

Moving Forward: Recommendations for State Action

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To the House Aging & Older Adult Services Committee

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Madam Chair, Mr. Vice-Chair and members of the committee, you've heard some compelling testimony this morning that speaks to the devastating impact that Alzheimer's & related dementias have on this Commonwealth. I'd like to close by outlining three areas where we believe you and your colleagues can make a real difference in the lives of many afflicted and their families.

1. Keep Our Annual Legislative Allocation Intact (& propose increasing it when economic conditions improve)

Over a decade ago, this legislature had the foresight to recognize the unique threat posed by Alzheimer's due to demographic trends that were just coming to the forefront in Pennsylvania. It allocated \$250, 000/ year for Alzheimer's Outreach, \$50,000 of which would be used by the Dept. of Aging for their in-house efforts, and \$200,000 to be distributed through them & split between what would become the two Chapters represented here today, Greater Pa. & Delaware Valley. The amount allocated has remained unchanged since then.

Because of our unique abilities to 'leverage' resources with our network of dedicated volunteers, these dollars go directly into the critical front-line services that you heard about earlier; our toll-free 24/7 help-line, support groups & family caregiver training, all of which are provided at no cost to families.

Based on the numbers of afflicted that were presented earlier, the annual allocation currently works out to just 50 cents per impacted family, a very modest outlay for which we're truly grateful, but also request to be seriously re-visited as soon as possible. It's some of the most cost-effective money the Commonwealth could ever spend in our judgment, as it enables us to reach out and serve greater numbers of families who desperately want the tools, skills and support to keep their loved ones safe & at home for as long as possible.

Above all else, PLEASE also do all that you can to ensure that this annual funding isn't cut or dramatically reduced as it was back in FY '04. The 'savings' for Pennsylvania would be miniscule, while diminishing our efforts to provide more of what we know our families want & need.

2. Keep Focusing On The Caregiver

As you've witnessed from previous testimony, Alzheimer's & related dementias are afflictions that create ever-changing caregiver challenges that are unique & often unprecedented. It also bears repeating that approx. 7 out of 10 of our afflicted citizens are being cared for at home, which is where they & their loved-ones wish them to remain for as long as possible. Empowering family & community caregivers with fully funded home & community-based services, including adequate transportation & Adult Day programs is not only the right thing to do ethically, but a fiscally sound policy for Pennsylvania's bottom-line. Delaying or deferring institutional placement for even a few months can save the Commonwealth millions of dollars each year in additional Medicaid expense alone.

One of the most laudable examples of this committee's attention to the above was the introduction & passage in March of HB 245,

amending the Family Caregiver Support Act & providing a long-overdue increase to its monthly & home-modification allowances for low-income caregivers, which have remained unchanged since the program's inception in 1990. The Family Caregiver Support Program was one of the first of its kind in the nation and is something for which Pennsylvania can take justifiable pride. By way of background, HB 245 is the 5th iteration of this legislation, two that were put forth under Rep. Mundy's leadership here & three others from Rep. Matt Baker, the first of which when he was a member of this committee back in 2005. It has been one of our top legislative priorities since 2003. Unfortunately none of these bills, including HB 245 to-date, have successfully progressed through all necessary committees in the Senate.

We & other advocacy partners such as the Senior Support Coalition, the Elder Law section of Pennsylvania Bar Association, & the Family Support Advisory Council are doing everything possible to get HB 245 moving out of the Senate Aging & Youth Committee & over into Appropriations. We ask that you also remain an active member of this partnership by urgently reminding your district Senate counterparts (especially if they're members of Aging & Youth or Appropriations) of the importance of this bill. As with Senate Bill 704, the Assisted Living legislation passed in 2007 after diligent attention by this committee, HB 245 is now an opportunity for the Senate to participate in a truly bipartisan, bicameral effort to benefit some of our most vulnerable citizens.

