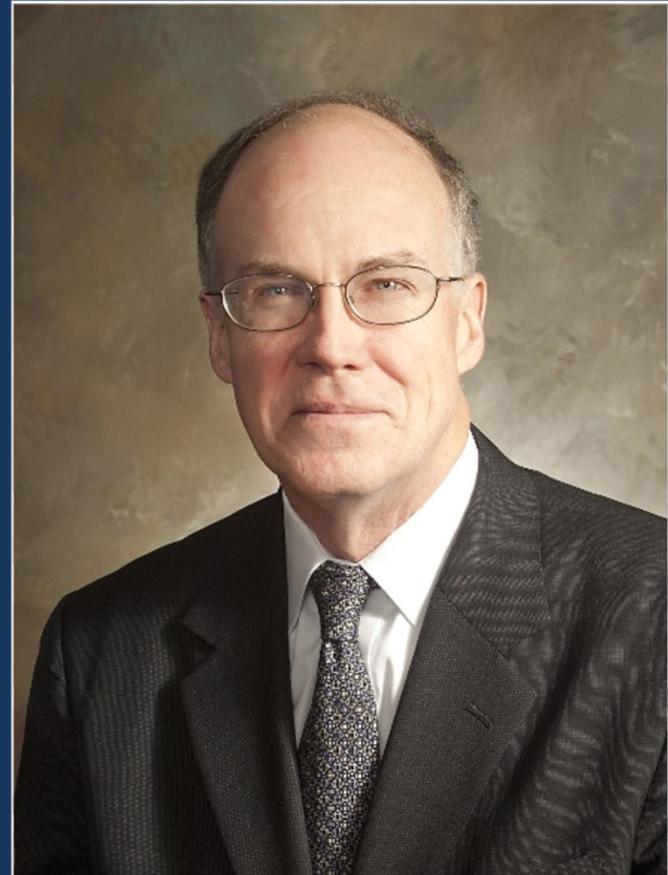


Keynote Presentation

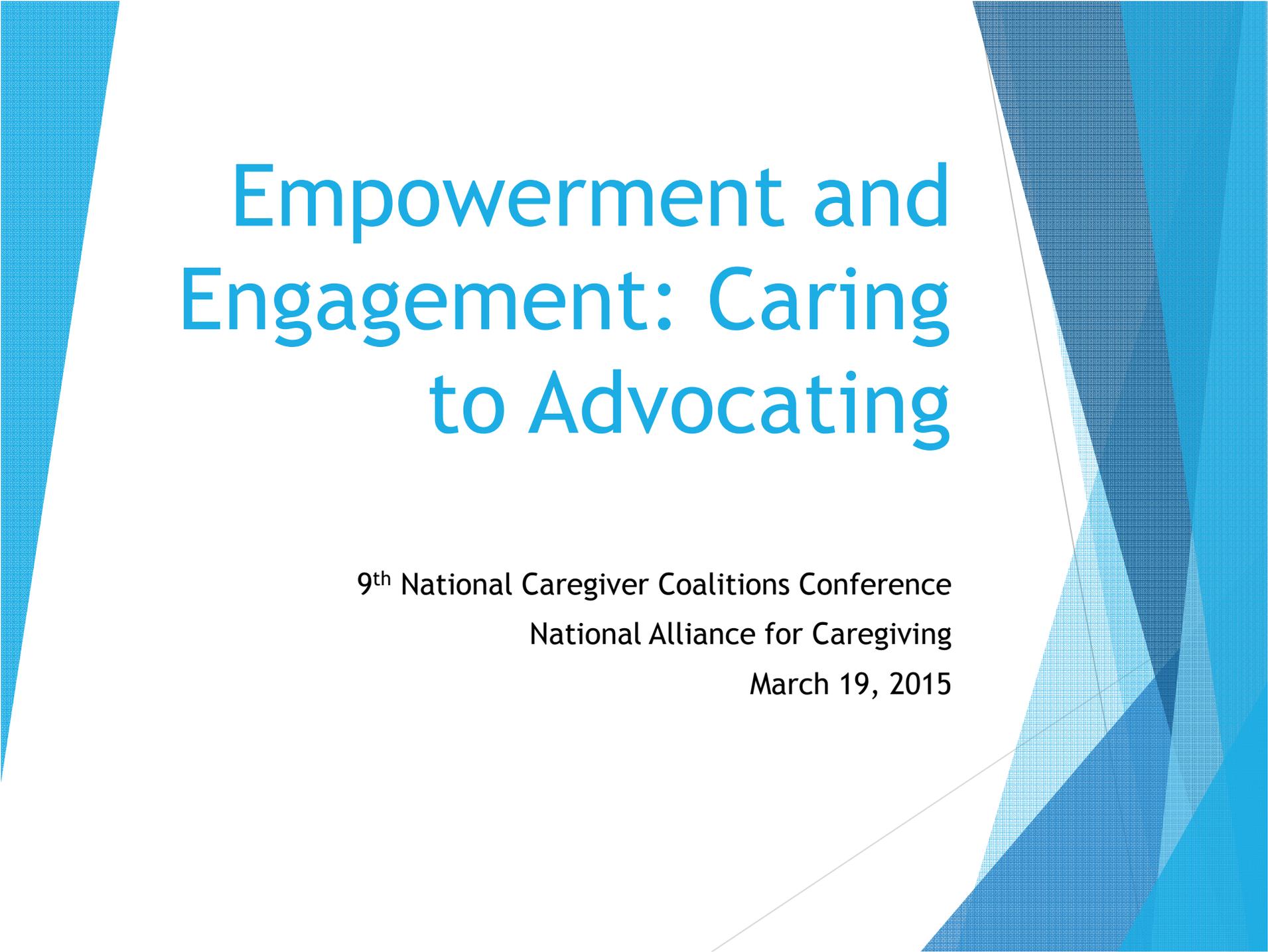
***Brian Duke,
MHA, MBE (Bioethics)***

Caregiving & Aging Advocate

Former Secretary of Aging,
