Supporting Family Caregivers Effectively: Lessons Learned from Research

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RESEARCH SUMMIT ON DEMENTIA CARE
Building Evidence for Services and Supports

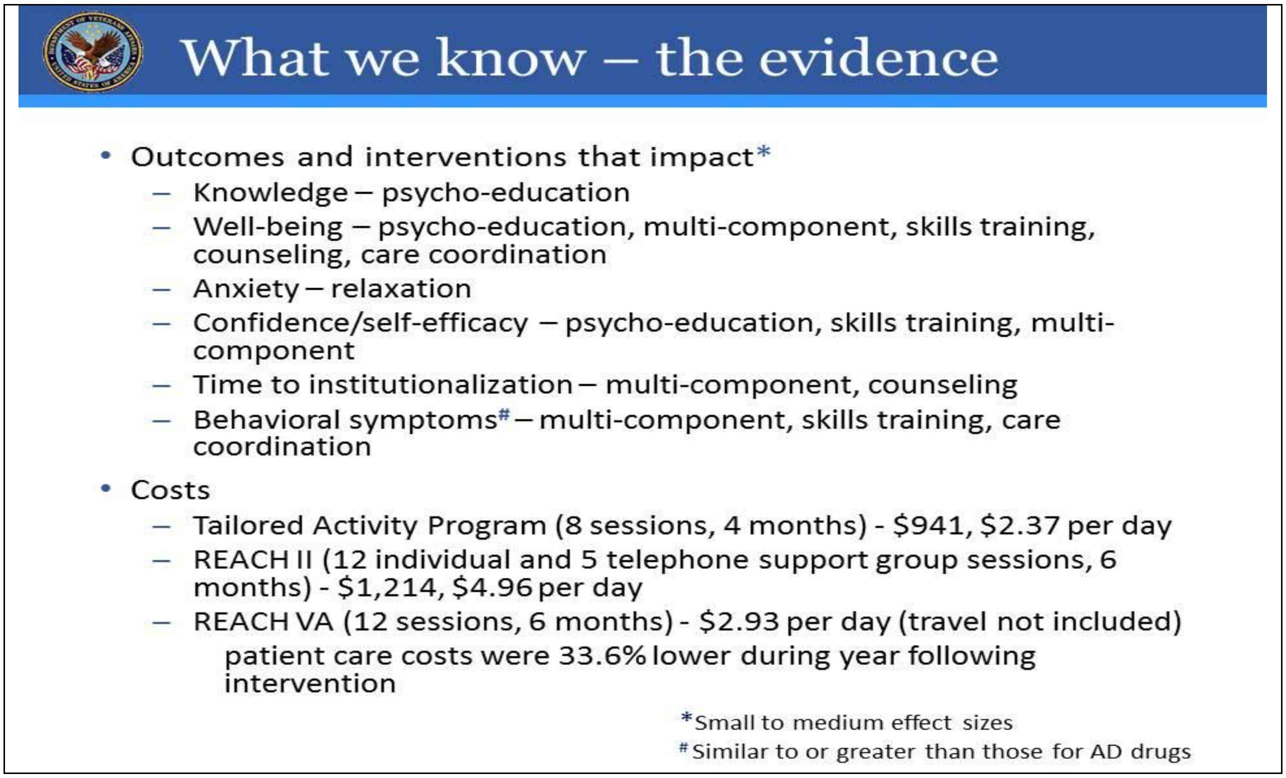
#DementiaCareSummit

How we know

- 7 meta-analyses and 17 systematic reviews of randomized clinical trials (RCTs) published 1966-2013
- 200 interventions tested with randomized designs
- Interventions
  - care coordination
  - behavioral management
  - professional support
  - respite
  - skills training
  - counseling/psychotherapy
  - multi-component approaches
  - psycho-education
  - self-care/relaxation

National Academies of Sciences, Engineering, and Medicine. 2016. *Families caring for an aging America*. Washington, DC: The National Academies Press.

