicit participation of RWU Elder Law Society to develop and deliver educational presentations and materials to various community partners, including senior centers.
 - Encourage primary care offices to upload health care power of attorney forms to their online portals.
 - Develop CME course material for medical professionals on the importance of advanced planning and the availability of educational materials for patient referrals.
 - Conduct specific outreach to faith-based organizations to augment or initiate educational programs that aid families with advanced planning for end of life care.
- Initiate potential partnership with DMV to make materials and forms available online and in hard copy at DMV locations across the state.
 - Improve awareness of the Rhode Island Bar Association's handbook, "A Guide For Getting Your Affairs In Order" on advance planning, and the "Ask a Lawyer" program as an additional conduit for encouraging advance planning.

iii. Senior Bullying

- Promote a statewide anti-bullying, anti-elder abuse campaign among seniors across all settings and programming including nursing

homes, assisted living residences, senior centers and adult day programs. These programs will be targeted at reducing incidences of bullying and dispelling misconceptions about Alzheimer's disease.

- Recruit state and community partners to work in concert with one another in order to reach a diversity of settings across the state.

IV. Workforce

A. Workforce Development, Training & Education

- Develop statewide strategy to address the shortage of outpatient providers (with specific emphasis on the shortage of geriatric psychiatry) and difficulty in connecting nursing homes with geriatric psychiatrists for patient consults.
- Foster improved communications and care coordination across settings for individuals living with Alzheimer's disease through new educational and training materials.
- Encourage participation in Alzheimer's training and education programs:
 - Promote participation among all staff members, including non-professional staff, within long-term care facilities and programs serving adults with Alzheimer's disease.
 - Develop incentives for administrator and management-level staff to participate in programs.
- Include strategies for addressing staff support to avoid burn-out, including mentorship structure and/or coaching among experienced staff and newer staff.
- Assess current status of Certified Nurses Assistant (CNA), nursing and physician training to determine the extent to which Alzheimer's disease awareness and capability are currently included in any curriculum.
 - Determine the feasibility of making this training a requirement for licensure.

B. Training and Education Uniformity

- Develop a statewide stakeholder group with input from state agencies, professional medical associations, long term care providers, and other stakeholders to develop a recommendation for inclusion of specific required dementia elements in healthcare education and certification programs.
 - Assess status quo of existing Alzheimer's curricula for physicians and nurses and develop recommendations for future augmentations if advisable.
 - Examine CNAs training programs statewide to assess whether additional augmentations or standardization is recommended.
 - Conduct a national search for best practices in primary, continuing education, and ongoing trainings.
 - Publish uniform definitions of the following to assist families in discerning what level of training staff have across facilities:
 - Dementia-capable
 - Alzheimer's trained
 - Certified in Alzheimer's Disease Care
- Explore a partnership between state college and university resources and the Alzheimer's Association to develop series of Rhode Island-specific online videos to upload to the RIAD Website (see section VI: Research) with two targets:
 - A focus on introducing families and caregivers to Alzheimer's disease and Alzheimer's disease resources across the state.
 - A series of short training modules for anyone interested in learning the basics of caring for someone with Alzheimer's disease (as long as people don't confuse viewing a video with training).

C. Additional Opportunities for Growth

- Assess interest level in, and identify resources for, developing a Leadership Institute for staff interested in obtaining a higher level of expertise in dementia care.
- Develop Continuing Medical Education Modules on relevant dementia topics.
 - Encourage inclusion of end of life planning segments in Continuing Medical Education.
 - Encourage development of CME track on Alzheimer's disease and palliative care.
- Engage RIGEC resources to develop and offer trainings on avoiding, diverting and managing aggressive behaviors among individuals' with Alzheimer's disease.
 - Incorporate lessons and best practices from Healthcentric Advisors nursing home quality improvement collaborative.
- Engage the behavioral health expertise of the Geriatric Psychiatry Program at Rhode Island and Miriam Hospitals for training on pharmacologic and non-pharmacologic approaches to managing aggressive behaviors.
 - Incorporate training into the development of CME track on Alzheimer's disease.
 - Work to disseminate best practices across providers, using the Rhode Island Alzheimer's Disease Website and Research Summits. For a discussion of both of these resources see section VI: Research.
- Encourage local hospitals with geriatric subspecialty programs to provide support to existing programs in the areas of medical care for individuals with AD.