Commonwealth of
Pennsylvania



#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

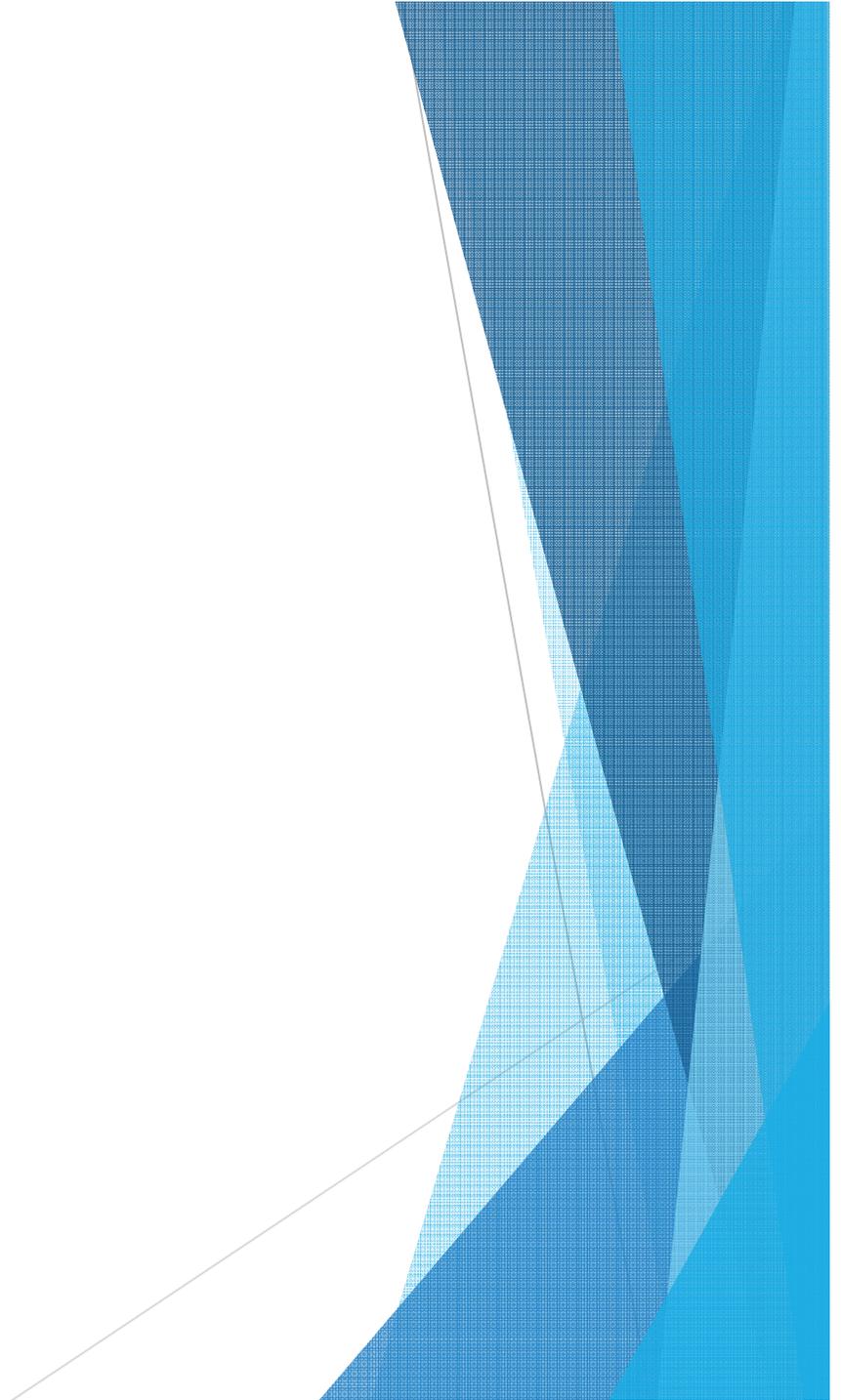
- ▶ Primary family caregiver
- ▶ Adult child/ parent
- ▶ Spouse
- ▶ Life/family history

