2019
UPDATE

RHODE ISLAND STATE PLAN

ON

ALZHEIMER'S DISEASE & RELATED DISORDERS

Office of the Lieutenant Governor
Daniel J. McKee

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A LETTER FROM THE LT. GOVERNOR

As Lt. Governor and Chair of Rhode Island's Long Term Care Coordinating Council, I am pleased to present this update to the State Plan on Alzheimer's Disease & Related Disorders.

According to the Alzheimer's Association's 2018 Alzheimer's Disease Facts & Figures report, there are 23,000 Rhode Islanders living with Alzheimer's or other dementia and over 53,000 family and friends providing care. Alzheimer's disease is now the 5th leading cause of death in Rhode Island.

The State Plan is a blueprint for how Rhode Island will continue to address the growing Alzheimer's crisis. It creates the infrastructure and accountability necessary to build dementia-capable programs and services for the growing number of Rhode Islanders with the disease.

In response to the rising number of affected Rhode Islanders, I convened an Executive Board on Alzheimer's that conducted extensive research, collected data, held town hall discussions with hundreds of Rhode Islanders, and examined best practices in dementia care. This led to the development of a set of policy action steps in this plan to prepare Rhode Island to meet the immediate and future needs of people affected by these devastating diseases.

I hope this plan will also serve as a tool to enable local small businesses and non-profits to take advantage of federal and state funding opportunities like the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act. The BOLD Act recently approved $100 million in federal funds to improve prevention, treatment, and care for individuals with Alzheimer's.

To access Rhode Island's 2013 State Plan, please visit, www.ltgov.ri.gov/alz.

Daniel J. McKee
Lieutenant Governor

ACKNOWLEDGEMENTS

The Lt. Governor's Office would like to thank the hundreds of Rhode Islanders who played a role in crafting this update to the State Plan on Alzheimer's Disease & Related Disorders including:

Members of the Alzheimer's Executive Board, a subcommittee of the Long Term Care Coordinating Council:

Dr. Brian Ott, Lifespan
Dr. Chris Gadbois, BehaveCare
Donna McGowan, Alzheimer's Association Rhode Island Chapter
Dr. John Stoukides, CharterCare
Kathleen Kelly, Rhode Island Assisted Living Association
Kathleen McKeon, Diocese of Providence
Laurie Mantz, Dementia Training for Life
Dr. Nasser Zawia, University of Rhode Island
Sandra Fournier, Neighborhood Health Plan of Rhode Island
Michelle Szylin, Division of Elderly Affairs
Tara Tang, Butler Hospital
William Menard, Butler Hospital
Dr. William Renehan, University of Rhode Island

The team of public health consultants who were commissioned to draft this plan:

Mike Splaine, Splaine Consulting
Kate Gordon, Splaine Consulting

Thank you to our partners at the **Alzheimer's Association Rhode Island Chapter,** the **Rhode Island Division of Elderly Affairs** and the **Rhode Island Department of Health** for their collaboration.

Special recognition to the organizations whose sponsorship and support made this plan possible:

TUFTS Health Plan FOUNDATION

RHODE ISLAND FOUNDATION

HISTORY OF THE STATE PLAN

2012 - In a joint resolution, the General Assembly directs the Lt. Governor's Long Term Care Coordinating Council to serve as the organizational umbrella for a work group to oversee the development of an Alzheimer's State Plan for Rhode Island.

2013 - The Lt. Governor's Office finalizes and widely distributes the first State Plan on Alzheimer's, noting the document will need an update in five years.

The Lt. Governor's Office begins working with state agencies to implement recommendations of the State Plan.

2015 - Lt. Governor Daniel McKee, convenes an Executive Board on Alzheimer's, a group of researchers, advocates, clinicians and caregivers to oversee the implementation and revision of the State Plan.

2018 - Lt. Governor McKee and the Alzheimer's Association Rhode Island Chapter secure $30K in grants from the Tufts Health Plan Foundation and the Rhode Island Foundation to update the State Plan.

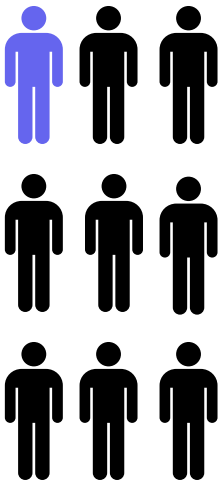
2019 - Lt. Governor McKee completes the update to the State Plan and presents it to the General Assembly for adoption.

RESEARCH PROCESS

The following methods were used to collect information to update the State Plan.

SURVEYS

A survey was conducted with core questions coming from a validated survey used in South Dakota during the needs assessment that led up to its State Plan. The survey was reviewed by the Caregiver Subcommittee and then disseminated widely in paper and electronic form through Survey Monkey, including a Spanish language version. **Nearly 200 surveys were completed.**



1 in 9

Rhode Islanders age 45 and over are experiencing confusion or memory loss that is happening more often or getting worse.

Rhode Island Medical Journal, 2017

TOWN HALL MEETINGS

A robust schedule of **23 local meetings** was conducted in early August to gather input from persons living with Alzheimer's disease, family, caregivers and interested members of the public. Each was moderated by a Splaine Consulting team member, the Alzheimer's Association Rhode Island Chapter, the Division of Elderly Affairs and the Lt. Governor's Office.

INTERVIEWS

The Alzheimer's Executive Board and the Lt. Governor's staff identified a list of **45 key persons** to be interviewed in person or by phone by the State Plan consultants. Individuals on the list represented government, voluntary sector, care providers, trade association members with an interest and the research community.

A structured interview was conducted with these key persons using the survey and additional specific questions about policy recommendations.

KEY FINDINGS

- Citizens want accurate and timely information about Alzheimer's disease.
- Identification of cognitive health issues in primary care and hospitals is not yet a standard of practice, and formal diagnostic services are in short supply.
- Useful information about reducing risk needs to reach the public from a trusted source.
- Biomedical research is hampered by a lack of volunteers, especially by lack of minority participation. While hopeful, most see this as a long-term concern, especially caregivers who are struggling to get through the next week or the next day.

- In Rhode Island, family is the basic long-term support for families with a member with Alzheimer's disease. Caregivers are concerned about their health, skills, finances and availability for the long haul.
- There are many competent dementia care communities and health care workers—but we face growing demands and need more persons trained in dementia care and a way to make this an attractive professional area.
- Understanding and evaluating cognitive decline across the life span should be a focus area in Rhode Island health care, medicine, aging services and public health when creating programs to address the needs of adults living with or at risk of developing dementia.

