

State of Rhode Island and Providence Plantations



**Department of Human Services
Division of Elderly Affairs
Catherine Taylor, Director**

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

From Plan to Practice: Implementing NAPA in Your State

**Washington D.C.
December 3, 2013**



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

- Genesis
- Guiding principles
- Process
- Recommendations
- Implementation



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

Genesis - February 2012

One week in the life of a State Unit on Aging Director



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- 24,000+ Rhode Islanders living with Alzheimer's disease
- 100,000+ family caregivers
- Approximately 10 percent of Rhode Islanders *directly affected*
- Almost everyone else is affected in some way, personally or professionally



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- Approached **Lt. Governor Elizabeth Roberts, Chair of the Long Term Care Coordinating Council.**
- May 2012 – Simultaneous to release of NAPA -- **RI General Assembly unanimously approved joint resolution** directing the Long Term Care Coordinating Council to write a State Plan on Alzheimer's and Related Disorders.
- Co-chaired by the Lieutenant Governor and the Director of Elderly Affairs.
- Plan due to Governor and General Assembly on July 1, 2013



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Lt. Governor and I strongly agreed on **guiding principals** for Rhode Island's plan:

- Build on – don't replicate -- national recommendations
- Tackle Rhode Island-specific problems
- Lead an inclusive process with the broadest possible involvement and support
- Look at the effects of Alzheimer's disease on our state from every possible angle
- Focus on what families need *now* until a cure is discovered
- Start with a State-wide inventory of:
 - What is excellent in RI
 - What is in place but could be improved or better coordinated
 - What needs to be scrapped
- Assume significant new funding is not imminent
- Create a living, breathing, dynamic document



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OUTREACH AND ENGAGEMENT:

- Throughout process, we encouraged the sharing of personal caregiving experiences
- Co-chair joint speaking engagements
- Email blasts from both offices with State Plan updates, information about related initiatives and educational opportunities in the state, and invitations to open meetings
- Numerous columns on aspects of the plan authored by myself and the press



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PROCESS

- Full group met periodically throughout the year
- Six Subgroups met monthly
 - Caregivers, Access, Legal, Workforce, Long-Term Care, Research
- Listening sessions conducted across the state in English and Spanish
- External stakeholder meetings
- Development of Drafts with Subgroup Chairs
- Review by Co-Chairs
- Feedback from Subgroup Participants
- Overview of Draft in Public Meeting
- Public Comment Period



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- Final plan unveiled to the public on June 25, 2013, at RI Alzheimer's Association Caregivers Journey Conference
- View at <http://www.ltgov.state.ri.us/alz/>
- Well received by General Assembly – written commitment from Senate President to support the recommendations with legislation.



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RECOMMENDATIONS-30 pages of them!

Centered around recurring themes:

- **Faster and more organized dissemination of information, research findings and best practices**
- **Standardized training and education programs for families, providers, staff, anyone who might encounter people with dementia personally or professionally**
- **Development of a comprehensive online resource**



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IMPLEMENTATION

- Large Group reconvened on October 30, 2013, to begin development of a **work plan** to prioritize the recommendations in the state plan.
- Original six subgroups were dissolved.
- Some recommendations to be assigned to existing commissions



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New Targeted Task Forces Established:

- Cultural Competency
- Online Resource
- Safe Driving
- Elder Transportation
- Family Caregivers Training
- Professional Workforce Training
- Legal



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Immediate opportunities to accomplish plan's goals:

- July 2013 promulgation of Nursing Home Greenhouse regulations
- State procurement for NEMT transportation broker near completion
- Dementia-capability training at Department of Corrections, Police and Fire Senior Advocates
- Department of Health EMS Innovations group – development of training for first responders with RIGEC
- URI's Living Rite program (\$14 million CMS innovations grant) to serve developmentally disabled with Alzheimer's and other chronic diseases
- Approval from CMS under RI's 1115 Waiver renewal application to expand Adult Day CNOM services to individuals under age 60 with a diagnosis of dementia
- Donation of \$15 million to URI for new institute on neurodegenerative diseases



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- Large Group will continue to meet periodically to monitor and motivate these initiatives.
- State Plan helping to frame long term services and supports budget priorities.
- Leadership sense of urgency: Lt. Governor Roberts' and my terms end at the end of 2014.