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
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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
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/](http://www.ltgov.state.ri.us/alz/)

- Well received by General Assembly – written commitment from Senate President to support the recommendations with legislation.
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
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.