TOP 3 RECOMMENDATIONS

Based on the findings of surveys, town hall meetings and expert interviews, the Alzheimer's Executive Board puts forth three main recommendations to improve Rhode Island's response to Alzheimer's disease:

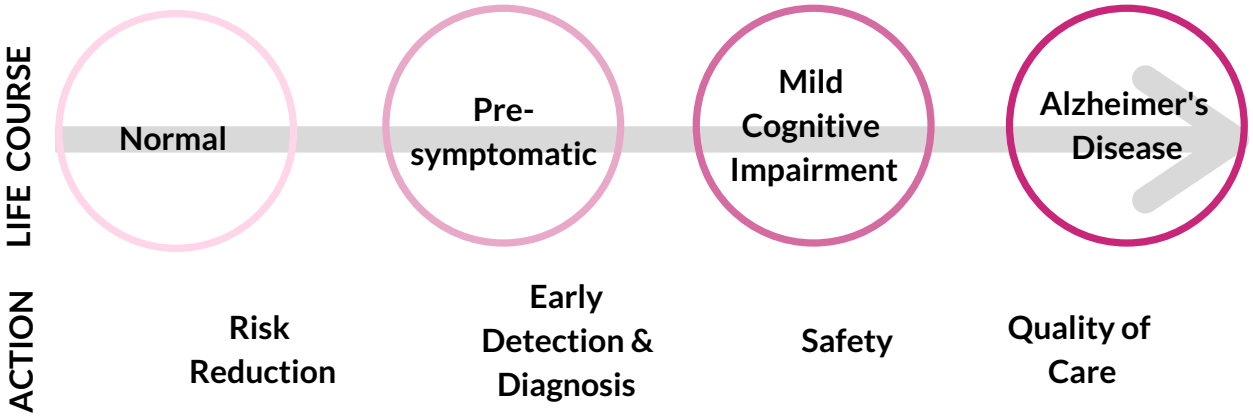
1. Allocate one director-level position within the Rhode Island Department of Health (RIDOH) to coordinate implementation of actions in this State Plan through the activities of public health and in close collaboration with the Lt. Governor's Office, the Division of Elderly Affairs and the Alzheimer's Association Rhode Island Chapter.

2. Promote Alzheimer's disease and related disorders research opportunities of all types, including federal funding, to a broad group of Rhode Island researchers.

3. Include brain health in existing publicly-funded health promotion and chronic disease management activities.

A SHIFT IN UNDERSTANDING: ALZHEIMER'S AS A LIFE COURSE DISEASE

This image represents a shift in perspective that the entire field has made in the five years since the publication of the State Plan.



Our understanding of dementia now is that it is a life course disease, not merely a condition or inevitability of advanced old age. We also now understand that the disease has discernible stages--not merely living with dependence and disability at the latter stages of the disease--and a clear pathway to diagnosis and knowable treatment protocols. This changed perspective encourages us to use survey tools and public health standardized methods to track risk factors, attitudes and access issues. These methods and improved education will lead to reducing health disparities and promoting health to a wide variety of communities. Alzheimer's disease and related dementias (ADRD) are no longer considered simply a very elderly person's disease. Along the life continuum, we can do things that will prevent what was once thought to be inevitable.

This understanding among professionals in the field is not always aligned with the knowledge of the general public which may lead to unfortunate mismatch. For example, a program promoting brain health and risk reduction may be offered to persons in the latest stages of ADRD when risk mitigation may not be possible. This graphic is a way to demonstrate the life course view and stages of the disease.

RECOMMENDATIONS

Rhode Island Department of Health

State and local public health departments are paying increasing attention to the issues of ADRD and caregiving and are incorporating cognitive health and caregiving into their plans of work. Many of their actions include leading policy and partnership development and monitoring the health of the population. There is a strong consensus that the tools and traditions of public health are what is most needed in making progress on these issues today.

Recommendations

- **Allocate one director-level position within the Rhode Island Department of Health (RIDOH) to coordinate implementation of actions in this State Plan in and through the activities of public health, in close collaboration with the Lt. Governor's Office, the Division Elderly Affairs and other agencies.**

  This position should guide RIDOH to develop its capacity to speak authoritatively on ADRD issues, working with medical, scientific and civil society authorities on ADRD already available in the state. This aligns with the actions of other states and the Federal Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act, now in markup in Congress, aligning public health resources on ADRD issues.

- **Develop and maintain web and offline information about ADRD.**

  Disseminate the resources to key secondary information brokers such as the POINT website, statewide 211 and local health departments. At minimum, information should be available in English, Spanish, Portuguese and standard Chinese. Any educational materials should be created with the specific culture and language nuances in mind, not just a translation of what is said from the English/Anglo perspective. Transportation and community services information should be a high priority.

RECOMMENDATIONS

Rhode Island Department of Health CONTINUED

Recommendations

- **Implement recommendations outlined in the Centers for Disease Control & Prevention and the Alzheimer's Association Healthy Brain Initiative Road Map to advance cognitive health as an integral component of public health.**

  Several states have implemented recommended actions, creating a great reservoir of case studies and educational materials that could be customized to meet Rhode Island's unique needs. For the long-term, concussion risk, smoking, healthy nutrition and brain health messages should be added to school-based health programs.

- **Implement and analyze public health surveillance through the caregiving and cognitive health related modules available for the Behavioral Risk Factors Survey.**

  Data should be analyzed and disseminated by the RIDOH. Rhode Island implemented the caregiving and cognitive health modules in 2015 and an update in 2019 will provide data to inform future actions.

RECOMMENDATIONS

Research

Pressured by the Alzheimer's community at large and recognizing the growing crisis, the United States Congress has appropriated the largest amounts ever available for ADRD research in the last two years, creating an unprecedented opportunity. At the same time, more pharmaceutical firms than ever are attempting clinical trials of treatment drugs for which more participants and sites are needed. Lastly, across ADRD research there are recruitment issues especially of members of minority groups.

Recommendations

- **The Lt. Governor's Office should convene and network biomedical, public health, social and care researchers and health systems evaluation researchers to promote collaboration, scientific exchange and develop the research workforce.**

- **Promote all Rhode Island Alzheimer's prevention registries more widely to persons with healthy cognitive functioning.**

  The Research Subcommittee should lead a statewide effort to promote the registries to minority groups, including adding the option to sign up for registries in Spanish. An annual report on all Rhode Island registries should be commissioned and disseminated by the Research Subcommittee. RIDOH should include registry promotion as a key point in its ADRD messaging.

- **Encourage the Rhode Island Commerce Corporation to support neuroscience research and propose new actions to increase support of state-based life science investments in brain research.**

  Special emphasis should be made to recruit faculty and graduate students from Rhode Island College and the University of Rhode Island to engage in ADRD research. This could aid in Rhode Island increasing its capacity to conduct clinical trials and attract ADRD-related pharmaceutical companies to invest in Rhode Island.