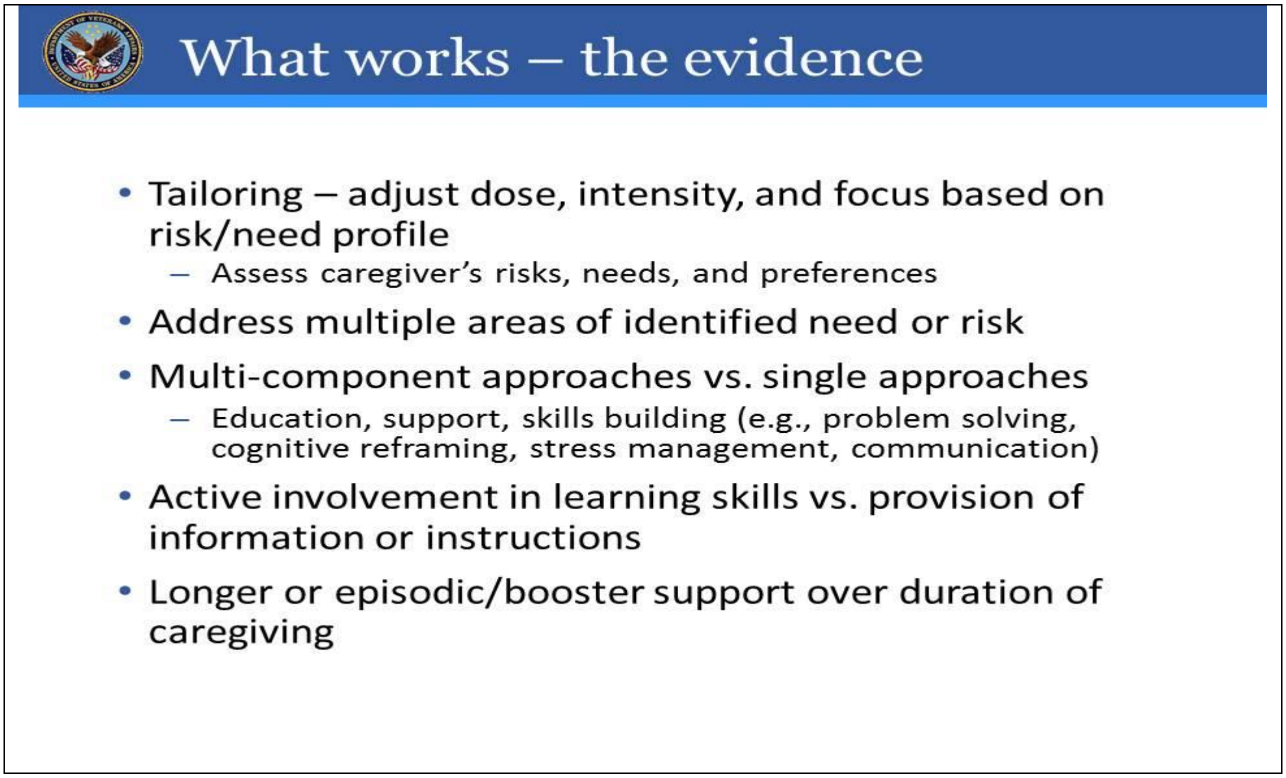
Gitlin, L., & Hodgson, N. (2015). Caregivers as therapeutic agents in dementia care: The context of caregiving and the evidence base for interventions. Gaugler, J., & Kane, R. L. (Eds). *Family caregiving in the new normal, pp 305-353*. Academic Press.



