

# *Alternative Solutions*

## **Finding LTSS: New Options or New Confusions for Consumers**

Tuesday March 28, 2017

9:00 – 10:15 am



**17th Annual Intercompany Long Term Care Insurance Conference**

# Session Producer and Speakers



- Eileen J. Tell, ET Consulting LLC
- Anne Tumlinson, Tumlinson Innovations and Daughterhood.org
- Lee Zacharias, The Zacharias Group

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## **Setting the Stage**

Anne Tumlinson



ANNE TUMLINSON  
INNOVATIONS

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**Growing  
Incidence of  
Late-Life  
Disability**

**Opportunity to  
Change Service  
Delivery for  
Aging Population**

**New Risk-  
Based Health  
Care Payment  
Models**

**Technology and  
Emergence of  
Aging Innovator  
“Class”**

# 3/4 Older Adults with LTC Needs Live at Home



Table 2, Freedman and Spillman (2014)

# Americans Rely on Unpaid Caregivers

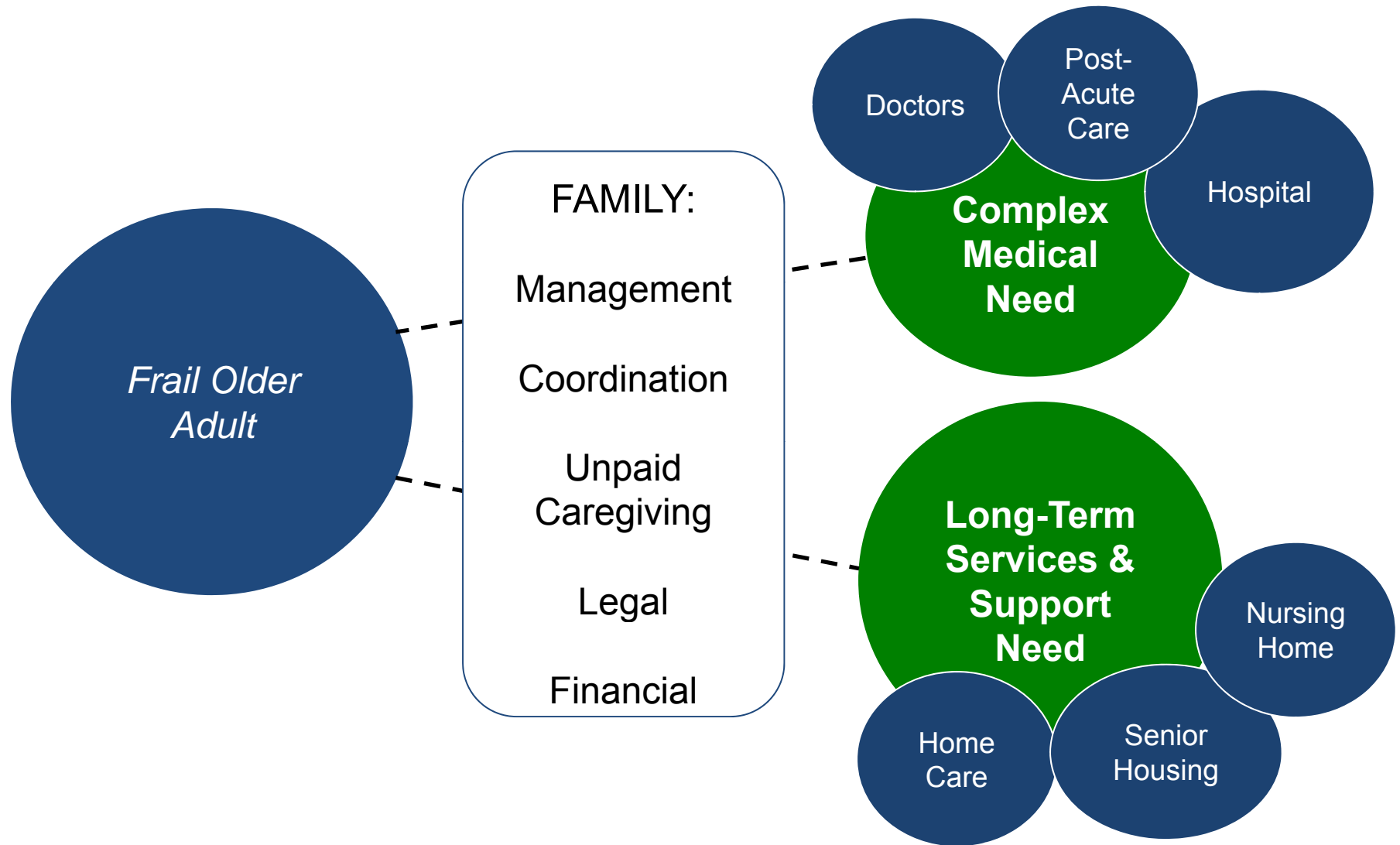


**Nearly 2/3**

of Older Adults with  
LTC Needs Living at  
Home Receive All  
Help from Unpaid  
Family and Friends

Note: Excludes individuals living in nursing homes  
Table 4, Freedman and Spillman (2014)

# Families: The Ultimate Accountable Care



# No Community-Based “Information Hub” for Families



**Medical Integration:**  
Gap in coordination, particularly in crisis

- IADLs:**
- Expensive
  - Lacks Appeal
  - Lacks Flexibility
  - Worker Quality is Poor

- ADLs**
- Expensive
  - Lacks Appeal
  - Lacks Flexibility
  - Worker Quality is Poor

**In-Home Technology:**  
Not yet well leveraged to substitute for Hub and Daily Care

**Hub:**  
*Most people do not receive any assistance entering the delivery system or managing it on an ongoing basis*

**Supportive Environment:**  
Most people live in single-family dwellings unsuited for family



# Online Information Sources Fail to Meet Needs



- Lack of transparency, trust-worthiness, clear expertise
- Information is too general and abstract and there's so much that it creates overload
- Endless redirection – one resource cites “check this resource” and so on
- Lack of normalization, context and emotional connection
- Situations highly unique – not like common developmental milestones that every parent will encounter in parenting

# Some are Inventing Care Navigation Services



- A variety of different types of organizations are attempting to provide decision-making assistance to family caregivers
- Idea is to scale the traditional geriatric care manager to one extent or another

• All are now online or telephonic