- **Promote ADRD research opportunities of all types, including federal funding, to a broad group of Rhode Island researchers.**

RECOMMENDATIONS

High Risk Populations

According to recent research from the National Alliance for Caregiving, African Americans have the highest risk of dementia. When compared with Caucasians, African Americans were twice as likely to develop Alzheimer's, while Hispanics are one and a half times more likely. Additionally, there appears to be uneven costs for different ethnic groups.

Persons with intellectual disability, especially those with Down syndrome, are at greater risk of developing Alzheimer's, beginning as early as their 40s. Detection may prove challenging in this group, and, with multiple cognitive disabilities, living and care challenges abound.

Recommendations

- **In alignment with the RIDOH strategic framework that calls for eliminating health disparities and promoting health equity, assure that the minority disparity in risk and burden be addressed in actions on health goals 2 and 4, here: http://www.health.ri.gov/about/strategicframework/.**
- **The Diversity Subcommittee should make the development of its minority outreach committee a high priority for the next year, including partnerships with key academic departments at Community College of Rhode Island (CCRI), Rhode Island College (RIC) and the University of Rhode Island (URI).**
- **Add dementia issues to the portfolio of community health educators that work in minority communities and build their capability to identify persons with cognitive impairment.**
- **Promote adoption of the Seven Hills program for persons with intellectual disability and dementia across the state as a standard of care. Program details here: http://www.sevenhills.org/intellectual-disability-and-dementia-a-caregivers-resource-guide.**

RECOMMENDATIONS

Health & Long-Term Care Workers

Persons with dementia are cared for everywhere in health and long-term care services, not just designated specialized care units or programs, which serve a small minority of persons with ADRD. To address the quality of dementia care, the workforce at all levels of healthcare needs training and continuing education. This would include physicians, nurses, nursing assistants, social workers, care managers, care providers to persons with intellectual disability, home care workers, program assistants at adult day care programs, assisted living staff, nursing home and assisted living administrators, law enforcement, emergency medical technicians and other first responders.

Recommendations

- **Create and implement standards of education for all healthcare providers entering the workforce and implement specifics in the continuing education requirements for neuro-cognitive disorders at all levels of healthcare including hours, content and methods.**
- **Allow labor costs associated with continuing education to be reimbursable under Medicaid and 100% state funded care programs.**
- **Increase collaboration between RIC, URI and CCRI Gerontology programs and consider a concentration in dementia care and services in these or health and aging services majors.**
- **Mandatory training in progressive neuro-cognitive disorders (dementia) prior to clinical rotations should be included in the curriculum of all state funded educational institutions providing education/training for healthcare workers.**
- **Increase collaboration between specialty high school programs graduating certified nurse assistants, junior college and college nursing programs to create a career track in dementia care.**
- **Create and implement a neuro-cognitive disorders training program specifically for members of law enforcement.**

RECOMMENDATIONS

Risk Reduction

Recommendation

- **Include brain health in existing publicly-funded health promotion and chronic disease management activities.**

Several modifiable risk factors for developing Alzheimer's disease have been identified which, if mitigated, could accelerate reducing the soaring costs of ADRD to healthcare, social and economic systems. The scientific basis now exists to message traumatic brain injury, smoking, diet, physical activity, and cardiovascular risk as modifiable risk factors for ADRD.

23K

Rhode Islanders are living with Alzheimer's or other dementia

53K

Rhode Islanders are providing care to a family member or friend with Alzheimer's or other dementia

Alzheimer's Association's 2018 Alzheimer's Disease Facts & Figures

RECOMMENDATIONS

ALZHEIMER'S AS A LIFE COURSE DISEASE

Stages: Pre-symptomatic, Mild cognitive impairment & Early

Nearly 90% of Americans say that if they were exhibiting confusion and memory loss they would want to know if the cause of these symptoms was Alzheimer's disease. Yet, over half of persons over age 45 with subjective cognitive decline have not talked with a healthcare provider about their questions and concerns.

Evidence indicates that less than half of people with dementia have been diagnosed by a physician. Among older adults who have been diagnosed with dementia, only 35% are aware they have the disease. And at least 20% of Medicare beneficiaries who are readmitted to the hospital within 30 days have ADRD.

Normalizing discussions about cognitive health in routine delivery of health care can support early detection and modification of risk factors. The earlier ADRD is diagnosed (and many times symptoms are not ADRD) the sooner care can be provided. A formal diagnosis allows access to treatment and participation in clinical trials, life planning, and taking healthy actions to live better with ADRD. Access to timely and accurate diagnosis is difficult in outlying areas of Rhode Island, and the few specialty clinics for ADRD have long waits. Health direction to persons identified with mild cognitive impairment is uneven and sparse beyond "contact us if you notice a change."

Most persons with dementia receive their medical care through non-specialists. The Geriatric Education Center has been in the lead in increasing primary care capacity and capability in use of cognitive testing in the Medicare reimbursed Annual Wellness Visit, the KAER (Kickstart, Access, Evaluate, Refer) toolkit, billing issues related to identification of cognitive impairment and in providing knowledgeable medical care to those affected.

RECOMMENDATIONS

ALZHEIMER'S AS A LIFE COURSE DISEASE

Stages: Pre-symptomatic, Mild cognitive impairment & Early Continued

Recommendations

- Consider pilots in tele-health alternatives for evaluation for dementia through rural community health clinics.
- A consensus document on the evidence of what health actions should be recommended by medical practices to persons diagnosed with mild cognitive impairment and/or early stage Alzheimer's disease should be developed by the Research Subcommittee and widely disseminated. This document should be reviewed at least every two years against new evidence emerging in the field.
- RIDOH should educate health professionals about the value of early diagnosis and the related treatment pathways through a "Dear colleague" letter like one developed in New York and other states. Example here:https://www.health.ny.gov/diseases/conditions/dementia/alzheimer/2016-11-30_dear_col_ltr_detect_diagnose_alzheimers.htm.
- The Rhode Island Geriatric Education Center should apply for any available federal funds and be a priority for new investment by the state should matching funds be needed to draw down federal assistance.

RECOMMENDATIONS

ALZHEIMER'S AS A LIFE COURSE DISEASE

Stages: Middle & Later

Ensuring the safety of persons with ADRD, providing quality care and supporting family caregivers become central issues in the middle and later stages of the disease. Most care and support of persons with ADRD is provided at home by family. There is increasing data that suggests that 1 in 3 ADRD caregivers report their health has gotten worse due to care responsibilities and that 18% of teenagers have eldercare responsibilities in their homes. Caregiving can extend for years in ADRD, and even when formal care services are used, it doesn't stop, it is shared.