3. Initiate Legislation Creating An Alzheimer's State Plan Task Force

All that you've heard this morning points to an ever-growing crisis in Pennsylvania as we confront the realities of our unique aging in-place demographic along with a surge of baby-boomers just beginning to enter into their own higher risk life cycle. The time is now to join over 25 other states (Appendix A) who have already taken action towards developing an Alzheimer's State Plan. This committee, with input

from the House Alzheimer's Caucus, is the ideal launching point for such an initiative. The last time something similar was done in Pennsylvania was in 1985, nearly 25 years ago. That task force created a one-time report with little subsequent follow-up when Alzheimer's was a mere 'blip on a screen' compared to what we're facing today. We can and must do better!

A comprehensive state Alzheimer's plan can ensure the infrastructure & accountability necessary to build dementia-capable programs & services across multiple cabinet-level agencies that currently serve our citizens in community or residential settings. It will bring key stakeholders around a single table, assuring best current practices of care while potentially eliminating or reducing overlapping programs or outreach. Our national policy office has also created a superb 'implementation' kit complete with a 4-phase timeline process and sample mandate & legislation language that we'll be pleased to share with members here. Getting this process started would be an immensely worthwhile way to commemorate National Alzheimer's Month in November & usher in the New Year.

Once again, we're truly grateful for this opportunity today. Please continue to partner with us so that together we can be the 'Voice' for multiple thousands in this Commonwealth who've lost theirs to these terrible diseases.

Thank You.

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Current Nationwide Efforts on Alzheimer State Plans

Since 2006, at least 25 states have taken concrete action towards developing an Alzheimer's state plan. The chart that follows denotes the most recent action as of July 2009 by each state in this process. More information on efforts in each state is available from the Washington Public Policy and Advocacy Divisions.

STATE	MOST RECENT ACTIVITY (as of July 2009)
AL	Phase 1: Bill failed (2009 HB 825). Potential 2010 reintroduction.
AR	Phase 2: Bill passed (2009 HB 1014). Task force begins meeting August 2009.
CA	Phase 2: Bill passed (2008 SB 491). Task force in the process of being set up.
CO	Phase 2: State plan due September 2010.
GA	Phase 2: Resolution passed (2009 SR 257). Task force begins meeting August 2009.
HA	Phase 1: Bill failed (2008 SB 2545). Potential 2010 reintroduction.
ID	Phase 1: Bill failed (2009 SB 1001). Potential 2010 reintroduction.
IL	Phase 3: State plan released July 2009. Working on prioritizing recommendations.
IN	Phase 2: State reconstituting existing state Alzheimer's task force to write plan.
IA	Phase 3/4: Continued advocacy for completed state plan's recommendations and oversight of recommendations won to date.
KY	Phase 3/4: Continued advocacy for completed state plan's recommendations and oversight of recommendations won to date.
LA	Phase 2: Resolution passed (2008 SCR 80). State plan due September 2009.
MD	Phase 2: Task force being assembled to draft state plan.
MA	Phase 1: Bill pending (2009 HB 3923).
MI	Phase 3/4: Continued advocacy for completed state plan's recommendations and oversight of recommendations won to date.
MN	Phase 2: Bill passed (2009 HF 1760). Task force begins meeting August 2009.
MO	Phase 2: Bill passed (2009 HB 272). Task force begins meeting fall 2009.
NH	Phase 1: Bill failed (2009 SB 62). Potential 2010 reintroduction.
NJ	Phase 1: Bill pending (2009 A 4008/ S 2872).
NM	Phase 1: Bill failed (2009 HB 113). Potential 2010 reintroduction.
NY	Phase 2: State plan due summer 2009.

STATE	MOST RECENT ACTIVITY (as of July 2009)
ND	Phase 2: Bill passed (2007 HCR 3022). Task force assembled, but state plan not drafted.
OK	Phase 2: State plan due September 2009.
OR	Phase 2: Task force being assembled to draft state plan.
SC	Phase 3: State plan released March 2009. Working on prioritizing recommendations.
TN	Phase 3: State plan released February 2009. Working on prioritizing recommendations.
TX	Phase 3: State plan due 2010.
VA	Phase 2: Bill passed (2009 HB 1617). Plan due fall 2010.
VT	Phase 2: State plan released July 2009.

Current State Alzheimer Disease Plans

In 2008 and 2009, several states released state Alzheimer's disease plans.