What we know – the evidence

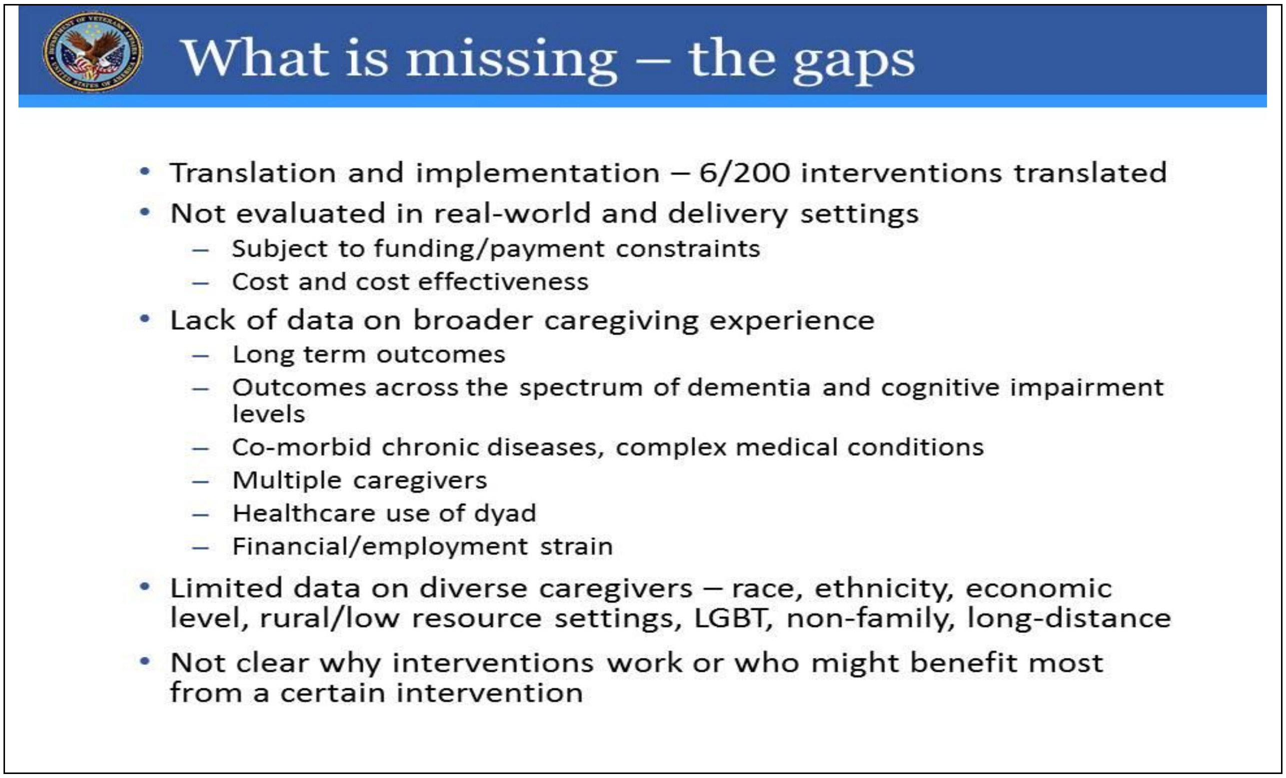
- Outcomes and interventions that impact*
  - Knowledge – psycho-education
  - Well-being – psycho-education, multi-component, skills training, counseling, care coordination
  - Anxiety – relaxation
  - Confidence/self-efficacy – psycho-education, skills training, multi-component
  - Time to institutionalization – multi-component, counseling
  - Behavioral symptoms# – multi-component, skills training, care coordination
- Costs
  - Tailored Activity Program (8 sessions, 4 months) - $941, $2.37 per day
  - REACH II (12 individual and 5 telephone support group sessions, 6 months) - $1,214, $4.96 per day
  - REACH VA (12 sessions, 6 months) - $2.93 per day (travel not included)
    patient care costs were 33.6% lower during year following intervention

