

# Family Caregiving and Public Policy

*Presentation to NCIOM*

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# My Story

- ▶ At age 31 husband Steven diagnosed with MS
- ▶ A degenerative neurological disease
- ▶ Currently needs help with all ADLs
- ▶ 1993 Co-founded National Family Caregivers Association, now considered one of the leading caregiver support, education, and policy organizations in the country.
- ▶ Retired 2013 and started Family Caregiver Advocacy to focus on issues related to caregiving and healthcare.

# Organizations Supporting Family Caregivers

- ▶ Caregiver Action Network
  - ▶ Family Caregiver Alliance
  - ▶ National Alliance for Caregiving
  - ▶ The Caregiver Space
  - ▶ US Administration on Aging
  - ▶ Next Step in Care
  - ▶ Lotsa Helping Hands
  - ▶ AARP
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# Key Facts

- ▶ Family caregivers (FCG) have always been America's solution for LTC
  - ▶ Traditionally family caregiving has been viewed as an aging issue and efforts to help family caregivers focused solely on HCBS
  - ▶ 65 million FCG in America, caring for loved ones across the lifespan
  - ▶ 46% of family caregivers do medical and nursing tasks
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# Principles Upon Which to Build FCG Public Policy

- ▶ First Written in 2003 still relevant today
  - FCG central to healthcare policy
  - Protection from physical, emotional and financial consequences
  - Respite care
  - Family-friendly work policies
  - Education and training
  - Coordination of health & social services across all settings
  - High quality and sufficient workforces
  - Assessment of caregivers' needs

# Current Public Policy That Helps Family Caregivers

- ▶ Family and Medical Leave Act
  - ▶ Nat'l FCG Support Program
  - ▶ Lifespan Respite Care Act
  - ▶ Affordable Care Act
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# Chronic Illness in America

- ▶ Our aging society and advances in science and medical care have made chronic disease the leading cause of death in America.
  - ▶ Medicine and healthcare delivery still focused on acute care
  - ▶ Change is happening – health IT, ACA - but family caregivers are still out in the cold
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# Three Proposals

- ▶ Document primary family caregivers in medical records. First step toward recognizing them as members of their loved one's care team.
- ▶ Care plans based on patient and family goals, be longitudinal and evolving.
- ▶ Treat patients with MCC and their primary caregiver as a single unit of care, reflecting the impact of one person's situation on that of the other.

**Where Do We Go From Here?**



# Thank You

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