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

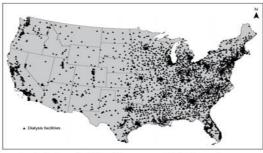


Fig. 1. Geographic distribution of U.S. dialysis facilities reporting standardized kidney transplant ratios in 2007-

Accessed at: www.usrds.org Plantinga et al. Am J Neprology 2014

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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



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 network of persons with Alzheimer's disease network of persons with are supported and their family caregivers who are supported and their family service providers and community service providers collaborating with medical service providers



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."



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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