- Explore potential supplemental funding through the RIGEC to provide trainings for frontline staff on older adults and, particularly, dementia care.
- Develop partnerships across communities and with a diverse range of partners to integrate existing training and education programs with best practices for the delivery of culturally competent care, including language skills where possible.

V. Long Term Care

A. Improving Accessibility of Long Term Care

- Develop content for Rhode Island Alzheimer’s Disease Website in order to outline the spectrum of long term care options in the state and describe the various public and private payment sources. For more information on the RIAD Website see section VI: Research.
- Facilitate peer-to-peer mentoring opportunities through Rhode Island Alzheimer’s Disease Website in order to pair experienced caregivers and family members with less experienced families and caregivers.
- Develop a statewide stakeholder group with input from state agencies, professional medical associations, long term care providers, and other stakeholders to develop a recommendation for specific dementia elements to be required in healthcare education and certification programs (*as recommended in section IV: Workforce*).
 - Form a recommendation, regarding standardized education and training requirements, for use of terms and phrases such as “dementia unit” and “specialized dementia care.”

B. Best Practices Across Long Term Care Settings

- Include dementia training as part of the quality incentive for nursing homes under DHS.
- Track dementia-specific work conducted out of Healthcentric Advisors and the disseminated best practice learned from the Nursing Home Collaborative to reduce use of medications and to improve transitions

C. Adult Day Programs as a Component in the Continuum of Long Term Care

- Develop an awareness campaign to educate families about the resources offered through Adult Day programs.
 - Conduct a national survey to inform policymakers and stakeholders in Rhode Island of potential changes to the payment structure for adult day programs to improve their long-term sustainability.
 - Explore potential for licensure of adult day programs to offer night-time hours under existing state regulations in partnership with the RI Department of Health.
- D. Best Practices in Home Care Provision
- Explore the possibility of allowing eligibility for home care services with a primary diagnosis of Alzheimer’s disease or a related disorder.
 - a. Develop recommendations for enacting this policy change at the state level.
- E. Specific Quality of Care Improvements Applicable Across Settings
- Forge community partnerships to encourage integration of culturally competent elements appropriate to patient diversity within each long term care setting, including: food and nutrition needs, skilled language needs, space and time for observation of religious or cultural practices and other accommodations as the need or desire is expressed. One proposed solution is to make training videos available in multiple languages.
 - Assess capacity within the network of Rhode Island’s existing long-term care providers for specialization in various languages and cultures.
 - Identify specific resources available to providers interested in and capable of moving towards such specialization.
 - Develop recommendations for the designation of any provider offering language and/or cultural specialty.
 - Develop educational units targeted at physician and nurse-level staff for incorporation into CME curricula to instruct healthcare professionals how to guide individuals and families through long term care transitions

and to advise them on advanced planning, including discussions about palliative care and hospice.

- Standardize the Continuity of Care Document used to transmit patient summaries between hospitals and nursing homes and other care providers.
 - Set and communicate standards for electronic submission to ensure uniform transmission.
- Improve medication reconciliation for dementia patients at transitions of care.

F. Long-Term Goals: Aspects of the Future State of Long Term Care

- Use social networking in order to foster neighborhood support and create awareness in the local community to help facilitate network support.
- Establish a list-serve or scheduling service that can be used on a voluntary basis by virtually every neighborhood across the state.
- Support the development of volunteer and non-professional programs across the state aimed at enriching the lives of individuals living with Alzheimer's disease.