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

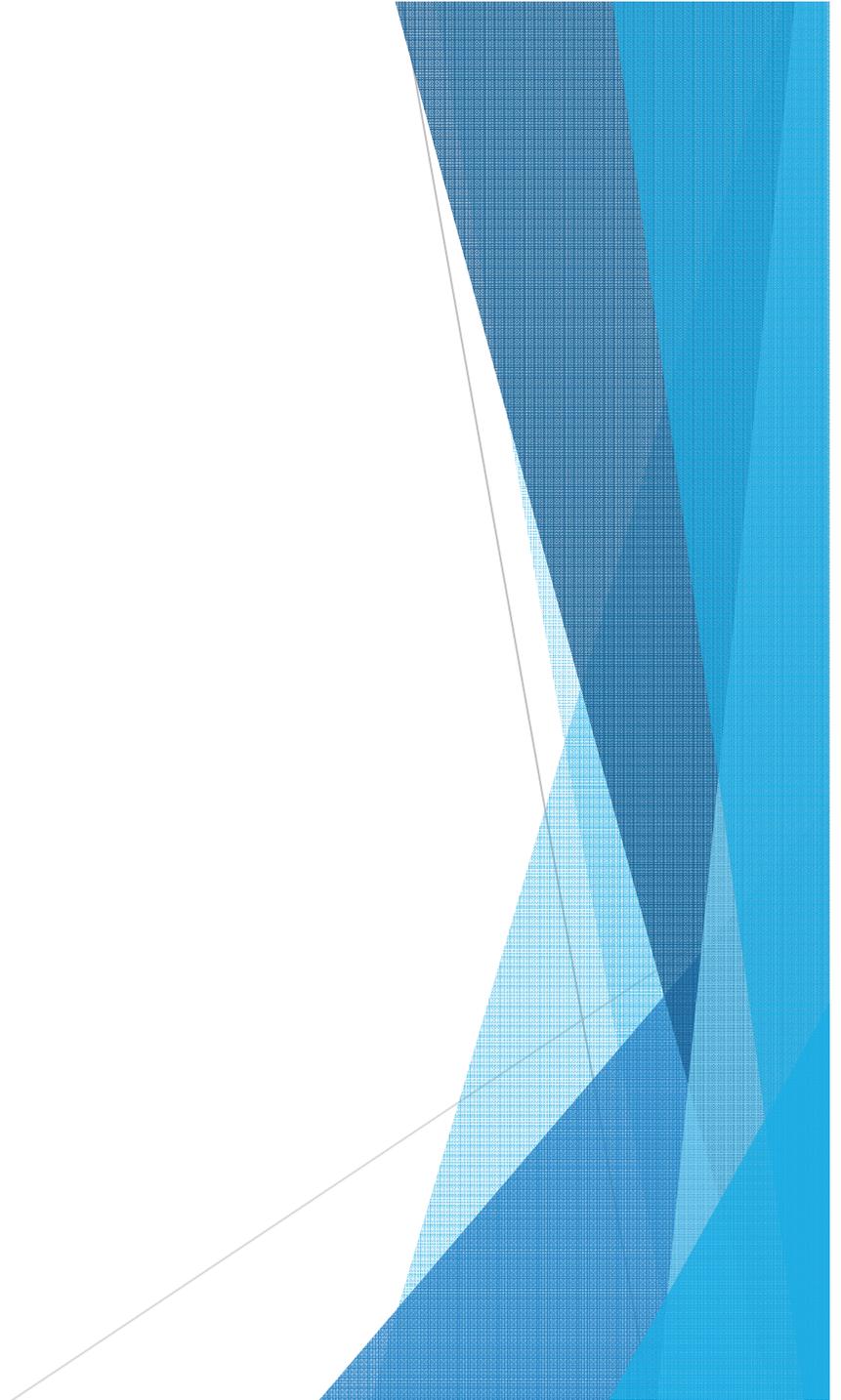
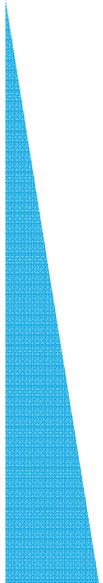
- ▶ Of care recipient
- ▶ Of health care system
- ▶ Of health professionals
- ▶ Of long term services and supports



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?

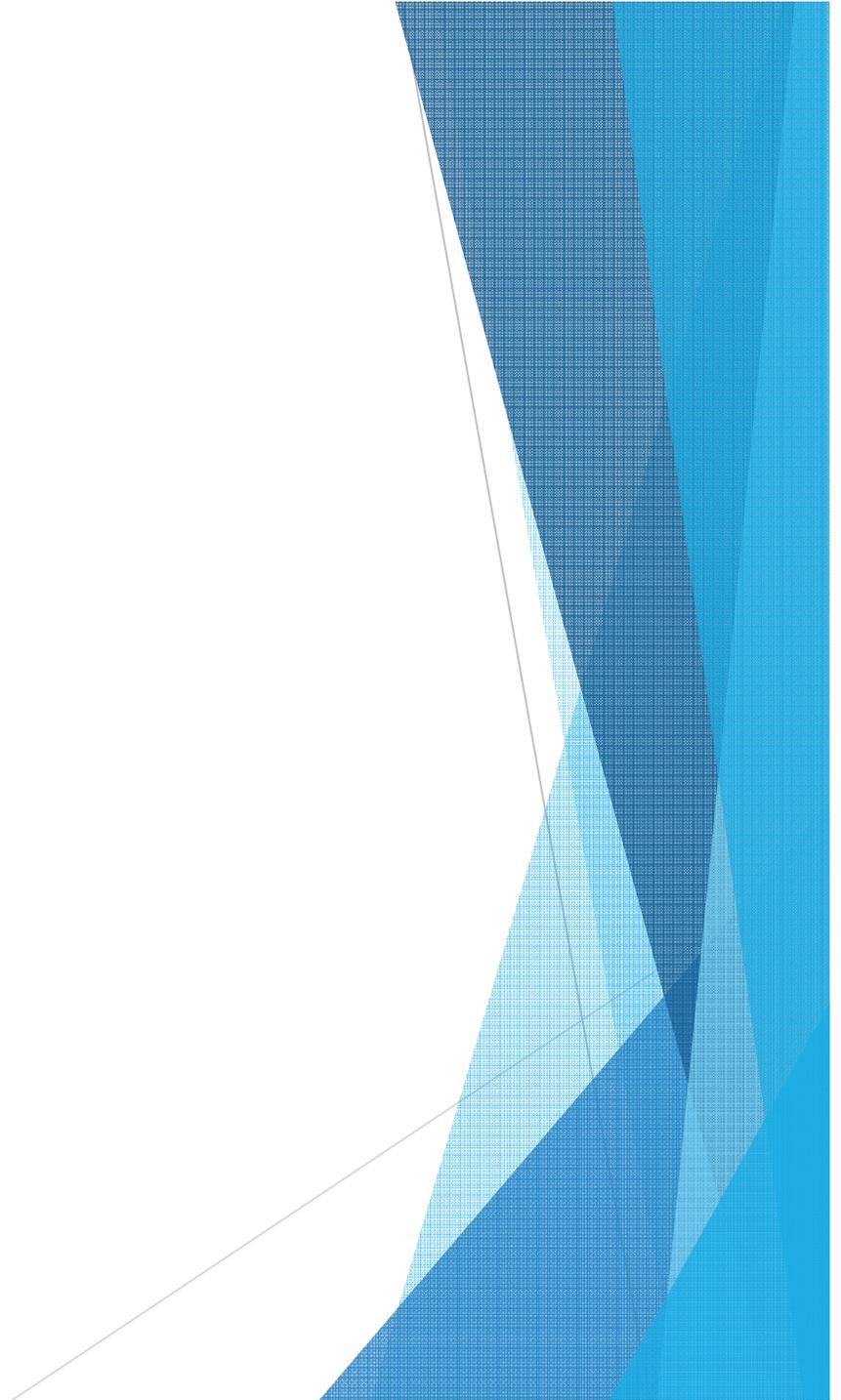
- ▶ Getting in and out of bed
- ▶ Getting dressed
- ▶ Helping bathe or shower
- ▶ Getting to and from the toilet
- ▶ Feeding the care recipient
- ▶ Dealing with incontinence and diapers