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# And Technology to Support Families



- Early research shows family caregiving can reduce healthcare utilization
- New technology being developed to enable leveraging and higher levels of support for family caregiving



# Understanding How Families Access LTSS: ASPE Study



- Navigating this maze was reason for ASPE study
- Used a single-state as case study to explore public and private sector “information & referral” resources
- Insights from consumer focus groups
- Environmental scan of available resources

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## **Consumer Voices: Findings from the Study**

Lee Zacharias



**17th Annual Intercompany Long Term Care Insurance Conference**

# STUDY OBJECTIVES



- Identify resources that help consumers define care needs and find LTSS
- Provide a descriptive analysis (Environmental Scan) of those resources
- Understand whether and how consumers are aware of and use these resources
- Identify factors that facilitate consumers in their search for LTSS
- Understand the obstacles in that process
- Identify ways to improve the consumer experience

# State-specific Case Study



- Want “typical” state regarding performance variables relevant to finding LTSS
- **Final selection: Pennsylvania**
  - Decentralized system for public aging network
  - Population demographics varied
  - Stronger public sector resources due to lottery funding
  - Can cost-effectively support focus groups with varied demographics



# Focus Groups



- Four groups, June 6-9, 2016
  - Pittsburgh (1)
  - Scranton/Wilkes-Barre (1)
  - Philadelphia (2)
    - One group all females
    - One mixed gender group





# Screening Criteria



- Adult family member needed LTC within past 2 years
- Care need lasted more than 3 months
- Individual was primary or joint decision-maker for LTSS
- Ages 40 to 69
- Private pay (all or in part)
- Articulation
- Balanced groups with regard to:
  - Age, gender, marital status, person cared for, duration of care need, type of care need, local or long distance, education, income, employment

# Identifying Needs



- Family members often unaware of “gradual” declines until acute event took place.

*“My mother, she fell, and there was a lot going on that we weren’t aware of. She was living by herself and we did not know...or recognize the signs of Alzheimer’s.”*

*...“you don’t need to know, we’re fine, we’re handling everything...”*

- Those that tried to plan and discuss in advance with parents were shut down.