- G. The Subgroup also spent time envisioning how the long term care system might adapt to meet the changing needs and desires of the Alzheimer's population. They developed three items: a potential model living community, a system-wide change, and a regulatory change as outlined below:

1) Model Long-Term Care Setting Within an Urban Center –

Develop a self-contained, safe, residential setting offering permanent housing for people living with Alzheimer's and their caregiver(s). Include day and night-time care and activities. Establish an indoor/outdoor memory garden with plants, fountains, handicapped-accessible walkways, park benches and picnic tables, birdhouses and other wildlife. Foster a holistic care culture that

highlights community, family, nutrition, wellbeing, and safe enriching activities.

- i. Encourage development to be a partnership among like-minded organizations and/or corporations willing to provide sponsorship.

- ii. Identify grant funding from a variety of sources.

2) **Transition to Private Rooms only** – Reduce and ultimately eliminate the practice of hospital and dormitory-style living accommodations for elders living in long-term care settings. Single rooms provide residents with the dignity and privacy they need and deserve. This transition will also improve health and wellbeing, and reduce disruptions to individuals' sleep and care.

- iii. Track increase in private living with reductions in medical error rates and infections.

- iv. Measure hospitalizations and readmissions of people living with Alzheimer's disease who are in private rooms versus the traditional model of multi-resident rooms.

3) **Establish a Statewide Accrediting Body to Serve as Adjunct to the Rhode Island Department of Health** – Employ this new entity to offer accreditation to all dementia care settings across the state. Move towards an incentive-based accreditation system that will encourage all dementia care providers to voluntarily obtain and maintain accreditation in lieu of the traditional regulatory compliance process and Department of Health survey system.

4) **Create an Innovation Center** – Develop a diverse network of innovators thinking and collaborating together to design the future of long term care, including new living environments, staffing plans and care delivery.

VI. Research

A. Identifying Research Priorities and Milestones

- Partner with the Rhode Island Advisory Commission On Aging to issue a Request for Information (RFI) to individual researchers and their institutions for input on funded research addressing Alzheimer’s disease and related dementias across the state.
 - Disseminate this information across the Rhode Island research community and inform the state’s policy makers of funded projects already underway, areas ripe for potential collaboration, and any concerns regarding gaps in research or participant engagement.
 - This catalog of current pre-clinical and clinical research efforts should be updated on a biannual basis, and disseminated widely.
 - Communicate statewide about the importance of increasing participation in research studies and clinical trials while also identifying ways to enhance recruitment of participants for clinical trials on pharmacologic and non-pharmacologic ways to prevent Alzheimer’s disease, and manage and treat its symptoms.
 - Develop new efforts aimed at communicating on an ongoing and targeted basis with primary care providers around the state about the importance of discussing participation in research studies and clinical trials.
- B. Support the collaboration and sharing of research and expertise across institutions and research organizations in Rhode Island.
- C. Expanding Research Aimed at Preventing and Treating Alzheimer’s Disease
- Publicize and encourage participation in the Alzheimer’s Prevention Registry (managed by Rhode Island Hospital) that is currently in place to enhance future recruitment of currently healthy “at-risk” participants into Alzheimer’s prevention trials.
 - This registry should be expanded, to include participation by all stakeholders across the State of Rhode Island, incorporating the work of the following partners;
 - Brown University’s Center for Gerontology

- Butler Hospital Memory Disorders Program
 - Butler Hospital Geriatrics/Geriatric Psychiatry
 - Memorial Hospital Geriatrics
 - The Providence VA Medical Center RIH Division of Geriatrics
 - The Rhode Island Hospital and Miriam Hospital Geriatric Psychiatry Program
 - RIH Memory Clinic
 - Roger Williams Medical Center
 - The University of Rhode Island's Geriatric Education Center
- Support efforts of the Norman Prince Neurosciences Institute and Aging Brain Center as well as the efforts of the Interdisciplinary Neuroscience Program (INP) at URI and other URI and Brown University programs focused on aging and neurodegenerative diseases.
 - Support community based behavioral health services treatment and delivery research.
 - Collaborate with the state's Assisted Living and Nursing Care facilities to work towards enhancing how brain donations to the Brown Brain Tissue Repository are recruited and tracked, as well as blood and spinal fluid donations.
 - Improve the tracking of clinical trial participants throughout the lifecycle, particularly once they have entered a long-term care residence.
- D. Specific Areas for Improvement to Clinical Trials Participation and Scope
- Develop new partnerships and initiate strategic outreach to address the challenge of enrolling sufficient and diverse numbers of people into research studies and clinical trials, including ethnic and racial populations that are at a higher risk for Alzheimer's disease.
 - Forge partnerships among the state's existing public health programs aimed at reducing potential environmental factors and other health-related problems such as obesity, hypertension, and diabetes.
 - Identify grant funding opportunities from the state, other local agencies and foundations.
 - Disseminate grant funding across various researchers in the state and