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

Who are caregivers

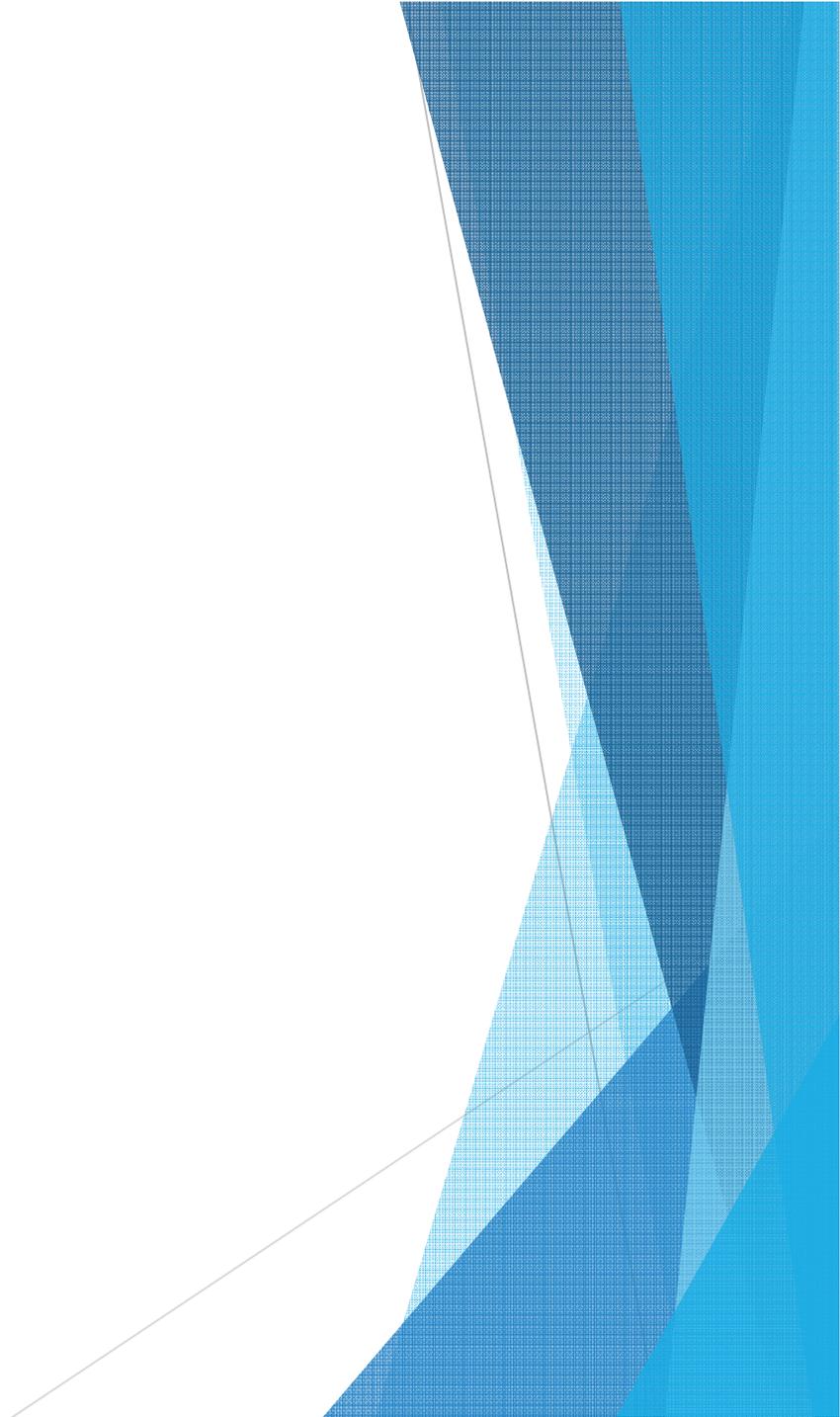
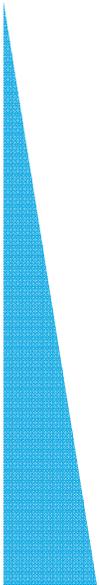
- ▶ Capacity
 - ▶ Resilience
 - ▶ Growth/Stress