State government has a large budgetary stake in how long-term care services and supports are delivered through its Medicaid budget and a quality of care oversight responsibility through its health care regulatory functions.

As integrated models of care and alternate payment strategies are developed, planners and payers must account for the unique needs of persons with ADRD and family caregivers in these models by including them in planning processes and data collection.

Recommendations

- **Increase income eligibility as authorized under the state 1115 Medicaid waiver to help ease the financial burdens associated with home and community-based care for persons not eligible for Medicaid.**
- **Complete the work by the Legal Subcommittee with the Department of Motor Vehicles medical evaluation of the driving fitness of persons with ADRD.**

RECOMMENDATIONS

Stages: Middle & Later Continued

Recommendations

- Powerful Tools for Caregivers is used across the country as an evidence-based intervention to support caregivers of persons with dementia. The current RIDOH website about this program should mention dementia as a covered condition and make the program better known to the Alzheimer's community, while listing other evidence-based caregiver support programs offered through Division of Elderly Affairs.

- Develop a common application for nursing home placement and encourage provision of standard written transfer information between hospital and care communities developed by the Society for Post-Acute Care Medicine (https://www.hqinstitute.org/sites/main/files/file-attachments/6_transfer_forms.pdf).

- Support community education about caregiver health and caregiver rights under the CARE Act (https://www.aarp.org/content/dam/aarp/caregiving/2017/11/ri-ich-care-act-flyer-aarp.pdf).

- Operationalize the Medicaid waiver provision that includes respite as a long-term support core service for elder Medicaid recipients and provide caregiver training as a Medicaid benefit.

- Improve non-medical home care by amending regulations to include a definition and requirement for meaningful activities for the person with ADRD within this service.

- The Division of Elderly Affairs and other entities should assist PACE programs with public relations and outreach (62% of PACE participants have a diagnosis of dementia).

- The Alzheimer's Executive Board and the Long Term Care Coordinating Council should consider the report on oral health (Appendix D) in a joint future meeting. We know of no state that has made this aspect of dementia care a priority, but the report is thoughtful and worthy of more conversation.

RECOMMENDATIONS

Special Populations

Younger onset persons at listening sessions reported little attention to their unique situation, suggesting that there be more partnerships with YMCA and similar organizations to create opportunities for physical activity, activities for working spousal caregivers in evenings and volunteer opportunities.

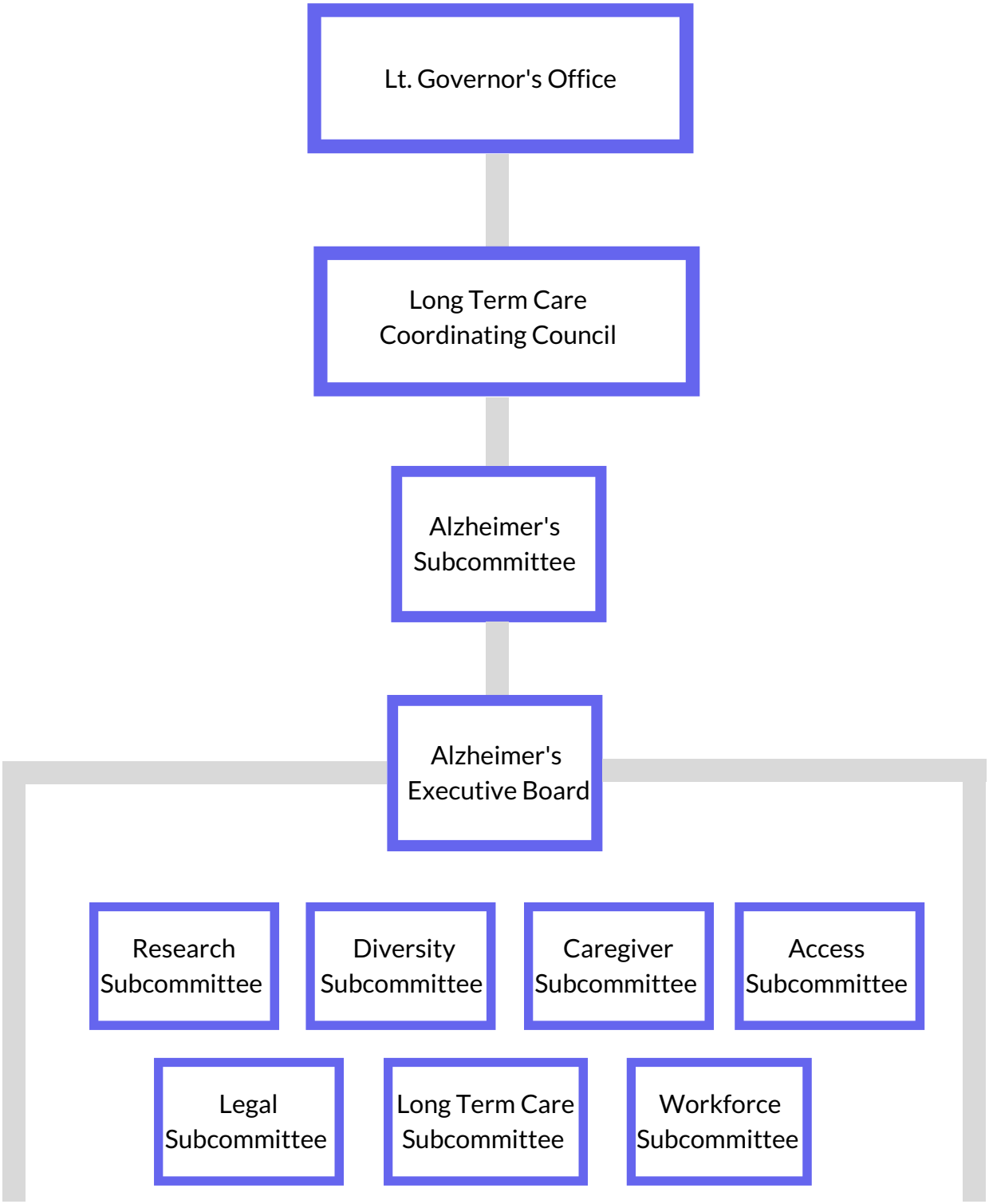
Recommendations

- **Work with the Department of Environmental Management to create dementia friendly recreation spaces, partnering with age friendly initiatives with improved signage, short walking trails, etc.**
- **Expand the Division of Elderly Affairs co-pay program to include persons under age 65 with ADRD.**

APPENDIX

APPENDIX A

Organizational Chart



APPENDIX B

Input Summary and Questionnaire

Survey

This survey that follows drew its core questions from a previously validated survey used in South Dakota during the needs assessment that led up to its state plan. It was reviewed by the Caregiver subcommittee and then disseminated widely in paper and electronic form through Survey Monkey, including a Spanish language version. Nearly 200 surveys were completed.

