

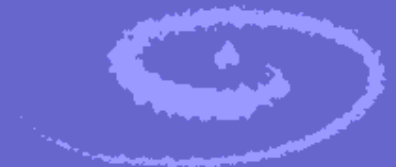


# Family Caregiver Boom: A National Perspective

**Nancy Hooyman, PhD**  
**Professor, School of Social**  
**Work; PI, Gero-Ed Center**

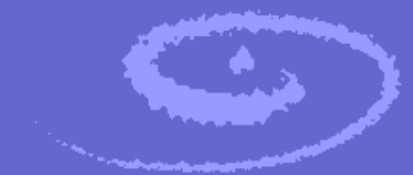
# ***What I Will Cover***

- **Trends: from invisibility to family-centered care in 3 decades**
- **Factors underlying greater attention**
- **Recognition of costs & gains of care**
- **Who are CGs nationally?**



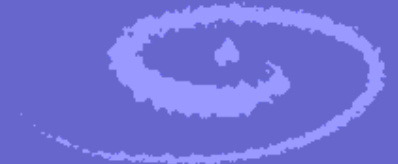
# ***What I Will Cover***

- **Concept of family-centered care**
- **Development of policies nationally**
- **Importance of evidence-based interventions**
- **Ongoing challenges**



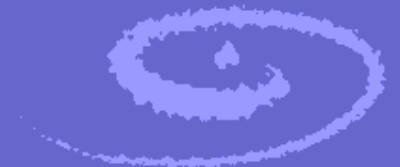
# ***Invisibility of Family Caregivers 30 Years Ago***

- **Assumed that families abandon their elders, despite research to the contrary**
  - **What families should do -- on their own**
- **3 decades of testimonials & research → CG's central role now documented**



# ***The new "normal" of being family CGs***

- **Term CG part of American lexicon: used by policy makers and popular press**
  - **Plethora of books, websites, media**
  - **Patchwork of policies**

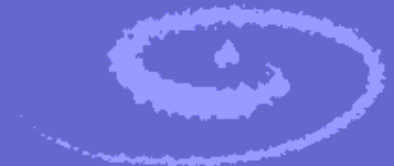


# ***Supporting Both Elder & Family Caregiver***



# ***Factors Underlying Greater Attention to Family Caregiving***

- **Increased life expectancy → growth of multiple generations & oldest old**
- **Pressures to reduce health care costs → earlier discharges**
  - **“High touch” & “high tech” care**
  - **Cuts in services → increased expectations of “informal supports”**



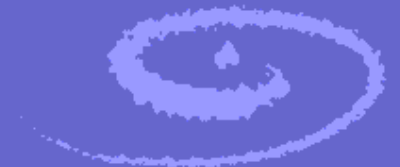
# ***Oldest-Old: Daughter 90 Cares for Mother 112***





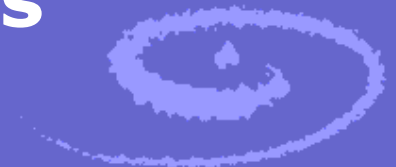
# ***Factors → Greater Attention***

- **More women employed**
- **Lower birthrate, later age → smaller number potential CGs**
- **More complex family structures**
  - **Single parent, blended, grandparent, LGBT & heterosexual domestic partnerships**



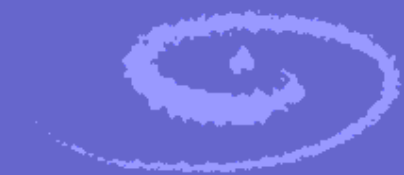
# ***Factors → Recognition of Economic Value of CG***

- **44 million family caregivers, 37 billion hours of care**
- **Economic value → implications for policy**
  - **Without CGs, cost of care to federal government: \$450 billion**
  - **LTSS would collapse without “shadow workforce” of CGs**



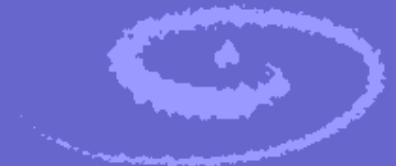
# ***Greater Recognition of Costs of Care to CGs***

- **Differentiation of objective & subjective burden → implications for services**
  - **Emotional burdens greatest**
- **Caring for vs. caring about**
  - **Qualitative nature & subjective appraisal → extent of stress/burden**

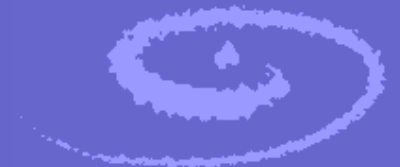


# ***Greater Costs for CGs of Color***

- **Higher rates of morbidity & mortality of elders of color → higher levels of care → greater costs for CGs**
  - **Acculturation & geographic mobility of adult children**
- **AARP: African American & Latina CG**
  - **Invisible, discounted, misunderstood**