- ▶ Capability



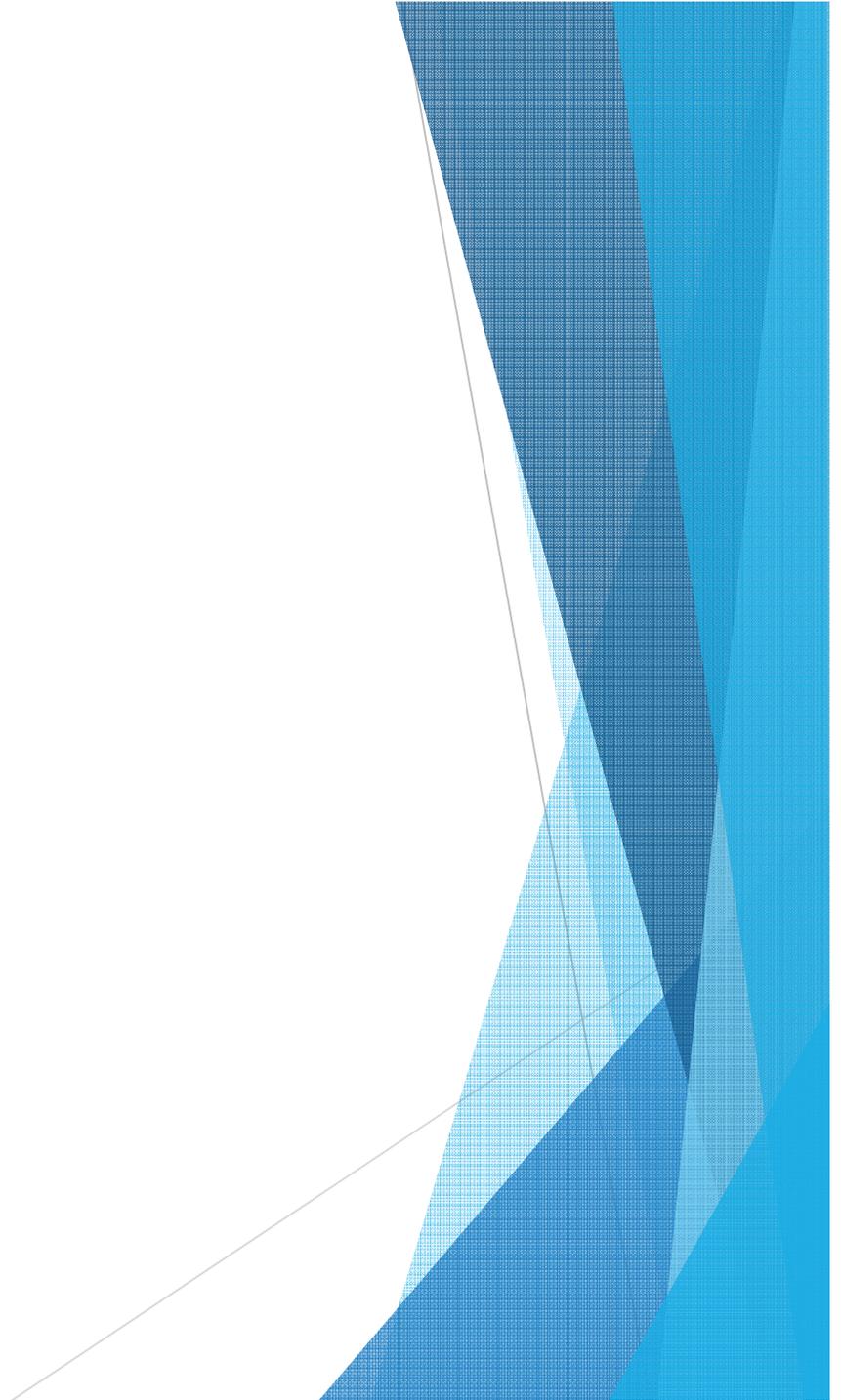
Areas of Concern

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



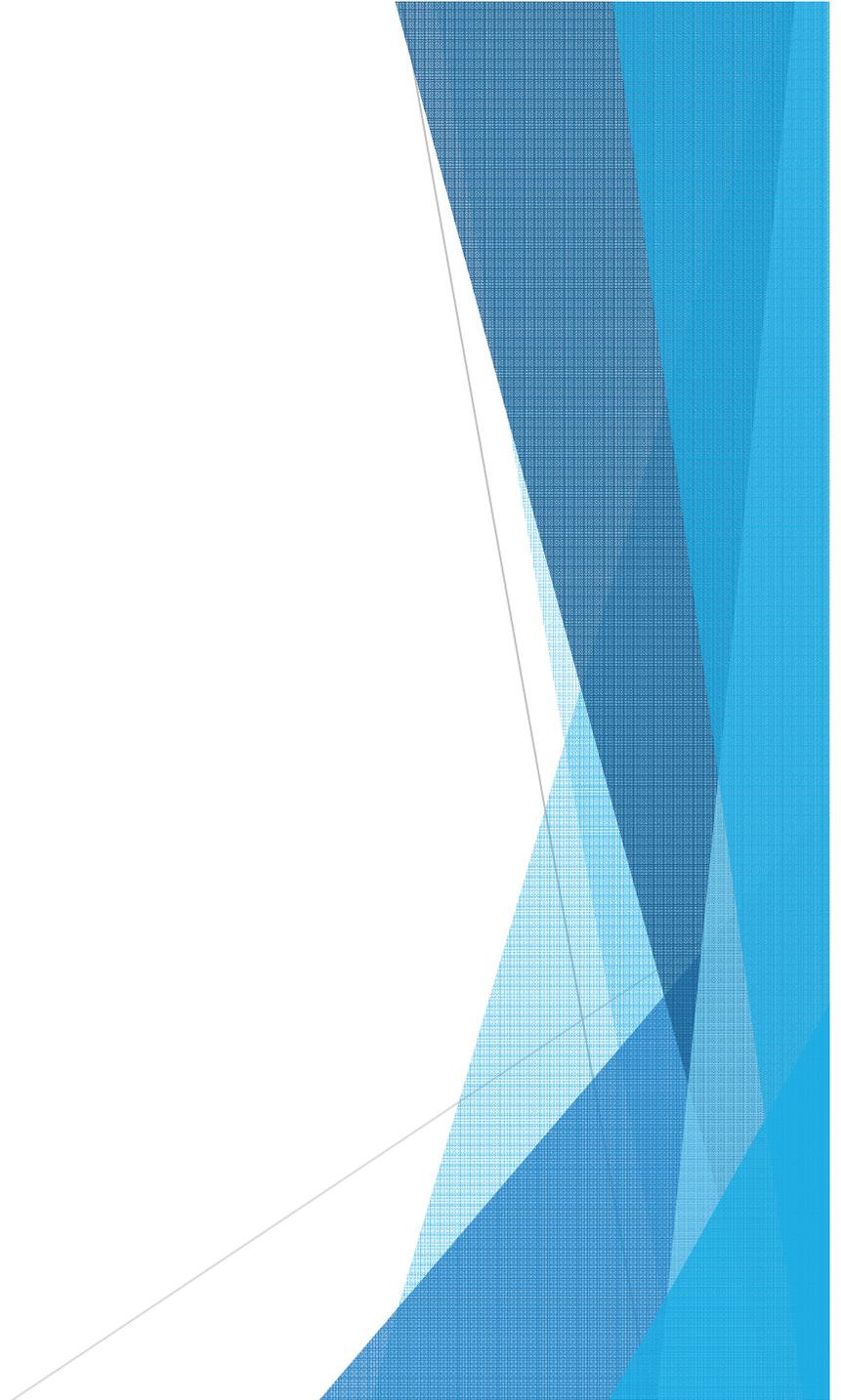
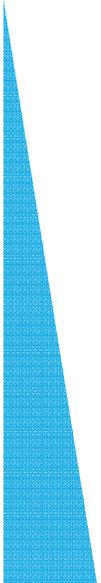
Loss of Self