*Small to medium effect sizes
#Similar to or greater than those for AD drugs



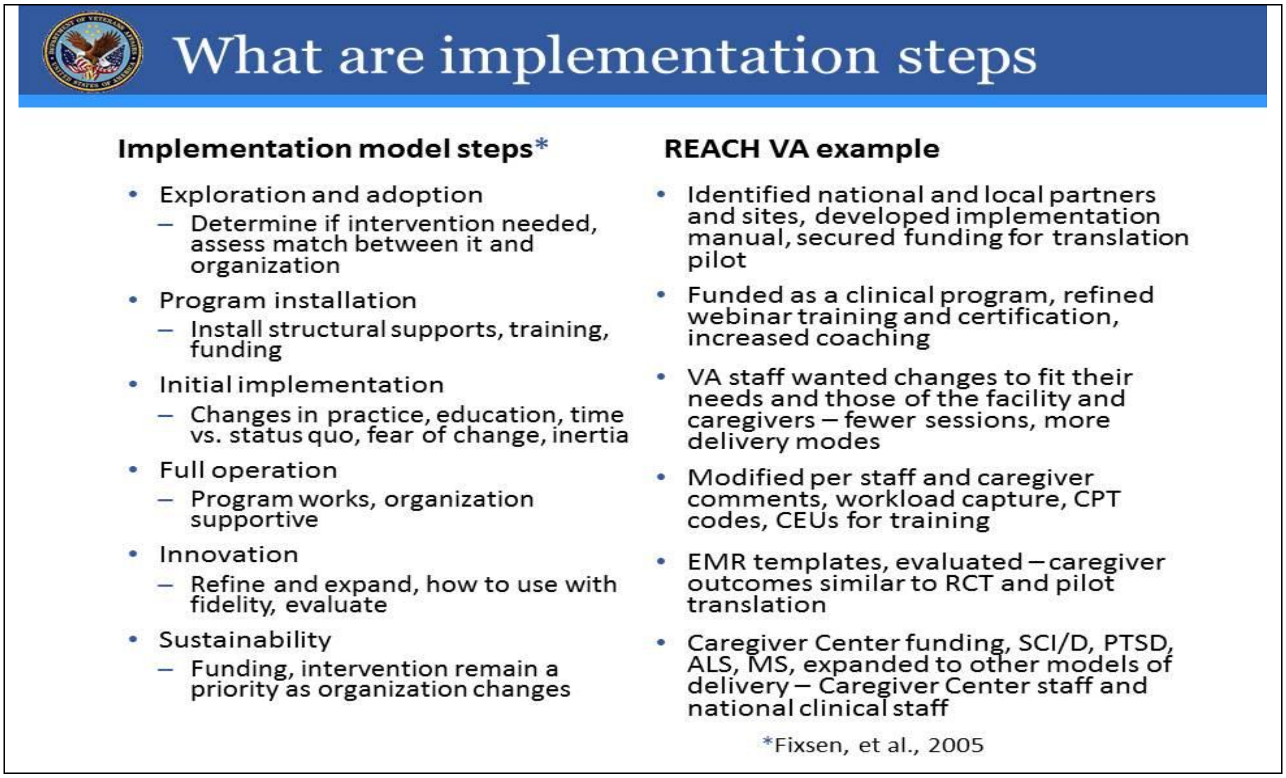
What works – the evidence

- Tailoring – adjust dose, intensity, and focus based on risk/need profile
  - Assess caregiver's risks, needs, and preferences
- Address multiple areas of identified need or risk
- Multi-component approaches vs. single approaches
  - Education, support, skills building (e.g., problem solving, cognitive reframing, stress management, communication)
- Active involvement in learning skills vs. provision of information or instructions
- Longer or episodic/booster support over duration of caregiving