Rhode Island State Alzheimer Plan Survey 2018

Rhode Island developed a state plan for Alzheimer's disease (and related dementia causing illnesses-ADRD) four years ago and has used many of its ideas. It is now being updated and we are asking for input from Rhode Islanders from all walks of life.

- Please list all services and resources available for ADRD in your community.
- Are there services or resources that are missing that would help ADRD people and their families?
- If you are a caregiver (family or professional), what are some problems you have experienced in getting ADRD services and resources?
- Are the symptoms and treatment of ADRD clearly explained by the medical services and resources you use?
- In your opinion, what does a community need to do to support those with ADRD?
- What is the most important thing that the Rhode Island work group on ADRD needs to understand?

Encuesta sobre la Enfermedad de Alzheimer 2018

Rhode Island desarrolló hace 4 años su primer plan estatal de Alzheimer, ahora este plan está siendo actualizado. Queremos escuchar lo que tiene que decir la comunidad sobre las necesidades que tienen de las personas con Alzheimer u otros tipos de demencia en Rhode Island. Actualmente este plan está siendo actualizado y estamos solicitando que las personas de Rhode Island, de todos los sectores sociales, aporten ideas.

- Por favor, nombre todos los servicios y recursos que hay disponibles en su comunidad para las personas con ADRD (por sus siglas en inglés).
- ¿Qué servicios hacen falta y ayudarían a las personas con ADRD y a sus familias?
- Si usted es cuidador/a (como familiar o profesional), ¿qué problemas ha enfrentado al tratar de conseguir servicios o recursos para ADRD?
- ¿Los síntomas y el tratamiento para ADRD están siendo claramente explicados por los servicios médicos y por los recursos que usted ha usado?
- En su opinión, ¿qué necesita hacer una comunidad para apoyar a aquellos que padecen ADRD?
- ¿Qué es lo más importante que el grupo de trabajo en ADRD de Rhode Island debe comprender?

APPENDIX B - CONTINUED

Input Summary and Questionnaire

Town Hall Meetings

A robust schedule of local meetings was conducted in early August to gather input from persons living with Alzheimer's disease, family and professional caregivers and interested members of the general public. Each was moderated by a Splaine Consulting team member, the Alzheimer's Association Rhode Island Chapter or the Lt. Governor's Office. Through the efforts of Kathy McKeon and Catholic Charities staff, a town hall meeting was conducted in Elmwood in Spanish and the consultants recieved a translated report the following week.

City/Town	Time	Location
August 6		
Warwick	11:30-1:00	Warwick Public Library, 600 Sandy Lane
Hopkinton	1:00-3:00	Wood River Health Services, 823 Main St.
Foster	1:00-3:00	Benjamin Eddy House, 6 S. Killingly Rd.
Cranston	5:30 -7:00	Hope Center, 25 Brayton Ave.
August 7		
Providence	9:00-10:30	RI Hospital, First Floor, George Auditorium 593 Eddy St.
Burrillville	10:00-12:00	St. Patrick's Church Hall, 45 Harrisville Main St.
Pawtucket	12:00-2:00	Leon Mathieu Senior Center, 420 Main St.
Coventry	3:00-5:00	Brookdale Senior Living 600 Centre of New England Blvd.
Pawtucket	7:00-9:00	St. Cecelia's Parish Hall 745 Central Ave.
August 8		
East Providence	2:00-3:30	Riverside Branch Library 475 Bullocks Point Ave.
Providence	2:00-3:30	St. Martin de Porres Senior Center 160 Cranston St
Providence	4:00-6:00	Temple Beth El 70 Orchard Ave.
August 9		
Middletown	10:00-12:00	John Clarke Center 600 Valley Rd.
Portsmouth	10:00-12:00	Portsmouth Public Library 2658 East Main Rd.
Tiverton	1:00-3:00	Tiverton Library 34 Roosevelt Ave.
Bristol	2:00-4:00	Rogers Free Library 525 Hope St.
N. Kingston	1:30-3:00	North Kingstown Senior Center 44 Beach St.
West Greenwich	4:00-6:00	Louttit Library Community Center 274 Victory Hwy.
August 10		
Johnston	9:00-11:00	Brookdale Johnston – Club Room 12 Old Pocasset Lane
Woonsocket	9:00-11:00	Woonsocket Senior Center 84 Social St.
Lincoln	1:00-2:30	CCRI Flanagan Campus Room Lecture Hall 1442
Westerly	1:00-2:30	Westerly Library 44 W Broad St.
South Kingstown	3:30-5:00	Neighborhood Guild 325 Columbia St.

APPENDIX B - CONTINUED

Input Summary and Questionnaire

Interviews

The Alzheimer's Executive Board and Lt. Governor's staff identified a working list of 45 key persons to be interviewed in person or the phone by the plan consultants. These were from government, voluntary sector, care provider and trade association members with an interest and the research community.
A structured interview was conducted with these key persons using the questionnaire and additional specific questions about policy recommendations.

Feedback and Dialogue

Themes and key findings were discussed with the Alzheimer's Executive Board, the full Long Term Care Coordinating Council and the Research Subcommittee. The draft policy recommendations report plus appendices was made available for discussion and comment to the Alzheimer's Subcommittee at its December 12, 2018 meeting, with some notes coming in via email immediately after.

APPENDIX C

Rhode Island BRFSS Data

alzheimer's association®

cognitive decline in rhode island

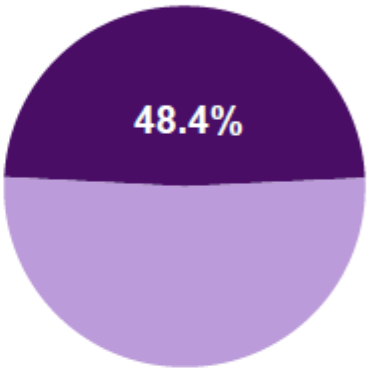
DATA FROM THE 2015 BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEM

In Rhode Island, 11.5 percent – one in nine – of those aged 45 and over report they are experiencing confusion or memory loss that is happening more often or is getting worse ("subjective cognitive decline").

Nearly half of them have not talked to a health care professional about it.

For those with worsening memory problems, 54.7 percent say it has created "functional difficulties" – that is, caused them to give up day-to-day activities and/or interfered with work or social activities.