- ▶ 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

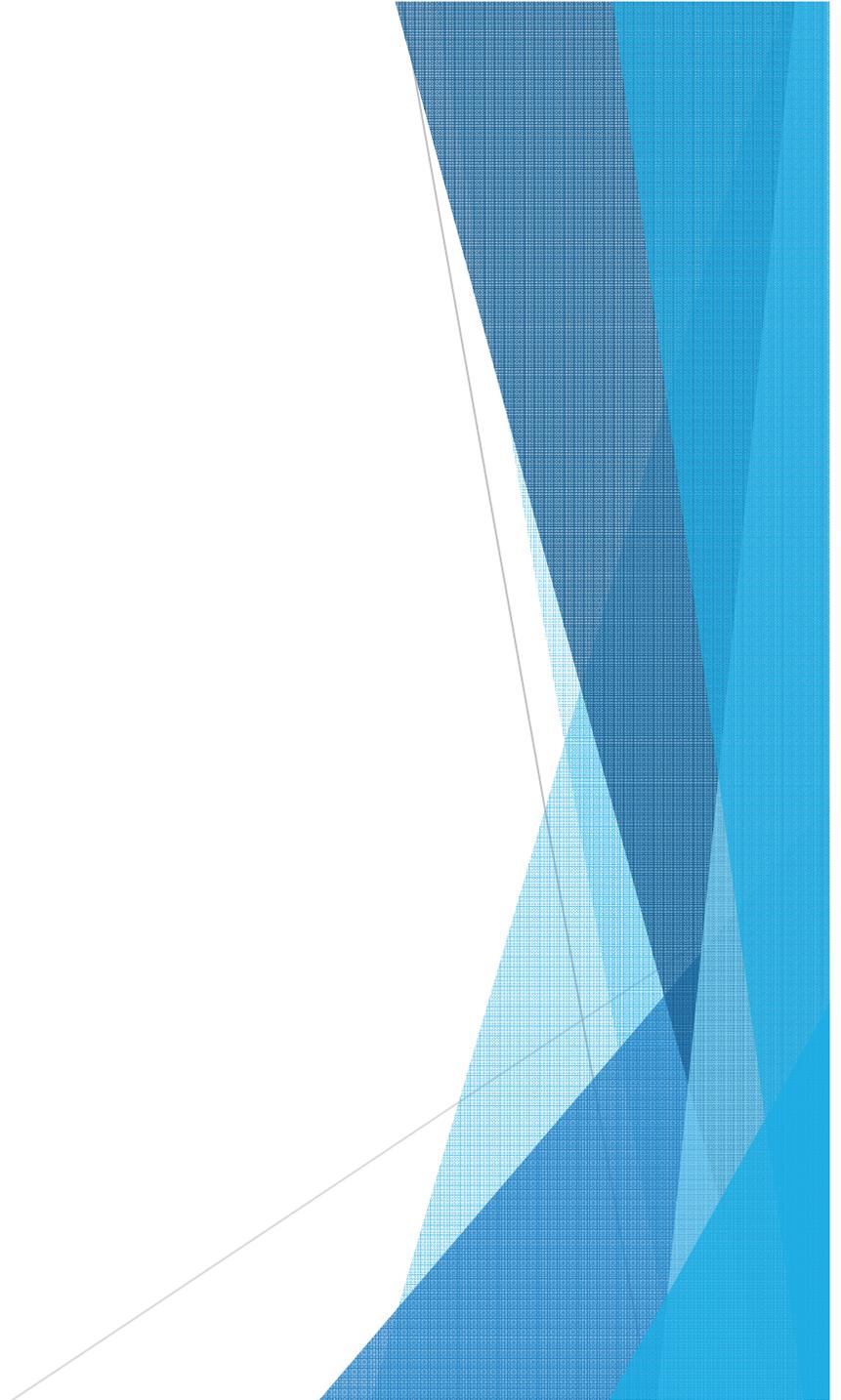
So what does it mean to be aware?