STATE	RELEASE DATE	TITLE
IL	July 2009	Alzheimer's Disease and Related Dementia State Plan
IA	Jan. 2008	Final Report Alzheimer's Disease Task Force
KY	Jan. 2008	Setting a Roadmap to Address Alzheimer's in the Commonwealth
MI	Jan. 2009	2008 Michigan Dementia Plan Update
SC	March 2009	Conquering the Specter of Alzheimer's Disease in South Carolina
TN	Feb. 2009	Tennessee Alzheimer's Disease Task Force Final Report
VT	July 2009	Alzheimer's Disease and Other Related Dementia State Plan

Previous Reports by State Alzheimer's Disease Task Forces

This chart details known plans published by State Alzheimer's Disease Task Forces and Advisory Committees prior to 2007. This list does not include state task forces or committee reports on long-term care that may have addressed Alzheimer-related issues.

STATE	YEAR	TITLE
AZ	1989	Final Report of the Arizona Advisory Committee on Alzheimer's Disease and Related Disorders
CA	1987	The California Alzheimer's Disease Task Force – Final Report
CT	1989	Connecticut Governor's Task Force on Alzheimer's Disease: Final Report
FL	1989	Alzheimer's Disease Initiative: Comprehensive Plan
GA	1985	Alzheimer's Disease Study Committee Report
ID	1988	Resolution of the Task Force on Alzheimer's Disease and Spousal Impoverishment
IL	2003*	Alzheimer's Disease Assistance Plan * The Alzheimer's Disease Assistance Act requires the Department of Public Health to prepare a state Alzheimer's disease plan. It is updated every three years in consultation with the Alzheimer's Disease Advisory Committee. (410 ILCS 405/5)
IN	1989	Alzheimer's Disease and Related Senile Dementia Task Force: Annual Report 1989
IA	1989	Iowa's Governor's Task Force on Alzheimer's and Related Disorders: Final Report
KS	1986	Kansas Alzheimer's and Related Diseases Task Force: Final Report
KY	1995	Kentucky Alzheimer's Disease Task Force Final Report
MD	1985*	Maryland Governor's Task Force Report on Alzheimer's Disease and Related Disorders * note that the 2004 Policy Study on Alzheimer's Disease Care was created by the MD State Attorney General
MA	1986	Final Report of the Special Committee Established to Make an Investigation and Study Relative to Alzheimer's Disease
MI	2003	Michigan Dementia Plan: Reducing the Burden of Dementia in Michigan

STATE	YEAR	TITLE
MN	1988	Minnesota Alzheimer's Disease/Dementia Task Force: Final Recommendations
MO	1989	Missouri Alzheimer's Disease and Related Disorders Task Force: Third Annual Report
NE	1987	Report of the Task Force on Alzheimer's Disease and Related Disorders to the Governor and Legislature of Nebraska
NH	1988	Impoverishment of Spouses of Persons with Alzheimer's and Related Disorders: Report to the Speaker of the House of Representatives, President of the Senate, and Governor of New Hampshire
NJ	1986	Final Report: New Jersey Alzheimer's Disease Study Commission
NY	1984	Alzheimer's Disease: Implications for Public Policy in New York State
ND	1990	North Dakota Alzheimer's and Related Dementias State Task Force: Report to the Governor
OH	1987	Alzheimer's Disease Initiatives Progress Report
OK	1989	Final Report: Oklahoma Task Force on Alzheimer's and Related Disorders
PA	1985	Alzheimer's Disease Task Force Report
RI	1984	Rhode Island Legislative Commission on Dementias Related to Aging, Final Report
SC	1993	Gray Plague Of The Twenty-First Century: Meeting the Needs of Individuals with Alzheimer's Disease, Their Families and Caregivers
TN	198?	Report of the Task Force Created by HJR 585 to Study Alzheimer's Disease
VA	2004*	Report of the Commission on Alzheimer's and Related Disorders * by statue the Commission must: "Develop the Commonwealth's plan for meeting the needs of patients with Alzheimer's disease and related disorders and their caregivers, and advocate for such plan; and Submit a report, including an executive summary, by October 1 of each year to the Governor and General Assembly regarding the activities and recommendations of the Commission" (Code of VA 2.2-720)
WI	1987	Final Report of the Wisconsin Task Force on Alzheimer's Disease and Other Irreversible Dementias