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# Learning Process



- New terrain for most participants
- Many started with internet search, but not sure how and what to look for

*"I'm on the internet. I think...what do I do? Where do I go? How do I start? And I just started reading."*

*"It was a wake up call. I never really thought about it till it happened."*

*"I just looked up nursing home, assisted care, because I didn't know what I was looking for."*

# Information Sources Varied



- Hospital – doctor, social worker, discharge planner
- PCP office nurse
- Word of mouth, recommendations from family and friends
- Familiarity – looking into places with which they were already familiar
- Familiarity was more common in smaller communities like Wilkes-Barre/Scranton

*“My family is born and raised here, and it was just a place we’ve driven by and then that just came to mind. I don’t want to tell you it was recommended – maybe it was.”*

*“I listened to the doctors.....And then the social workers presented me with choices of places. From there, I asked everyone I knew about that place.”*

*“I searched out from word of mouth...people I knew that had elderly parents that maybe went through it. That’s how I found out.”*

# Process is not a “once and done”



- People spoke of the challenge of changing care needs
- An acute event might disrupt facility care and require a new placement
- Or it might signal the need to move from in-home care to facility care

*“So it was a constant work in process. Anybody says you put your person in one place and that’s where they stay until they die. But I don’t see it. I just don’t see it.”*

*“My mom was in one place and I didn’t like it. So I had to put her somewhere else. Then she went in the hospital for 10 days. They said to pay for the bed but I said ‘I’ll take my chances.’ Well, then the bed was gone. So then I researched and found I place I liked much better.”*

# Choosing a Facility Requires Vetting



- Once a facility was identified, some used the internet to learn how it compared with others with regard to staffing, complaints, services and other features.
- While many said they did on-line research including looking up quality rating or state certification information, the critical next step was the actual visit.
- Deciding factors usually cost, location and availability

*“The internet will give you direction. But – I’m hands-on...and I’m sure everybody in this room is. You have to go to the facility, you have to look at the people and you have to eyeball them when you’re there. You have to check on the meals.”*

*“Even if you find a great place, you also have to think about money, availability and the convenience.”*

# Public Sector Resources – Mixed Feedback



- Some familiarity with AAAs but no clear sense of what they do; mentioned social services, meals, transportation.
- Not seen as a place to go for a needs assessment, care plan, or information about providers.
- A few tried, but were frustrated that they only got lists and not recommendations.

*“They bring in activities for seniors versus actually coordinating any type of services. At least that’s what I see in Southwestern PA.”*

*“When you call the Area on Aging, they are so blasé. You can’t get a straight answer out of ‘em. [They tell you]... ‘well this is here and this here.’ [If you ask] what’s the best? [They say] ‘well they’re all good.’ Well, no, they’re not all good.”*

# Reviewing Quality Data



- Some mentioned using the internet to find information on quality of care, rankings, services and violations.
- Most mentioned state-sources of information.
- Receptive to the type of information and ability to compare using NursingHomeCompare and HomeCareCompare. But none were already familiar with the resource or had used it.
- Some skepticism about the data – how current? If facilities know they are going to be reviewed, they “spruce up” for it.
- And you still have to see it for yourself and/or know someone else who had a good experience there.

*[Talking about Nursing Home Compare...]*

*“It’s got good information in it that would be hard to assemble elsewhere.”*

*“It’s a good starting point. But it’s not an end-all.”*



# Use of Private Sector Resources



- Surprisingly little familiarity with the large and growing number of on-line businesses promoting help finding care
- Some had heard of the most aggressively advertised ones: A Place for Mom and Care.com
- Little awareness of the various business models including the provider “pay to play” or the fact that they are not all inclusive

# Thoughts on On-Line I&R



- *From those who used them...*

*“They’re getting the recommendation of the ones that are gonna pay for the referral. But it wasn’t a good fit for us.”*

*“We did tour a couple places. They gave us the one out in Haverford? I’m like...why wouldn’t I go to the one in Media?”*

*“I did sign up...I went through all the steps and they did call me and took a lot of my dad’s information...they recommended some places not really close.”*