▶ 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

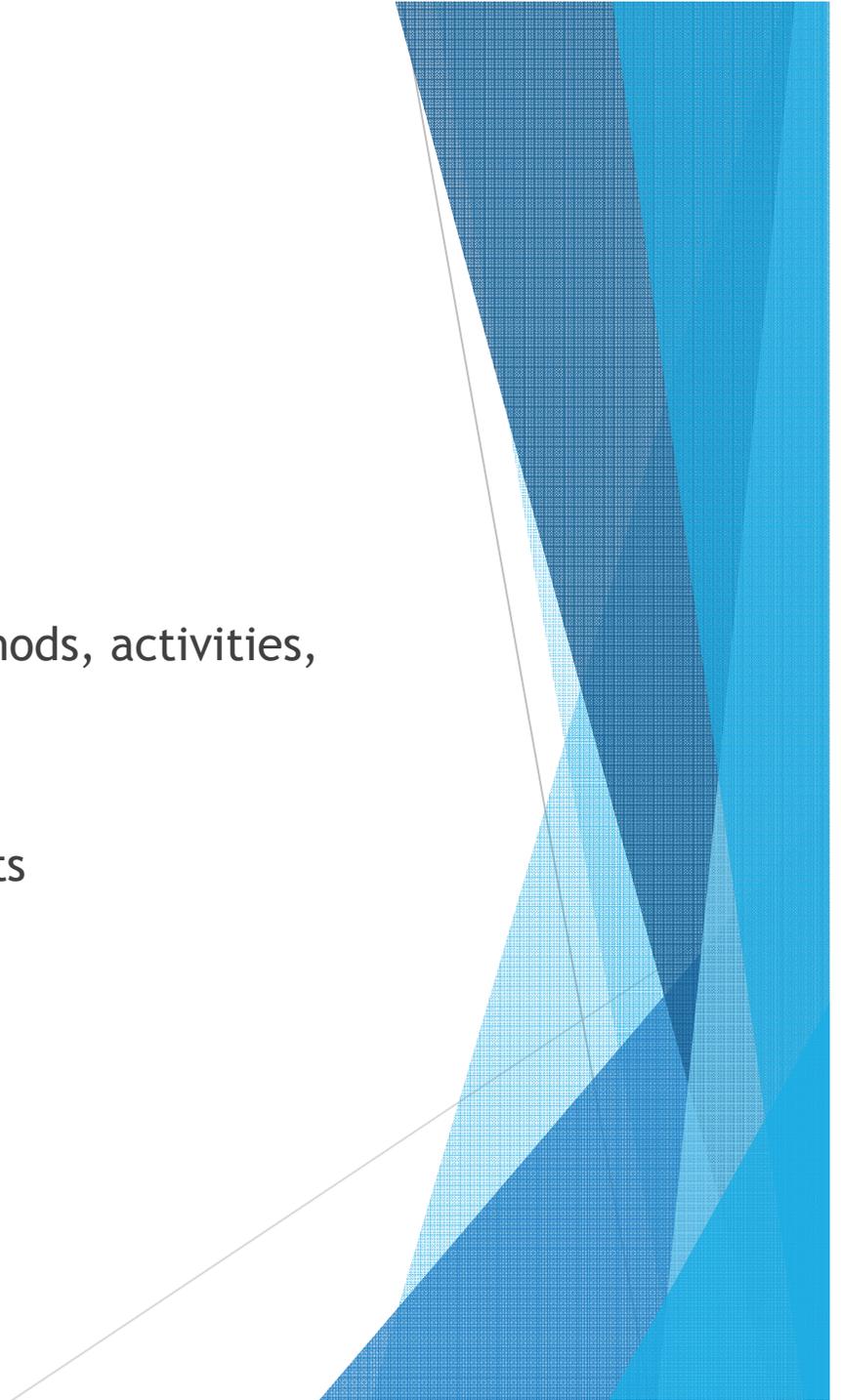
Empowered

- ▶ 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 how caregiving affects their own health.

Family Caregivers Self-Awareness and Empowerment Project A Report on Formative Focus Groups FINAL Report September 2001 The National Family Caregivers Association and the National Alliance for Caregiving by Lake Snell Perry & Associates

Barriers to Empowerment

- ▶ 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.

Family Caregivers Self-Awareness and Empowerment Project A
Report on Formative Focus Groups FINAL Report September 2001
The National Family Caregivers Association and the National
Alliance for Caregiving by Lake Snell Perry & Associates

Caregivers and Advocacy

- ▶ 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.

Family Caregivers Self-Awareness and Empowerment Project A
Report on Formative Focus Groups FINAL Report September 2001
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Required engagement

- ▶ “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.+

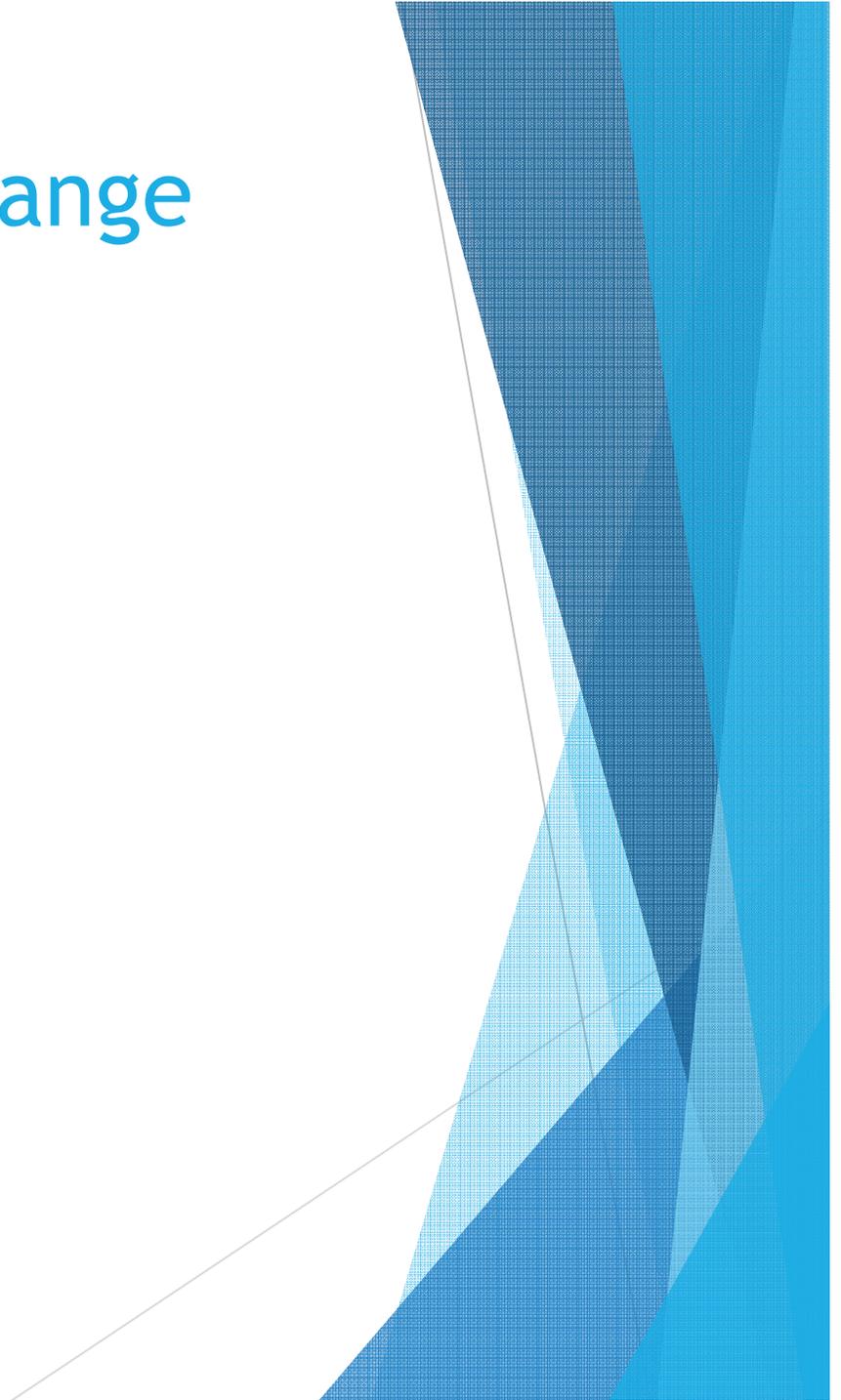
<http://www.communitycatalyst.org/resources/tools/meaningful-consumer-engagement>