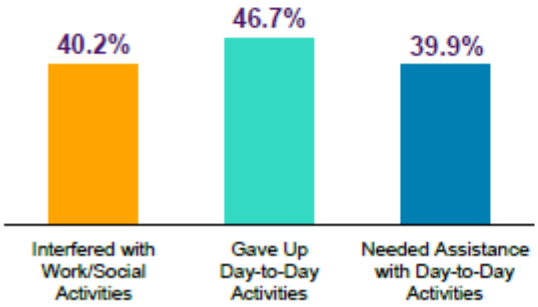
Percent with memory problems who have not talked to a health care provider



Percent of Those Aged 45+ with Subjective Cognitive Decline

All	Gender		Age					Educational Attainment			
	Men	Women	45-59	60-64	65-74	75-79	80+	< High School	High School	Some College	College Grad
11.5%	13.5%	9.8%	13.5%	11.0%	8.5%	6.5%	13.3%	22.0%	9.6%	12.8%	7.4%

Percent with memory problems who say it created difficulties and burden



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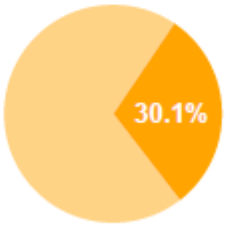
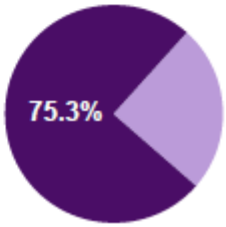


Percent with memory problems who live alone

Percent with memory problems who have at least one other chronic condition*



*Defined as arthritis, asthma, COPD, cancer, cardiovascular disease, and diabetes

APPENDIX D

Subcommittee Suggestions - Oral Health

Alzheimer's disease (AD) is a multi-system affliction and an effective approach to care considers the whole person. The following issues and recommendations regarding oral health were raised by the Oral Health Subcommittee of the Long Term Care Coordinating Council, which includes individuals who have been and continue to be involved with the oral health of people with AD.

Education

Dental providers should be competent in assessing the needs and providing treatment to people with dementia. Adequate didactic and experiential training should be available in training programs (DA, RDH, GPR/AEGD) and in continuing education. Examples of content include: Screening for dementia; understanding and working with care-resistant behavior and modifying treatment plan for a person-centered approach

Non-dental providers (nursing, behavioral, social workers, medical) receive training to assess oral health, refer for care, and facilitate effective mouth care. Collaborate with dental providers on person-centered care, accepting treatment that can accomplish basic goals.

Strengthen understanding about the importance of oral health in older adults and evidence-based strategies at different stages of dementia. Improve oral health literacy to facilitate productive, person-centered, discussions about treatment options and preventive approaches.

Financing

Recognize that oral health is part of overall health and quality of life, and support financing mechanisms which promote routine care. Expand coverage and benefits to include comprehensive dental care as an "essential health benefit" under the Affordable Care Act, Medicare, Medicaid, and private insurance options.

Alternative delivery systems

Support programs that improve access to care. Recognizing that on-site dental care provides benefits to residents, resident representatives, facility staff, and others, assure that both nursing homes and other long term care sites have appropriate equipment for safe, comfortable, and efficient dental care.

APPENDIX E

Subcommittee Suggestions - Workforce Subcommittee

Create a separate division in Health and Human Services to be responsible for overseeing the new state plan.

Implement standards of education for all healthcare providers entering the workforce, and currently in practice to address the needs of those with neuro-cognitive disorders.

Implement specifics in the CE requirements for neuro-cognitive disorders at all levels of healthcare: Including hours, content, methods for: MDs, RNs, APRNs, NPs, PAs, all therapists (OT, PT, ST, Mental health), CNAs, SWs, CMs, lab/diagnostic professionals, EMTs, First Responders, dentists and dental hygienists.

Train all staff in workplaces including: Hospitals, SNFs, ALFs, home care organizations (both medical and non-medical), adult day programs, hospice and palliative care, senior centers, VA facilities, group homes for IDD.

All educational institutions providing education/training for healthcare workers should include mandatory training in progressive neuro-cognitive disorders prior to clinicals.

Follow the model implemented in MA for mandatory referrals to the Alz. Association, dementia capable hospitals, and training for all healthcare workers for licensing/renewal.

Implement mandatory training for all First Responders.

Implement/require all licensed service professionals (ie: hairdressers, barbers, etc.) receive basic education re: communication and interaction with those with cognitive impairment.

Implement training for restaurant/food service businesses. (Purple Table App)

Implement basic training for all staff in banking/financial organizations.

Implement a single website for information re: community services, educational programs, treatment/care centers, facilities, research, caregiving, etc.

APPENDIX F

Subcommittee Suggestions - Access Subcommittee

Include under Top Recommendations: Work with our community leaders, Chambers of Commerce, faith based resources, and senior resources to promote Dementia Friendly Communities. By providing more education, support and resources at the community level we will support more individuals diagnosed to remain safe and engaged in their homes and communities.

Include under Risk Reduction: Create and implement at the high school level, a healthy brain curriculum that emphasizes: Healthy brain lifestyle choices; concussion awareness; prevention of cognitive impairment; caring for the caregiver (to help with the numbers of teens providing care for their parents) and mental health awareness and the impact of stress on cognitive function.

Reference the BOLD Act, recently signed into law at the federal level which calls for establishing Alzheimer's and related dementias Public Health Centers of Excellence. The Centers will increase education of public health officials, health care professionals, and the public on Alzheimer's and related dementias, brain health, and health disparities. Centers will provide technical assistance to public health departments across the country in implementing effective interventions. Interventions will focus on priorities such as increasing early detection and diagnosis, reducing risk, preventing avoidable hospitalizations, reducing health disparities, supporting the needs of caregivers and supporting care planning for people living with the diseases. Finally, the Centers will expand innovative public private partnerships that focus on addressing cognitive impairment and health disparities.

Apply for funding from the BOLD Act. Funding is available to public health departments to help state, and local public health departments implement effective Alzheimer's interventions, including those identified by the Alzheimer's Centers of Excellence. This funding will also help public health departments implement strategic actions like those identified in the Healthy Brain Initiative's Public Health Road Map.

Promote access to new grants through the BOLD Act to fund research, care and support that will directly benefit Rhode Island residents, communities and businesses while supporting for those with ADRD.

