

**Innovative Programs and Practices:
Family Caregivers
Grantmakers in Health & Grantmakers in Aging
July 2016**

**Kathleen Kelly, MPA, Executive Director
Family Caregiver Alliance
National Center on Caregiving
785 Market Street Ste 750
San Francisco CA 94103
415.434.3388
www.caregiver.org
kkelly@caregiver.org**

Overview of Remarks

- **Top Trends**
- **Key Family Caregiver Activities**
- **Challenges**
- **Opportunities**

A Few Definitions

- What are “caregiver support services”? **Explicit**
 - care planning/coaching/management
 - training on direct care skills (medical, ADL’s, IADL’s)
 - information about chronic health conditions
 - behavioral management skills
 - counseling
 - short term therapy groups targeting coping/decision skills
 - family meetings
 - in-person and online support groups
 - respite

Caregiver is the eligible service target

A Few Definitions

- What are services used by the care recipient that also support the family caregiver? **Implicit** Typically HCBS....
 - home health services including personal care
 - adult day care
 - transportation
 - nursing visits/consultations
 - care coordination
 - chore services
 - medication management
 - social & creative activities

The care recipient is the eligible service target

A Few Definitions

- **Process Improvement:** where family caregivers are included in systems of care like health or social services, examples include:
 - Care transition models or policies
 - Brief caregiver assessment within HCBS if plan of care rests on presence of family caregivers

Caregiver may receive some service(s) but metrics are usually focused on the patient

Top Trends

- **Demographic & Public Awareness**
- **ACA/Health and Federal Policies**
- **Advocacy: Federal, State & Local Policies**
- **Technology**

Trends and Policies are Changing – And the Pace of Change is Faster

***There has been more change in the
past five years than in the past 25
years***

Caregiver Interventions

- **After 1980 - especially in the past 25+ years - explosion of research on caregiver assessment and interventions**
- **While most populations of caregivers are studied (stroke, cancer, heart disease, diabetes) the real explosion is in the area of caregivers of dementia**
- **Key evidence-based intervention practices emerge from the research: REACH, Mittleman: NYU Counseling Protocol, Chronic Disease Self-Management Modules, Powerful Tools, Savvy Caregiver, etc.**

Challenges for Caregiver Interventions

The metrics have changed with the shift to integration with health care:

dual outcome for caregivers and care recipients: how does the intervention benefit/effect both parties?

Interventions are costly, not to scale and may not tied into any assessment of need by caregiver in community setting

how might we provide interventions to working caregivers who are particularly time-starved?

how might we use of technology platforms for delivery & scale?

Challenges for Practice

- **Shift from spousal caregivers to adult children brings a new meaning to family dynamics**
- **With adult children as caregivers, coordination and communication are key**
- **Employment and caregiving responsibilities and conflicts are common**
- **Interactions with adult children caregivers must be convenient, on-demand, abbreviated for the time-constrained**
- **Demographics have changed to more culturally ethnic family caregivers – practice needs to change**

Key Caregiver Activities: Policy

- **State, regional or city planning efforts: Alzheimer's, Caregiver Plans**
- **Incorporation of family caregivers into Age-Friendly Communities initiatives or other regional, county or city efforts**
- **Policy changes around care transitions, paid family leave and employment at state and local levels**
- **Programming expanding to cultural, education and civic institutions**

Challenges

- **Scale**
- **Sustainability & Cost**
- **Impact**
- **Technology/start-ups/for profits**
- **Changing demographics & changing practice**

Opportunities

- **Can we create a national database of family caregiver experience across age and diagnosis?**
- **Can we refine service models to better serve diverse family caregivers?**
- **Can we scale efforts through use of technology or broad adoption methods?**
- **Can we have a national consensus on caregiver assessment and data collection across programs?**

Opportunities

- **Can we focus on evaluation methodologies that maintain the well-being of both the family caregiver and the patient?**
- **Can we incentivize states to put in place LTSS financing or social insurance programs?**
- **Can we agree on quality metrics for basic elements of caregiver services?**
- **Can we encourage more state, regional or local planning or focus on the caregiver efforts?**

Contact Information

Kathleen Kelly, MPA, Executive Director

Family Caregiver Alliance,

National Center on Caregiving

785 Market Street Ste 750

San Francisco CA 94103

415.434.3388

www.caregiver.org

kkelly@caregiver.org

Key Family Caregiver Activities

- **Information and Referral:** Are they tailored to need?
- **Support Groups & Education:** Are they convenient?
- **Evidence Based Practices:** Are they scalable? How many sessions and delivery platform?
- **Training on Direct Care:** Does it cover medical tasks, ADL's, IADL's & behavior management?
- **Respite:** Is it substantial and does it offer choice to families as to options?
- **Caregiver Assessment:** Is it included and what are the components?