Reflections

Laura Gitlin

Opportunities  Limitations

- We operate within a space between opportunities and limitations imposed by legislative rules/regulations guiding activities
  - Understanding this space is particularly challenging for new members
- Within this space, the Advisory Council serves a very critical role and has achieved significant progress
- Four Key Goals for 2 year Chair appointment
  - Enhance engagement of all members and more responsibility of subcommittee chairs/members
  - Link recommendations/activities to five goals/strategies/actions of Plan
  - Identify ways to be more impactful
  - Examine ways to systematically evaluate accomplishments and identify future directions

Primary accomplishments per goal

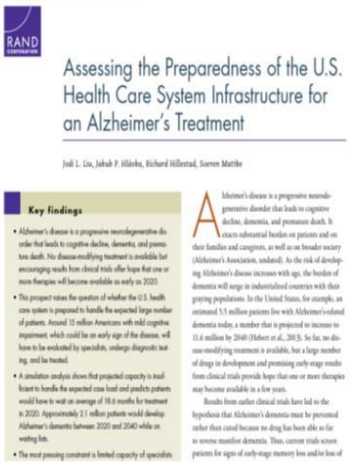
- Goal: Enhance engagement of all members and more responsibility of subcommittee chairs/members
  - Subcommittee chairs plan one meeting a year on a topic relevant to their respective NAPA Goals and recommendations
- Goal: Link recommendations/activities to five goals/strategies/actions of Plan
  - Presentations and federal report outs tied to goals/strategies
- Goal: Identify ways to be more impactful
  - Executive summary of recommendations as talking points for nonfederal members to use to engage with state and federal legislators
  - Elevation of NAPA goals (esp. #2,3, 4) with the First National Resaerch Summit on Care and Services
  - that will now be sustained as part of the NIA infrastructure for research milestone development
  - Understanding of dementia across trajectory from prevention to end of life, as complex, requiring multi-sector, multidimensional, coordinated actions
- Goal: Examine ways to systematically evaluate accomplishments and identify future directions
  - Driver Diagram
  - Indicators of progress (how do we know we are moving forward; how will we know when goals are accomplished)
  - Moonshot and 4-D approach

Recommendations moving forward

- Expand reach of Advisory Council meetings:
  - Increase social media presence and concerted outreach to the public to tune in
  - Sponsor meetings/pre-conferences at major meetings (AAIC, GSA etc)
- Chairs/subcommittee chairs - Formulate clear goals for what to accomplish; clearly link meetings/speakers to evolving recommendations
- Prepare for 2025:
  - Evaluate what has been accomplished
  - Evaluate what needs to be accomplished
  - Provide strong rationale for continuing Advisory Council

Key Area Needing Immediate Attention

- Advance an infrastructure for treatment delivery
  - Projected capacity insufficient to handle expected case load for treatments
  - Key constraint - limited capacity of dementia specialists for diagnosis, limited access to infusion centers to deliver treatment
  - Addressing capacity constraints needs to involve payment policy, regulatory requirements, workforce considerations, and capacity planning at national and local levels as well as ground awareness; development of quality indicators etc



RAND

Assessing the Preparedness of the U.S. Health Care System Infrastructure for an Alzheimer's Treatment

Jodi L. Liu, Jakub P. Hlávka, Richard Hillestad, Soeren Mattke

Key findings

- Alzheimer's disease is a progressive neurodegenerative disorder that leads to cognitive decline, dementia, and premature death. No disease-modifying treatment is available but encouraging results from clinical trials offer hope that one or more therapies will become available as early as 2020.
- This prospect raises the question of whether the U.S. health care system is prepared to handle the expected large number of patients. Around 15 million Americans with mild cognitive impairment, which could be an early sign of the disease, will have to be evaluated by specialists, undergo diagnostic testing, and be treated.
- A simulation analysis shows that projected capacity is insufficient to handle the expected case load and predicts patients would have to wait on average of 18.6 months for treatment in 2020. Approximately 2.1 million patients would develop Alzheimer's dementia between 2020 and 2040 while on waiting lists.
- The most pressing constraint is limited capacity of specialists

Alzheimer's disease is a progressive neurodegenerative disorder that leads to cognitive decline, dementia, and premature death. It exacts substantial burden on patients and on their families and caregivers, as well as on broader society (Alzheimer's Association, undated). As the risk of developing Alzheimer's disease increases with age, the burden of dementia will surge in industrialized countries with their graying populations. In the United States, for example, an estimated 5.5 million patients live with Alzheimer's-related dementia today, a number that is projected to increase to 11.6 million by 2040 (Hebert et al., 2013). So far, no disease-modifying treatment is available, but a large number of drugs in development and promising early-stage results from clinical trials provide hope that one or more therapies may become available in a few years.