What is missing – the gaps

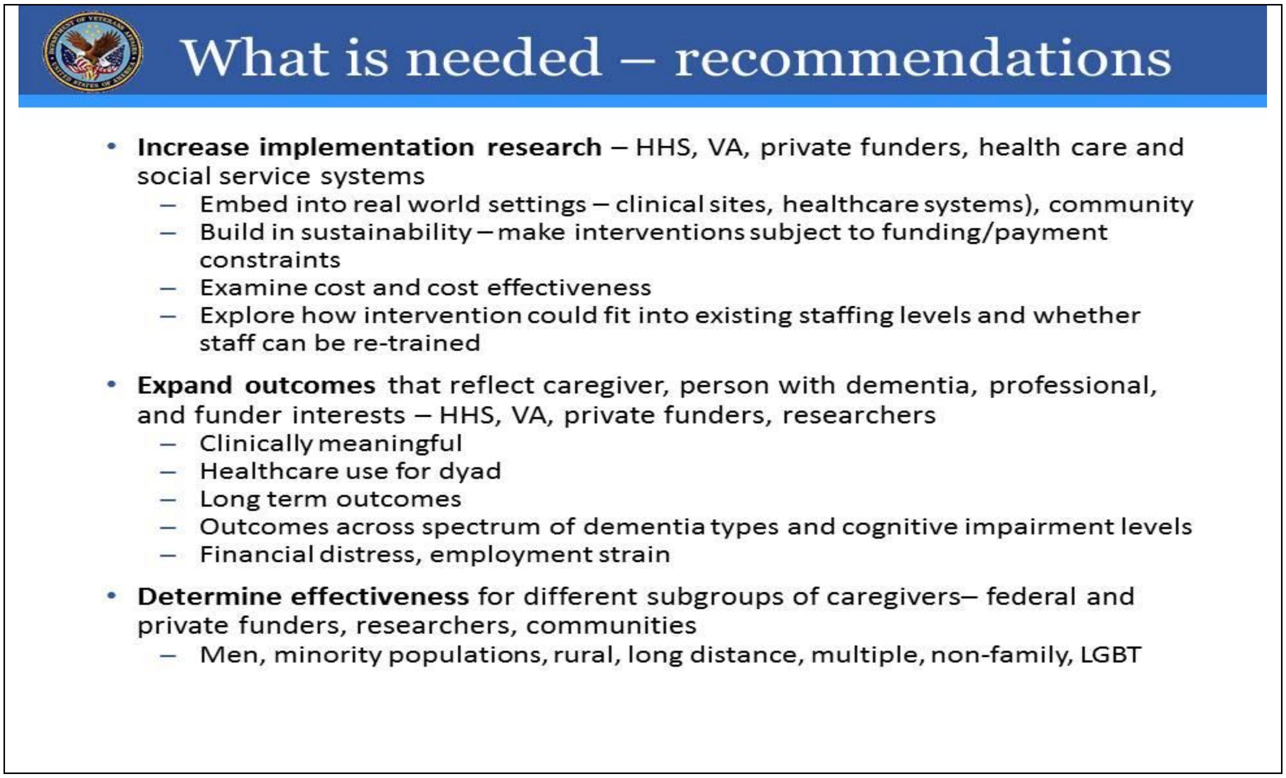
- Translation and implementation – 6/200 interventions translated
- Not evaluated in real-world and delivery settings
  - Subject to funding/payment constraints
  - Cost and cost effectiveness
- Lack of data on broader caregiving experience
  - Long term outcomes
  - Outcomes across the spectrum of dementia and cognitive impairment levels
  - Co-morbid chronic diseases, complex medical conditions
  - Multiple caregivers
  - Healthcare use of dyad
  - Financial/employment strain
- Limited data on diverse caregivers – race, ethnicity, economic level, rural/low resource settings, LGBT, non-family, long-distance
- Not clear why interventions work or who might benefit most from a certain intervention



