Keynote Presentation

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#CareAdvocate  @NA4Caregiving
Empowerment and Engagement: Caring to Advocating

9th National Caregiver Coalitions Conference
National Alliance for Caregiving
March 19, 2015
Monica

Year 1 - Began showing signs of forgetfulness
Year 2 - Husband died
Year 3 - Journey toward diagnosis of AD began
Years 4-7 - Progression of disease, co-morbid conditions, complications
Years 1-7 - Caregiving journey
Year 7 - Death
My Story with Monica

- The difference between capacity and capability among siblings
- Need for respite arose
- Creative options out of conversations
- Admission to SNF did not end caregiver role—it changed it
- Bereavement and caregiver
The Family Role

- Primary family caregiver
- Adult child/ parent
- Spouse
- Life/family history
Unspoken Expectations

- Family
  - Capacity under duress
  - Deferred conversations
  - Caregiving career
  - Cumulative loss
  - Geographically distant
  - Perception of responsibility
  - Disagreement and agreement
  - Knowledge of system
  - Culture of family
Expectations

- Of care recipient
- Of health care system
- Of health professionals
- Of long term services and supports
Caregiving

Definition

Progression
What are caregivers doing?

- Transportation
- Housework
- Grocery shopping
- Preparing meals
- Managing finances
- Helping with medications
- Arranging or supervising paid services

*Care for the Family Caregiver, A Place to Start*, Emblem Health/National Alliance for Caregiving, March 2010
What are caregivers doing?

- Getting in and out of bed
- Getting dressed
- Helping bathe or shower
- Getting to and from the toilet
- Feeding the care recipient
- Dealing with incontinence and diapers

*Care for the Family Caregiver, A Place to Start*, Emblem Health/National Alliance for Caregiving, March 2010
Who are caregivers

- Capacity
  - Resilience
  - Growth/Stress

- Capability
Areas of Concern

- Legal
- Financial
- Medical Care
- Home-Safety and Maintenance
- Transportation
- Social
- End of Life
- Care of the Caregiver
Loss of Self

- Health and Wellness
- Patience and Endurance
What have we done?

- Caregiver recognition
- Educational outreach
- Caregiver support
Advice to male caregivers

- Men and women different
- Simply aware that more men are filling caregiver roles
- Suggest support groups
- Educate yourself
- Meditate or Me time
- Have all necessary documents - insurance, deeds, wills,
- Stay involved in hobbies
- Lead with strengths - arranging doctor appointments, managing finances, running errands
- Ask for help - fragmented health care and aging system
So what does it mean to be aware?

- Recipient
  - Is more aware of him/herself and current **lived experience**
  - Knows more about a resource, service, diagnosis, prognosis
  - Knows how to find help
  - Is inspired to act
  - Connects with others
Empowered

- Relationship
- Role
- Responsibilities
Advocacy cycle

- Identify issue or problem
- Research cause and effect
- Plan goals, objectives, indicators, methods, activities, and timeline
- Act
- Monitor and evaluate actions and results
Effective Advocacy

- Know the facts.
- Use the facts
- Have clear and concise message
- Nurture relationships and work collaboratively
- Engage the public
- Make your voice heard!
- Say thank you
- Citizen’s Committee for Children of New York
Barriers to Empowerment

- Caregivers focus on their loved one, not on themselves.
- Many caregivers are hesitant to share duties with other family members.
- Most caregivers are unfamiliar and uncomfortable with outside services.
- Caregivers are reluctant to discuss their caregiving responsibilities at work.
- Many caregivers are reluctant to talk about - or even speculate on - whether or not caregiving affects their own health.

There is little or no awareness of caregiving organizations

While there are significant barriers to self-awareness, there are some who have crossed the barrier emphatically to become empowered.
The idea of caregivers as a political constituency is foreign to most caregivers, and some are very wary of it. Nevertheless, the potential advantages of political mobilization are clear and powerful to some caregivers.
As new state demonstrations to improve and integrate care for Medicare-Medicaid enrollees (also known as “dual eligibles”) move forward, health plans and provider groups (here, referred to collectively by the term “delivery systems”) must employ meaningful consumer engagement strategies. Federal guidance from the Centers for Medicare and Medicaid Services calls upon states to ensure the voices of older adults, persons with disabilities, and their caregivers are heard in the design, implementation, and oversight of the demonstrations. ”

http://www.communitycatalyst.org/resources/tools/meaningful-consumer-engagement
Engagement in care delivery

“To sum it up, active, meaningful consumer engagement gives delivery systems and their consumers the tool they need the most to improve and maintain health and quality of life - information that leads to action. Delivery systems need information from consumers and their caregivers about the stronger and weaker aspects of care delivery - aspects that impact the system’s bottom line as well as consumers’ health outcomes and quality of life. Similarly, consumers and their caregivers need easy-to-understand information about how to best navigate their newly integrated delivery system and how the system is using consumer feedback for continued quality improvement. This “feedback loop” between consumers, their caregivers, and the entire health care delivery system will be critical to the success of the demonstrations.”

http://www.communitycatalyst.org/resources/tools/meaningful-consumer-engagement
Moving to Empowerment
Drivers- Desire for change

- Has to be better
- Need info to help me now
- Change for others benevolence
- Fight to change
- Gather support
Attributes effective caregiver

- Meaning-Focused Coping

- “The processes of appraisal and reappraisal allow for interpretation of the meaning and significance of the demands and challenges the caregiver is facing. When appraised as deeply meaningful and important to an individual’s values and purposes, energy for coping expands empowering individuals to persist, survive, and grow.”

Development of a Caregiver Empowerment Model to Promote Positive Outcomes Patricia S. Jones, PhD, RN, FAAN1, Betty W. Winslow, PhD, RN1, Jerry W. Lee, PhD, RN2, Margaret Burns, DNSc, RN and Xinwei Esther Zhang, EdS, MS1 Journal of Family Nursing 2011 17(1) 11-28
Messengers

- To Caregivers or With Caregivers
- Importance of seeing themselves
Message: Advocacy can work

- You can make a difference
- People working together can make a difference
- People can change laws
- Lobbying helps find real solutions
- Policymakers need your expertise

Center for Lobbying in the Public Interest: Strategies for Nonprofit Engagement in Legislative Advocacy

https://www.councilofnonprofits.org/sites/default/files/documents/Make_a_Difference_RG%5B1%5D.pdf
Conclusion

- Lived experience empowers the caregiver as they care
- There are drivers which comprise the desire for change
- Effective caregivers are more aware, know more, know how, are inspired and connect with others
- Effective advocacy needs to know the facts; be engaging and achieve success through nurtured relationships.
Conclusion

- Meaning focused coping
- Meaning driven empowerment and engagement
- Integrate into advocacy