APPENDIX G

NCSL Alzheimer's LegisBrief

NCSL

NATIONAL CONFERENCE of STATE LEGISLATURES

LegisBrief

A QUICK LOOK INTO IMPORTANT ISSUES OF THE DAY

NOV 2018 | VOL. 26, NO. 42

Preparing for Alzheimer's in America's 'Age Wave'

BY SAMANTHA SCOTTI

Alzheimer's disease, the most common form of dementia, is a progressive neurological illness that impairs thinking and the independence of millions of people worldwide. The risk of developing the sixth-leading cause of death in the United States increases with age. And, with the oldest baby boomers turning 72 this year, the generational shift—or "age wave"—is well underway, resulting in a substantial increase in the number of Americans living with the disease.

An estimated 5.7 million Americans currently live with Alzheimer's, and reports anticipate this number will double to 11.6 million by 2040. Alzheimer's disease is usually diagnosed in people 65 and older, but it starts earlier with subtle neurological changes occurring years or even decades before symptoms appear.

With rising numbers of diagnosable cases and the large impact the disease has on state and federal budgets, states have a keen interest in Alzheimer's and dementia policy. As dementia affects physical and cognitive functions, such as speech and memory, people with Alzheimer's are more likely to use long-term services and supports (LTSS). These range from home and community-based services (HCBS) that assist with everyday activities to more intensive care provided in a facility, such as a nursing home. A considerable amount of care is also provided by unpaid caregivers—16.1 million Americans—who are often spouses, family members, friends or others. Alzheimer's disease and its impact on patients, families and caregivers is a growing public health concern.

Medicaid, the largest payer of LTSS, covers more than half of national LTSS costs. Medicaid payment services related to Alzheimer's for Americans 65 and older living with the disease or other dementias vary substantially by state. National Medicaid payments totaled over $46.5 billion in 2018, a number anticipated to increase 30 percent by 2025.

Did You Know?

- An estimated 5.7 million Americans currently live with Alzheimer's disease.
- Alzheimer's is the sixth-leading cause of death in the United States.
- Medicaid payments totaled over $46.5 billion in 2018 for Americans 65 and older living with Alzheimer's or other dementias.

APPENDIX G - CONTINUED

NCSL Alzheimer's LegisBrief

State Action

States consider various policy options to support people with Alzheimer's and their care providers. Some policies are broad in approach—such as strengthening payment and delivery systems for all LTSS or supporting unpaid family caregivers through connections to services and resources. Other policies are more narrowly targeted to individuals with the disease.

■ **Alzheimer's State Plans.** To address and prepare for the Alzheimer's epidemic, since 2007, 49 states and territories have published a state Alzheimer's disease plan. These written reports explore the current impact of Alzheimer's disease in the state and outline steps the state must take over the next three to five years to improve its services for and support to people with Alzheimer's and their families.

Almost all state plans include recommendations for dementia training for health care and support workers. Most state plans also have provisions on improving the health care received by those with the disease and assisting unpaid caregivers. Other subjects common among state plans include improving and expanding home and community-based services, increasing public awareness, improving data collection and improving the safety-related needs of those with Alzheimer's.

■ **Early Detection and Diagnosis.** Virginia SB 305, enacted in 2018, directs the Department of Health to educate health care providers about the importance of early detection and timely diagnosis of cognitive impairment, and to increase the understanding and awareness of the early warning signs of Alzheimer's disease and dementia.

Massachusetts HB 4116, also enacted in 2018, requires health care providers to complete a one-time continuing education course on the diagnosis and treatment of patients with cognitive impairments. It also requires hospitals to develop and implement a plan for recognizing and managing patients with dementia. The law allows doctors to share an Alzheimer's diagnosis and treatment plan with a family member or legal representative within the existing framework of federal and state privacy laws.

■ **Building a Dementia-Capable Workforce.** Recognizing that individuals with Alzheimer's or other dementias have unique health care needs, states are considering policies to support care providers and facilities, along with family caregivers.

California Health and Safety Code § 1337.1 requires skilled nursing and intermediate care facilities to have a specified number of training hours to address Alzheimer's and dementia needs. New Hampshire SB 161, enacted in 2017, establishes a commission that evaluates the direct care workforce and preparedness of long-term support services for aging adults with dementia. And Oklahoma's 2017 HB 1620 directs the State Board of Health to promulgate rules requiring certain dementia training.

■ **Dementia Training for First Responders and APS Workers.** Dementia training is also needed for adult protective services (APS) officials, first responders and law enforcement. They frequently interact with people with Alzheimer's and other dementias and are generally among the first to be contacted regarding emergencies, abuse and exploitation.

In 2014, Connecticut enacted SB 179, establishing mandatory dementia-specific training for a wide range of personnel, including emergency medical technicians (EMTs), probate judges, paid conservators and protective services employees. The legislation requires that the refresher training required every three years for EMT recertification includes training in Alzheimer's disease and dementia symptoms and care.

■ **Alzheimer's and Dementia Task Forces.** Various states have created task forces to coordinate statewide efforts to ensure quality care for those living with Alzheimer's or other dementias.

Wisconsin Assembly Speaker Robin Vos (R) formed the Task Force on Alzheimer's and Dementia to recommend policy initiatives to improve care, which led to the "Wisconsin Cares Legislative Package." The Legislature enacted three of the bills introduced in the 2015-2016 session. They included funding for caregiver respite, mobile crisis unit training and developing a pilot program to ensure that people with dementia who are experiencing a crisis are placed in an appropriate setting—Assembly Bill 787, Assembly Bill 790 and Assembly Bill 786, respectively.

Federal Action

The Centers for Medicare & Medicaid (CMS) promulgated a rule, which went into effect in January 2018, to allow for Medicare reimbursement under a new code for certain services. They include improving detection, diagnosis, and care planning and coordination for patients with Alzheimer's disease or other dementias and their caregivers. The code was developed to provide reimbursement for comprehensive evaluation of a new or existing patient who exhibits signs and/or symptoms of cognitive impairment.

Training is needed for adult protective services officials, first responders and law enforcement. They frequently interact with people with Alzheimer's and other dementias and are generally among the first to be contacted regarding emergencies, abuse and exploitation.

Additional Resources

- Alzheimer's Association
- Assessing the Preparedness of the U.S. Health Care System Infrastructure for an Alzheimer's Treatment
- Long-term Services and Supports: FAQs

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APPENDIX H

Public Health Road Map Action Items

Making Alzheimer's Our Next Public Health Success Story

HEALTHYBRAIN INITIATIVE

Are communities ready to respond to a large population of older people with dementia? Current projections indicate the number of people living with Alzheimer's and other dementias is ballooning as the Baby Boom generation gets older. Those with dementia will require more and more support as cognitive, behavioral, and physical functioning worsens over time. This means Medicare and Medicaid costs are rising dramatically, and the additional burden on family caregivers is endangering their own health.