What are implementation steps

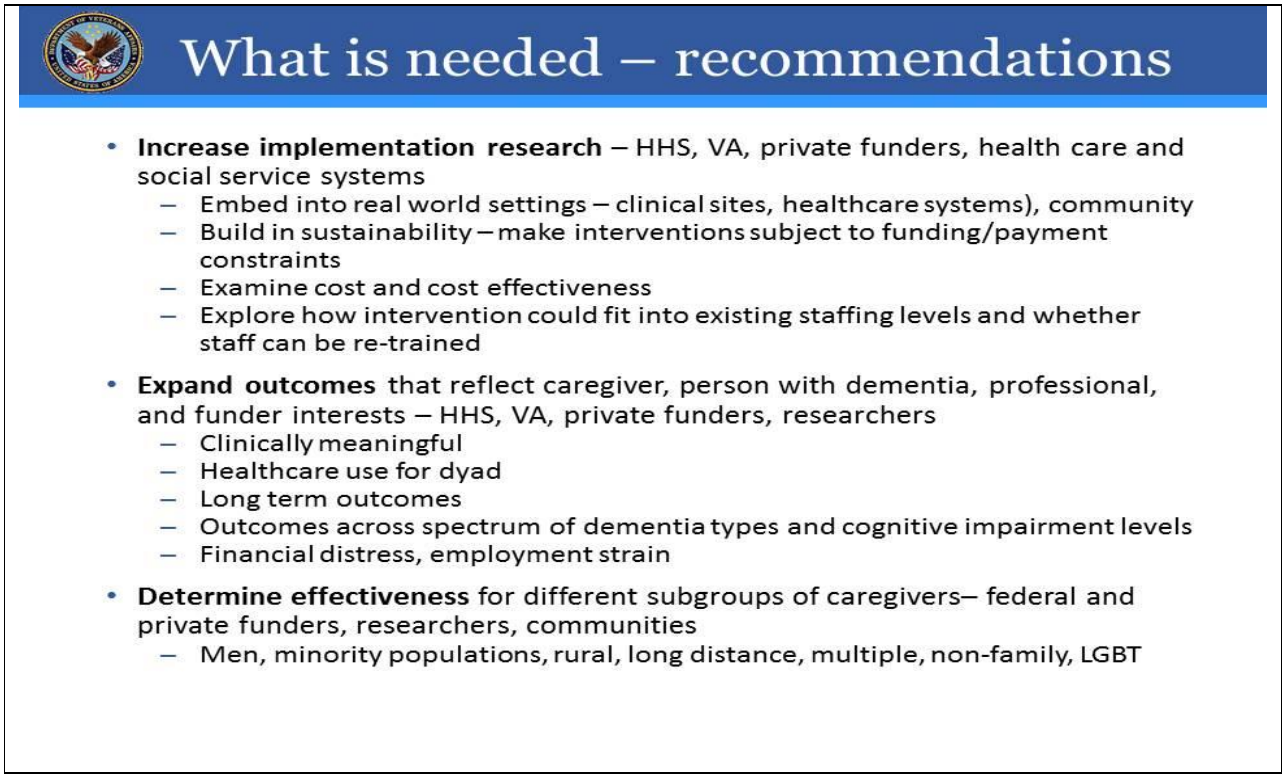
Implementation model steps*	**REACH VA example**
Exploration and adoption – Determine if intervention needed, assess match between it and organization	Identified national and local partners and sites, developed implementation manual, secured funding for translation pilot
Program installation – Install structural supports, training, funding	Funded as a clinical program, refined webinar training and certification, increased coaching
Initial implementation – Changes in practice, education, time vs. status quo, fear of change, inertia	VA staff wanted changes to fit their needs and those of the facility and caregivers – fewer sessions, more delivery modes
Full operation – Program works, organization supportive	Modified per staff and caregiver comments, workload capture, CPT codes, CEUs for training
Innovation – Refine and expand, how to use with fidelity, evaluate	EMR templates, evaluated – caregiver outcomes similar to RCT and pilot translation
Sustainability – Funding, intervention remain a priority as organization changes	Caregiver Center funding, SCI/D, PTSD, ALS, MS, expanded to other models of delivery – Caregiver Center staff and national clinical staff

*Fixsen, et al., 2005



What is needed – recommendations

- **Increase implementation research** – HHS, VA, private funders, health care and social service systems
  - Embed into real world settings – clinical sites, healthcare systems), community
  - Build in sustainability – make interventions subject to funding/payment constraints
  - Examine cost and cost effectiveness
  - Explore how intervention could fit into existing staffing levels and whether staff can be re-trained
- **Expand outcomes** that reflect caregiver, person with dementia, professional, and funder interests – HHS, VA, private funders, researchers
  - Clinically meaningful
  - Healthcare use for dyad
  - Long term outcomes
  - Outcomes across spectrum of dementia types and cognitive impairment levels
  - Financial distress, employment strain
- **Determine effectiveness** for different subgroups of caregivers– federal and private funders, researchers, communities
  - Men, minority populations, rural, long distance, multiple, non-family, LGBT