their respective institutions.

- Dissemination of Research Findings
 - Harness existing resources in the state such as the RIGEC at URI and the Gerontology Center at Brown that are capable of translating findings into practice.
 - Identify partnerships among local agencies and institutions to disseminate research findings to networks of providers and researchers.
 - Incorporate annual geriatric psychiatry seminar offered by Butler Hospital and open to the public.
 - Explore potential to build upon monthly conference offered to Lifespan staff members interested in geriatrics and make selected conferences available to the public.
 - Develop proposal for reimbursement formula reflective of high-quality care based on best practices and reflective of the necessity for increased provider education.
 - Propose website resources that will serve individuals living with AD and related dementias, their families and caregivers, providers, long-term care residences and other impacted community service providers.
 - Explore the development and hosting of the website at URI and identify partners in state government to assist with ongoing community outreach and engagement to generate, develop, and drive website content.
 - Develop a sustainability model for the website's lifespan.
 - Propose annual research summit goals, identify attendees, and potential sponsors.
 - Identify a future "home" or committee to facilitate and support the Rhode Island Alzheimer's Disease Website, research summit, and the ongoing engagement of all partners involved in this work.

- Convene insurance providers to facilitate the dissemination of informational material on dementia to subscribers on a yearly basis. This communication could also include information for on-going training.
- Develop a list of geriatric specialists in medicine, neurology and psychiatry and make it widely available on the RIAD Website.
 - Work to ensure the ongoing accuracy of the list.

XI. Appendix D

CareBreaks Information

CareBreaks

Supporting family caregivers in what they do best!

As many as 217,000 Rhode Islanders will find themselves caregivers of a family member or friend this year. Whether you have a child with special needs, a spouse who is a disabled veteran, or an elder needing daily assistance to remain at home, care giving is hard work.

Maybe you need a break.

CareBreaks helps family caregivers arrange for, and perhaps pay for, a break that may include bringing a volunteer or temporary worker into the home, arranging for your loved one to attend a safe day program, or even placing your loved one in an overnight facility for a short period of time.



Call 401-421-7833 Monday - Friday, 8:30 a.m. to 4:30 p.m.,
and ask for *CareBreaks*

To qualify for *CareBreaks* you must be:

- ✓ A Rhode Island resident
- ✓ Caring for a disabled adult or child who cannot be safely left alone
- ✓ Not currently receiving help to pay for a respite break

Paid respite care is provided on a cost share basis that is usually determined by the income of the person for whom you care

CareBreaks is funded by the U.S. Administration for Community Living, Administration on Aging; the State of Rhode Island; and the Diocese of Providence Office of Community Services and Catholic Charities

XII. Appendix E

Senior Transportation by Town

Yes	No
Barrington	Central Falls
Bristol	Charlestown
Burrillville	Exeter
Coventry	Foster
Cranston	Hopkinton
Cumberland	Jamestown
East Greenwich	Johnston
East Providence	Little Compton
Glocester	Middletown
Lincoln	New Shoreham
Narragansett	Newport
North Kingstown	Portsmouth
North Providence	Providence
North Smithfield	Richmond
Pawtucket	Tiverton
Scituate	West Greenwich
Smithfield	West Warwick