Results from earlier clinical trials have led to the hypothesis that Alzheimer's dementia must be prevented rather than cured because no drug has been able so far to reverse manifest dementia. Thus, current trials screen patients for signs of early-stage memory loss and/or loss of

- Pragmatic Trials offers the science help advance an infrastructure
  - We have some evidence
    - It often does not fit health systems
    - Takes time, effort and frustration to fit
    - In fitting, we may damage th peg


What is the MoonShot to improve Quality of Life Now?
Ideas grounded in evidence that are:
MOON SHOT
• Ambitious, but not unattainable
• Can make a real difference
• Possible to accomplish in next few years.
• May change, influence recommendations, legislation, policy, practice, research
• Multi-sectorial (not one action)
• Focus on dementia care to improve quality of life


Moonshot has to be multi-sectorial and coordinated
Workforce prep
Ground awareness
Reimbursements for evidence-based programs
Improve Quality of Life
Quality indicators
Measurement of progress

The 4 Disciplines of Execution (4DX)" to Achieve our "Wildly Important Goal"

- Discipline 1: Focus on the Wildly Important
  - Define crucial goals and narrow the team's focus to those goals.
- Discipline 2: Act on Lead Measures
  - Consistently carry out and track results on those high-leverage activities that will lead to the achievement of WIGs.
- Discipline 3: Keep a Compelling Scoreboard
  - Visibly track key success measures on a goal.
- Discipline 4: Create a Cadence of Accountability
  - Regularly and frequently plan and report on activities intended to move the measures on the WIG scoreboard.

Act on Lead Measures

Lag Measure: the historical measure of a goal or WIG achievement expressed in terms of *from X to Y by when*

Ex: Increase annual water production from 175 million liters to 185 million liters by end of year

Lead Measure: the measure of an action planned and taken as a means to achieving a WIG

- *Predictive*: if the lead measure changes, the lag measure will also change
- *Influence-able* by the team

Ex: Increase the percentage of shifts with full crews from 80 to 95 percent.

10

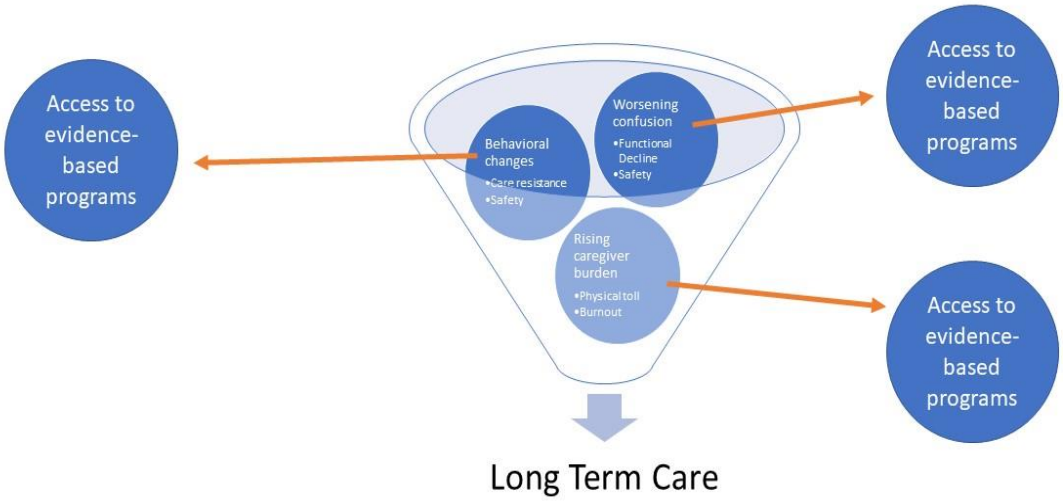
Example of a Wildly Important Goal

- By 2025, increase by 25% the average length of time after diagnosis that a person with dementia can remain a community-dwelling adult
  - Lag measures
    - Reduced number of admissions to LTC
    - Reduction of caregiver burden
  - Lead measures
    - Increase of support services
    - Increased caregiver education

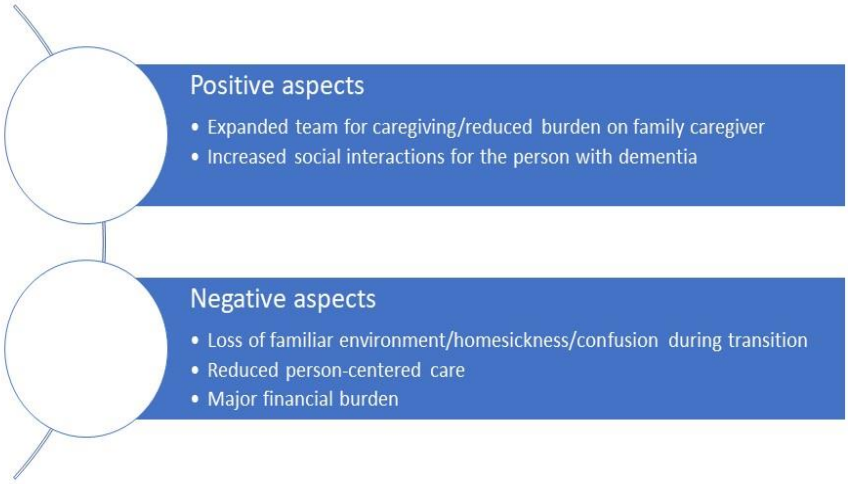
Questions/Issues

- How do we measure preferred environment"
- How to we ask people with advanced dementia (in nursing homes, potentially) if they are in their preferred environment
- Preferred environment may change with disease trajectory and how to account for?.
- How to assure caregivers have training and resources they need to manage behavioral symptoms and other clinical symptoms?
- How to account for time of diagnosis and time of LTC – what administrative data sets are available?
- Is LTC defined as facility-based placement (MDS data source for non-SNF stays; doable), use of long-term home-based services (data source?) or both?
- Is there a way to build in goals of care discussion (which is a Medicare service with a billing code – ACP) into this?
- Consider as a lead measure % of people with a diagnosis of dementia who have a care plan.
  - What is current % - i.e. baseline?

What drives placement to long term care?



What is the impact of a transition to long term care?



Reflections from Non-federal Members Leaving the Advisory Council