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



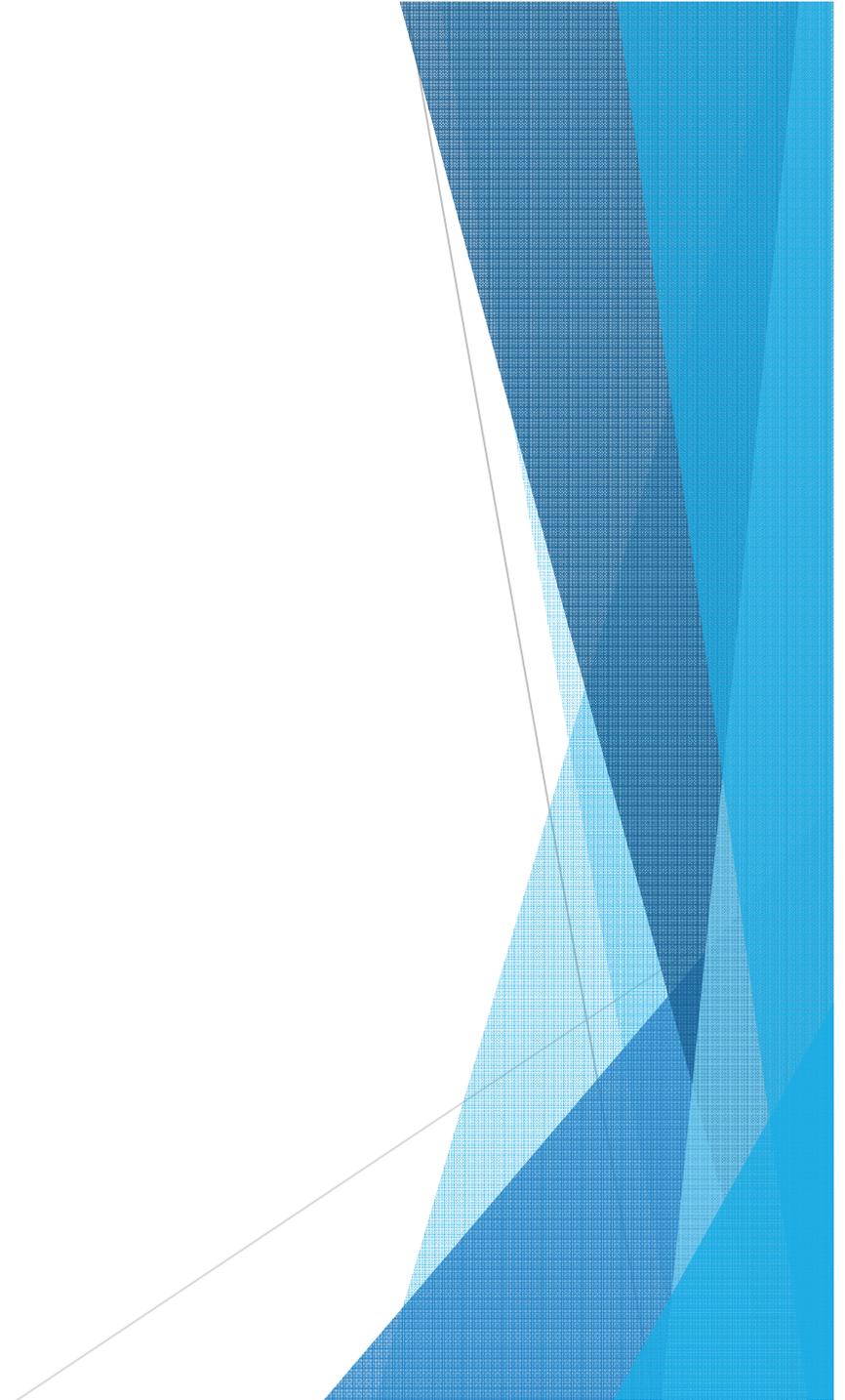
Attributes effective caregiver

- ▶ 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, RNand 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