*“Even if you’re provided with a list, you can research it and you find that they have great reviews....but I don’t just pick people out of the phone book. If it’s a good review, I have to have another family that said their experience was very good. Without that, I’m not going to blindly accept somebody’s review or a list....”*

# What Would Make a Better Experience?



- More help and information from one's health plan, hospital or doctor
- Receptive to idea of public sector, non-profit entity to help
- Some saw a role for AARP especially since they are so "pushy" and familiar to many
- Appeal of concept of geriatric care manager but few familiar with that

*"There needs to be a liaison, somebody to help people make informed decisions right when it happens."*

*"Maybe the health care companies need to take some responsibility....develop something that could help us, that we would know who to contact."*

# Concluding Thoughts



- The “crisis” nature of the need and the ever-changing needs add to an already emotionally charged and challenging process
- Easily overwhelmed
- Labor-intensive process – visit facilities and monitor constantly
- Emotions and guilt
- Satisfying numerous constraints: care options that are affordable, available, nearby and reliable (good quality)
- Communities with more local caregivers and aging-in-place showed heavier reliance on family doctor and local hospital or health plan

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## **Public & Private Sector Resources**

Eileen J. Tell,  
ET Consulting LLC



**17th Annual Intercompany Long Term Care Insurance Conference**

# When Someone Asks Me to Help Them Find Care...



Finding LTSS: New Options or New Confusions for Consumers

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# Environmental Scan



- Identify and describe public and private sector resources for LTSS information & referral
  - National resources and community-specific
- Resources identified by: project team input, consultation with ASPE, internet and literature reviews
- Used information in public domain where feasible
- Some follow-up conversations where needed

# Areas of Inquiry



- Consumer outreach
- Who pays
- Nature/depth of provider information
- Data sources, validation and update
- Extent of offering:
  - Information only
  - Assessment
  - Information and referral
- Service and support options
  - Peer group support
  - User reviews
  - Literature and check lists
  - Provider background checks/payroll support



# Private Sector On-line Resources



- Large and growing market
- Some facility care only (e.g., A Place for Mom) and others just in-home care (CareinHomes)
- Some serve both consumers and providers (e.g., Care.com)
- Different business models:
  - Business-to-Business-to-Consumer (B2B2C)
  - Direct-to-Consumer (D2C)
    - Providers pay
    - Consumers pay
    - Hybrid



# Advantages to the User



- Often available at no cost
- Access to a “Senior Care Advisor”
- Rapid (& persistent) response
- Detailed information on providers
  - Sometimes standardized format vs. provider creates own entry
- Value-add information (articles, checklists)

# Best Practice Models



- Transparency regarding provider participation and inclusion criteria
- Has some geriatric care expertise
- Offers “buy up” services like assessments and care management
- Site “curates” and standardizes provider information
- Up to date data, information on availability and service specificity
- Users can decide how they want to use the site