With a strong response, public health can mitigate the future impacts of Alzheimer's and other dementias, especially among vulnerable populations. The Alzheimer's disease continuum spans decades, providing many opportunities to change outcomes across communities. Just as with other chronic and degenerative conditions, public health can reduce risk in populations, further early detection and diagnosis, improve safety and quality of care for people living with cognitive impairment, and attend to caregivers' health and wellbeing.

The Healthy Brain Initiative's (HBI) ***State and Local Public Health Partnerships to Address Dementia, The 2018-2023 Road Map*** will chart a course for state and local public health agencies and their partners to act quickly and strategically to prepare their communities by stimulating needed changes in policies, systems, and environments. To focus the public health response, experts developed an agenda of 25 actions for public health leaders to promote brain health, better care for people with cognitive impairment, and increase attention to caregivers. Other Road Map actions build public health capacity.

Alignment of HBI Road Map actions with Essential Services of Public Health ensures that initiatives to address Alzheimer's can be easily and efficiently incorporated into existing public health initiatives. Cross-sector partnerships, data, and pursuit of health equity are critical to achieving major gains against Alzheimer's—just as they underlie public health successes in HIV/AIDS, cardiovascular disease, and cancer.

Accelerated progress against dementia requires state and local public health leaders to chart a course for better outcomes. The HBI Road Map outlines the most needed and practical steps that state and local health departments can accomplish. Implementation of the HBI Road Map enables public health to lead with urgency and act for impact.

SELECT FACTS

- Today, nearly 6 million Americans are living with Alzheimer's dementia, with annual costs topping $277 billion. In 2050, 14 million will be affected, with an annual cost to the U.S. of $1.1 trillion.
- African Americans, Hispanics, and women are particularly at risk of developing Alzheimer's and other dementias.
- More than 95% of people with dementia have one or more other chronic conditions.
- In 2015, there were 1,471 emergency department visits for every 1,000 Medicare beneficiaries with dementia.
- About 1 in 3 Alzheimer's caregivers report their health has become worse due to care responsibilities.

Conceptual Framework for the *Healthy Brain Initiative Road Map*

The Action Agenda of the HBI Road Map aligns across four Essential Services of Public Health. Each action was developed with attention to three guiding core principles.

The companion *Healthy Brain Initiative: The Road Map for Indian Country* is specifically designed for public health systems serving American Indians and Alaska Natives.

APPENDIX H - CONTINUED

Public Health Road Map Action Items

>> The HBI Road Map has an agenda of 25 actions for state and local public health agencies and their partners to accomplish. Actions highlighted with a >> are primed for implementation.

EDUCATE & EMPOWER

>> **E-1** Educate the public about brain health and cognitive aging, changes that should be discussed with a health professional, and benefits of early detection and diagnosis.

>> **E-2** Integrate the best available evidence about brain health and cognitive decline risk factors into existing health communications that promote health and chronic condition management for people across the life span.

>> **E-3** Increase messaging that emphasizes both the important role of caregivers in supporting people with dementia and the importance of maintaining caregivers' health and well-being.

E-4 Promote prevention of abuse, neglect, and exploitation of people with dementia.

E-5 Provide information and tools to help people with dementia and caregivers anticipate, avert, and respond to challenges that typically arise during the course of dementia.

E-6 Strengthen knowledge about, and greater use of, care planning and related tools for people with all stages of dementia.

>> **E-7** Improve access to and use of evidence-informed interventions, services, and supports for people with dementia and their caregivers to enhance their health, well-being, and independence.

DEVELOP POLICIES AND MOBILIZE PARTNERSHIPS

>> **P-1** Promote the use of effective interventions and best practices to protect brain health, address cognitive impairment, and help meet the needs of caregivers for people with dementia.

P-2 Assure academic programs, professional associations, and accreditation and certification entities incorporate the best available science about brain health, cognitive impairment, and dementia caregiving into training for the current and future public health workforces.

>> **P-3** Support better informed decisions by educating policy-makers on the basics of cognitive health and impairment, the impact of dementia on caregivers and communities, and the role of public health in addressing this priority problem.

P-4 Improve inclusion of healthcare quality measures that address cognitive assessments, the delivery of care planning to people with diagnosed dementia, and improved outcomes.

P-5 Engage public and private partners in ongoing planning efforts to establish services and policies that promote supportive communities and workplaces for people with dementia and their caregivers.

P-6 Assure public health plans that guide emergency preparedness and emergency response address the special needs of people with dementia and their caregivers, support access to critical health information during crises, and prepare emergency professionals for situations involving people with dementia.

ASSURE A COMPETENT WORKFORCE

>> **W-1** Educate public health and healthcare professionals on sources of reliable information about brain health and ways to use the information to inform those they serve.

W-2 Ensure that health promotion and chronic disease interventions include messaging for healthcare providers that underscores the essential role of caregivers and the importance of maintaining their health and well-being.

>> **W-3** Educate public health professionals about the best available evidence on dementia (including detection) and dementia caregiving, the role of public health, and sources of information, tools, and assistance to support public health action.

>> **W-4** Foster continuing education to improve healthcare professionals' ability and willingness to support early diagnoses and disclosure of dementia, provide effective care planning at all stages of dementia, offer counseling and referral, and engage caregivers, as appropriate, in care management.

W-5 Strengthen the competencies of professionals who deliver healthcare and other care services to people with dementia through interprofessional training and other strategies.

W-6 Educate healthcare professionals about the importance of treating co-morbidities, addressing injury risks, and attending to behavioral health needs among people at all stages of dementia.

>> **W-7** Educate healthcare professionals to be mindful of the health risks for caregivers, encourage caregivers' use of available information and tools, and make referrals to supportive programs and services.

MONITOR & EVALUATE

>> **M-1** Implement the Behavioral Risk Factor Surveillance System (BRFSS) optional module for Cognitive Decline in 2019 or 2020, and the BRFSS optional module for Caregiving in 2021 or 2022.

M-2 Support national data collection on dementia and caregiving.

>> **M-3** Use data gleaned through available surveillance strategies and other sources to inform the public health program and policy response to cognitive health, impairment, and caregiving.

M-4 Embed evaluation into training and caregiving support programs to determine program accessibility, effectiveness, and impact.

M-5 Estimate the gap between workforce capacity and anticipated demand for services to support people with dementia and their caregivers.

alzheimer's association CDC

cdc.gov/aging
alz.org/publichealth

STATE OF RHODE ISLAND AND PROVIDENCE PLANTATIONS

RHODE STATE OF ISLAND

HOPE

OFFICE OF THE LIEUTENANT GOVERNOR