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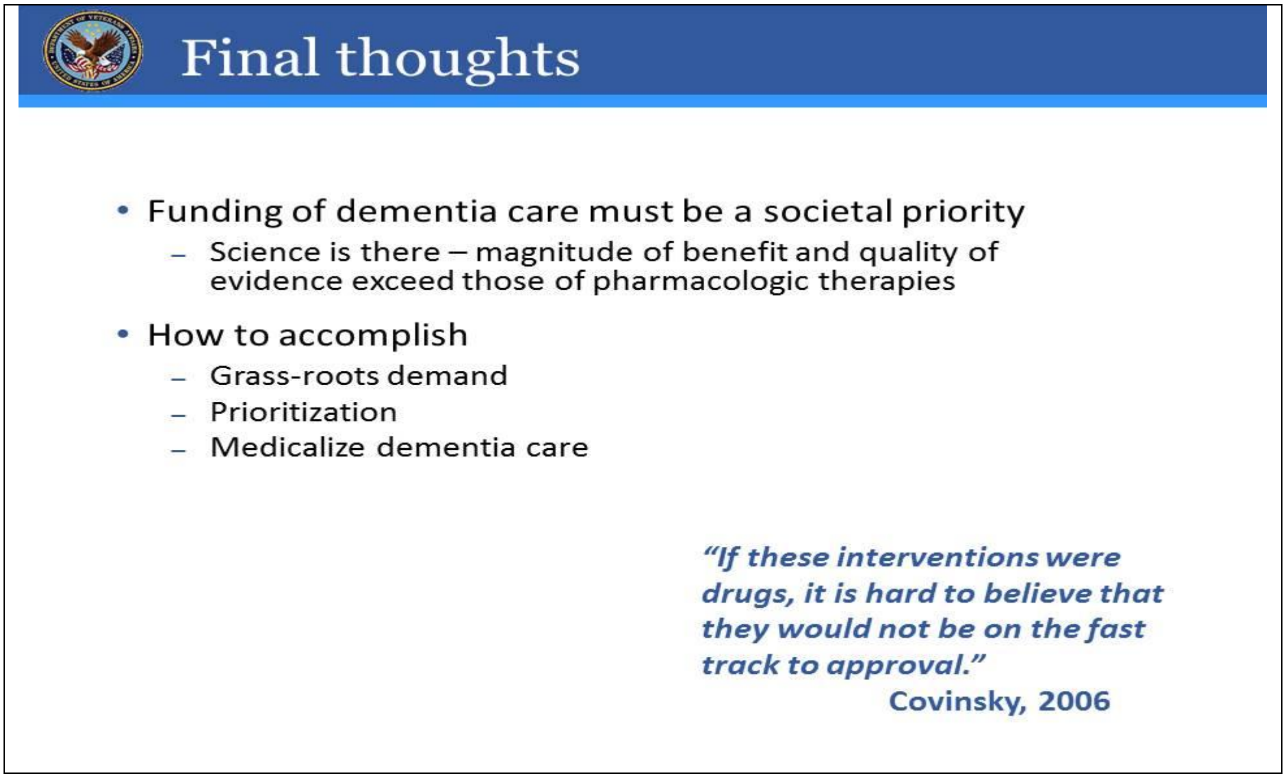

Final thoughts

- Funding of dementia care must be a societal priority
  - Science is there – magnitude of benefit and quality of evidence exceed those of pharmacologic therapies
- How to accomplish
  - Grass-roots demand
  - Prioritization
  - Medicalize dementia care

> ***"If these interventions were drugs, it is hard to believe that they would not be on the fast track to approval."***
>
> **Covinsky, 2006**