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# Concerns

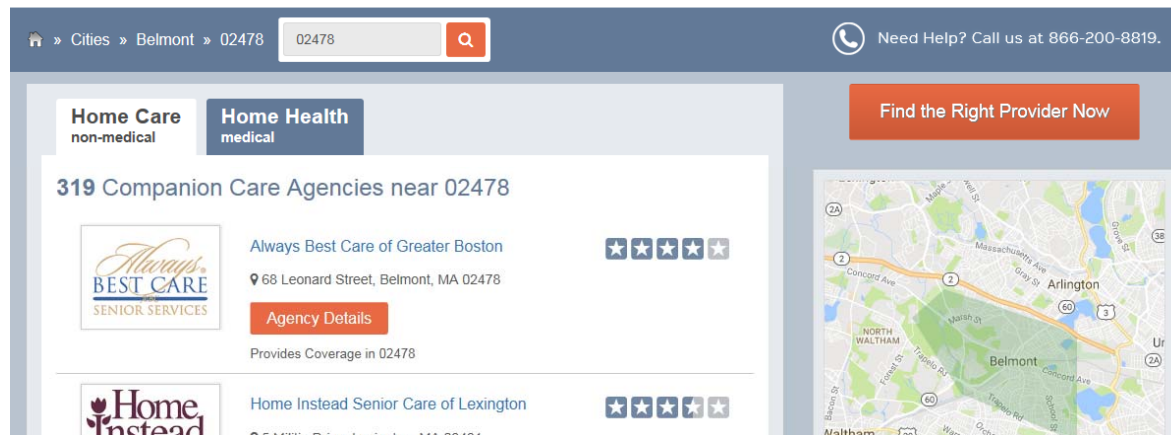
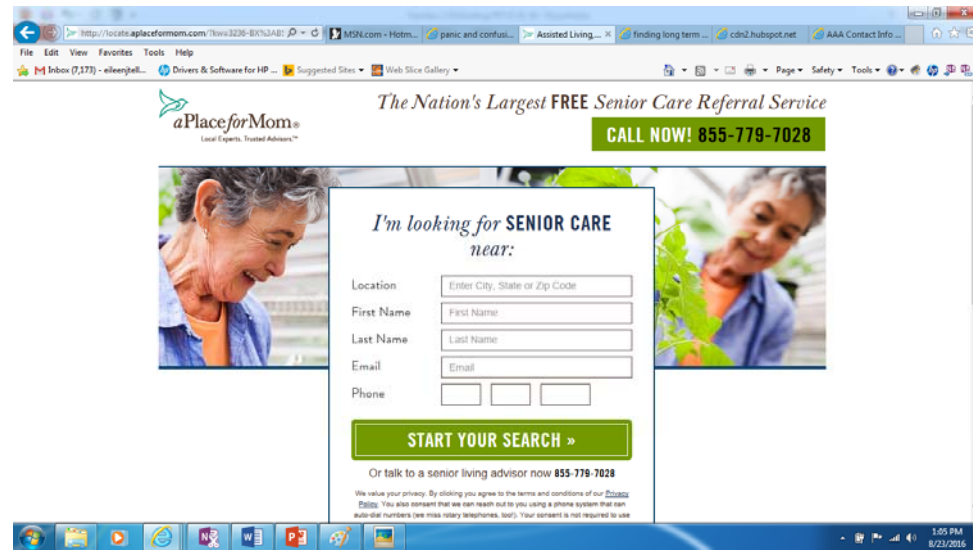


- Lack of transparency about provider selection and participation
- Users have little flexibility in how they interact with the site
- Consumer complaints – difficulty unsubscribing, too much provider contact, needs not well matched
- Lack of geriatric care expertise
- Little or no needs assessment driving referrals



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# “Gated” vs. “Not-Gated”



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- Explore if/how aging services network providers in study community interact with private-pay population
- Depends in part on demographics of the areas they serve
- Resource constraints limit ability to take on an expanded service population
- Other challenges: traditional outreach channels don't reach the "adult child" family caregiver that often drives the LTSS search
- Provide expertise, information and "how to" guidance but cannot offer provider-specific referrals (seen as "endorsements")

# Developing Private Pay Capabilities



- 2013 survey of AAAs – 25% had or planned to develop private pay programs
- Use increased revenue base to enhance service to non-paying clients
- Requires investments in staffing, marketing, service provider contracts and more
- n4A working with ACL (Business Learning Collaboratives) to help AAAs establish contracts with health care entities to better reach private pay consumers

# Regional Variations



- Montgomery/Bucks County AAAs most favorable demographics to support outreach to private pay
- State pilot to move into private pay ---- currently on hold
- PCA exploring, but challenged by large low-income population
- Allegheny is pilot site to contracted with managed care organizations
- AAAs looking to contract with health plans, but I&R is not initially part of the private pay product mix



# What AAAs Need to Play a Role



- AAAs best positioned to launch private pay programs:
  - High percent of middle income older adults and caregivers (and access to them)
  - High recognition at community level for service delivery
  - Partnerships with providers that help broaden their service package
  - Strong governance and support for such growth
  - New technology, training and customer service

## For Further Inquiry



- Better understand role of MD, hospital, health plan in guiding LTSS decisions
- Is there a market for “new and improved” private online business models? Trends for this emerging industry?
- Evaluate the actual customer value in these services
- Is there a role for public aging network w/ private pay needs?
- Encourage and enable advanced planning – given so much that is unpredictable (about needs and resources), is it even feasible?
- Raise awareness about existing free resources and getting people to the right ones at the right time
- Can we “systemize” the word of mouth that people value?

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# QUESTIONS



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