

Moving Forward Faster to Provide Care Together

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#DementiaCareSummit



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We Didn't Make It

5 Million Americans



www.nia.nih.gov



www.alzheimers.org





We Didn't Make "It" Either

- Medicare spends \$30 billion to provide care for 400,000 persons with ESRD
- Medicare and Medicaid spend \$250 billion for 5 million persons with AD
- US has more dialysis centers than dementia specialists



Fig. 3. Geographic distribution of U.S. dialysis facilities reporting standardized kidney transplant ratios in 2007-2010.

Accessed at: www.usrds.org

Plantinga et al. Am J Nephrology 2014



Face Reality

- Number of families suffering from Alzheimer's disease will double
- Technology will not save us from needing to provide hands-on care
- Family caregivers will provide the majority of care



www.nia.nih.gov



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Pivot to Plan B

Build a home-based system of care for persons with Alzheimer's disease based on a network of persons with Alzheimer's disease and their family caregivers who are supported by community service providers and collaborating with medical service providers



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Pray for Potatoes with a Hoe in Your Hand

- **Jump start social networks**
- **Redesign the home**
- **Move resources to the community**
- **Intensify demand for palliative care**
- **Provide career for formal caregivers**
- **Generate demand for the new system**



Millet 1861



Elephants in the Room

- Unclear boundaries between the medical system and social system
- Uncertainty in balancing personal autonomy with safety
- Conflict over who should pay for the services families actually need
- Data-driven vs culture-driven decision-making



"I'm right there in the room, and no one even acknowledges me."



Thinking Outside the Box

- Systems of care must build from the foundation of family caregivers
- Research must be coupled with political and community activism
- New research to learn how to support family caregivers