	South Kingstown	
	Warren	
	Warwick	
	Westerly	

XIII. Appendix F

Driver Training Referral List

ABC/ACE Driving School

Rumford, RI 02916

Phone: 888-446-5189

LaRue's Blackstone Valley Driving School

14 Rosewood Drive

Lincoln, Rhode Island 02865

Phone: 401-722-1864

National Driving School

1999 Putnam Pike

Chepachet, RI 02814

(401) 568-0911

Allstate Driving School

211 Williams Crossing Road

Greene, RI 02827

Phone: 401-397-5525

JR's Driving School

502 Harvard Court

Woonsocket, RI 02895

Phone: 401-765-8987

Ocean State Driving School

11 Oak Hill Drive

Johnston, RI 02919

Phone: 401-465-1435

Joan's Driving School

100 Elena Street
Cranston, RI 02920
Phone: 401-944-4884

Behind the Wheel and Beyond

210 Airport Street Suite 10
N. Kingston, RI 02852
Phone: 401-667-7473

Abdul's Auto Academy

115 Commonwealth Ave.
Attleboro Falls, MA 02736
Phone: 508-695-1780

XIV. Appendix G

Living Rite Summary

In July 2012, the University of Rhode Island was awarded a 3-year \$14 million grant by the Centers for Medicare & Medicaid Services (CMS) to provide comprehensive chronic care management and preventive care for intellectually and developmentally challenged adults and/or individuals with Alzheimer’s disease / dementia – with two or more chronic conditions who receive Medicare and Medicaid benefits. The project, entitled *Living Rite- A Disruptive Solution for Management of Chronic Care Disease*, is part of CMS’s Healthcare Innovation Challenge, a highly competitive initiative that seeks to identify and support innovative opportunities to improve care delivery and achieve its three-part aim of “improving the individual experience of care, improving the health of populations, and reducing the per capita costs of care for populations.”

The new model's "disruptive solution" theory of change houses Living Rite Centers in two developmental disability agencies in the state, Access Point RI-in Cranston and Seven Hills RI -in Woonsocket ensuring that care is provided in an environment very familiar to the client. The model uses individual interdisciplinary care management teams, including two new community health worker positions, and remote care technology combined with a patient activation model called Multiple Health Behavior Change (MHBC) that teaches clients how to best manage their chronic diseases. The Living Rite initiative's goal is to deliver seamless and comprehensive care in an efficient manner, improving the health, well-being and employment opportunities for its target population and at the same time lowering costs for both the Medicare and Medicaid programs. It has been estimated that the Living Rite initiative will save the public health programs an estimated \$15 million over the course of the grant by preventing illnesses, stabilizing and improving chronic conditions, reductions in emergency room

visits and hospitalizations, and ensuring that Alzheimer and DD clients reside in the least restrictive settings of care.

The Living Rite project was launched (program enrollment was initiated) on May 1, 2013. A month and a half later (June 20), the two Living Rite Centers have patient enrollments totaling 68 clients with developmental disabilities, 3 of whom have a concurrent diagnosis of Alzheimer's Disease. There are 81 additional "presumed eligible" individuals awaiting consent forms. All patients are enrolled in an electronic health record system which allows all of their individual interdisciplinary team members to access and share information. Members include not only traditional health providers but also two new community health workers who are people with disabilities, a DD peer specialist and a Living Rite Life Coach which requires a bachelor's degree level of education. The first services provided to each of the enrollees are prescription reconciliation and a complete physical with state of the art accessible equipment including scales and examination tables. Within two weeks of enrollment they are also given assessments, which include but are not limited to, health, employment, quality of life and a test for severe impairment. Assessment results assist the client in setting realistic goals that will have a positive impact on their potential to pursue the least restrictive lifestyle possible. Furthermore, individual care plans for participants are then developed and managed based upon assessment results. The Centers are looking forward to Year 2, in which targeted outreach to Alzheimer's disease day center clients will take place, along with providing Healthy Lifestyle and behavior modification services to their Developmentally Disabled clients to assist them in better managing their chronic conditions.