# ***Strengths of CGs of Color***

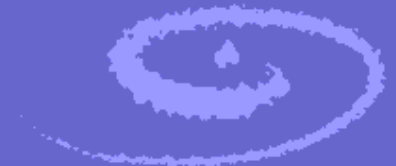


## ***Gender-based Nature of CG***

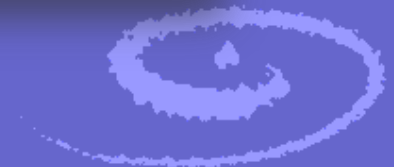
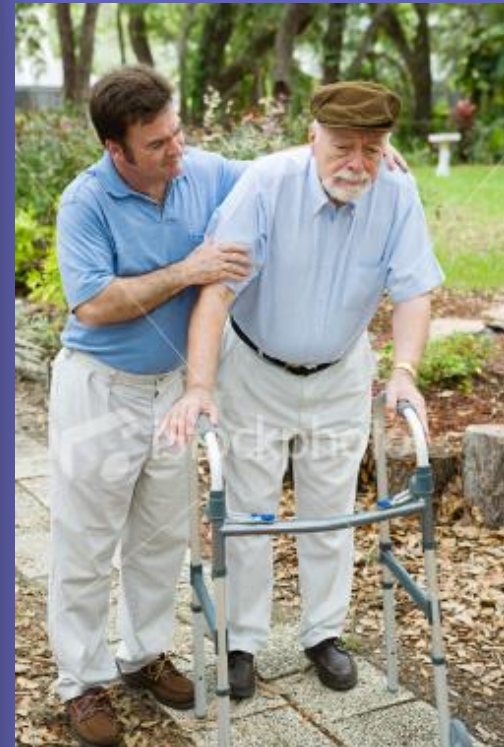
- **66% are women**
  - **Over 50% of women provide elder care at some point in lives**
  - **Spend more years caring for an older relative than parenting child**
- **Age 49, female, married, employed w/ \$35,000 income, nearly 5 years, 25 hours/week**

# ***Increasing Diversity of Caregivers***

- **CGs of color, including immigrants**
- **Male CGs, especially husbands**
- **Same-sex partners**
- **Younger adults (grandchildren)**
- **Adults caring for grandchildren & older relatives**



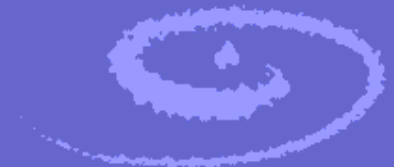
# ***Increasing Diversity of CGs***





# ***Policies to Support Family CGs***

- **Family & Medical Leave Act 1993**
  - **50% of states introduced legislation for paid leave, but for child care**
- **National Family CG Program 2000**
  - **1<sup>st</sup> formal recognition of CGS by AOA**
  - **State units required to serve CGs as “clients”**
  - **Shift for providers**

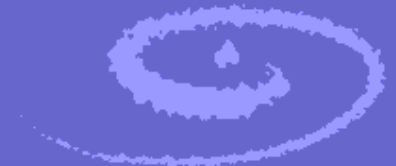


# ***Policies to Support Family CGs***

- **2005 National Consensus Development conference hosted by National Family Caregiver Alliance**
  - **Families as central to LTSS**
  - **Assessment to be reimbursed**
  - **CGs require own care plan**
  - **Concept of family-centered care**

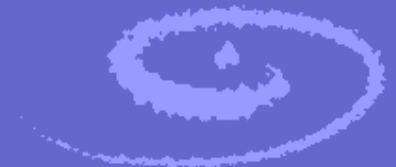
# ***Family-Centered Care***

- **Amplifies person-centered care by supporting CG's vital role**
  - **CG more than hours of care**
  - **Elder & CG are our "clients"**
  - **CGs not just "resource" but individuals who may need information, training, support**



# ***Family-Centered Care***

- **Thoroughly assess CG's health & well-being as part of care plan**
- **Care plan reflects goals, values & preferences of both elder & CG**
- **Build on family strengths**
- **Recognize “whole person,” including spiritual & cultural traditions & values**



# ***Evidence-Based Family-Centered Care***

**Do not need research on CG but on interventions**

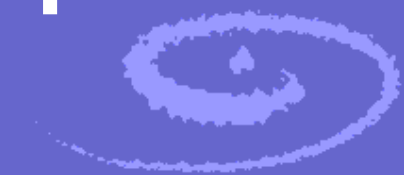
- **Evidence-based: What works, what are outcomes, how to disseminate**

- **Rosalyn Carter Institute's CG Intervention Database**

- **"Science in support of family caregivers," including TCARE**

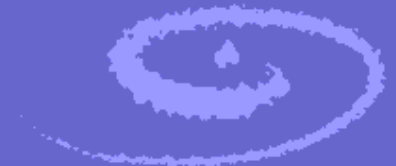
# ***Family-Centered Care: When Services Have Impact***

- **(TCARE<sup>®</sup> – Tailored Caregiver Assessment & Referral):  
comprehensive assessment**
- **Multi-component**
- **Tailored & flexible to fit CG context**
- **Promote CG's active participation in decision-making**



# ***Challenges: Imperative of Public & Private Policies to Support CGs***

- **National public education & prevention to reach CGs early in CG cycle**
- **Increased funding for National Family Caregiver Support Program, Medicaid HCBS waivers**
- **National Alzheimer's Planning Act:**
  - **Increasing focus on special populations**



# *Shrinking of the Eldercare Workforce*

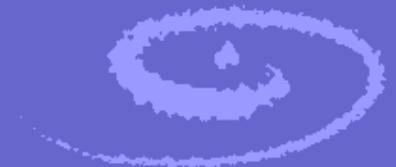
**Don't let a precious  
resource disappear**





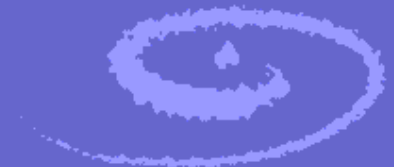
# ***Challenges: Care Coordination***

- **Evidence-based models of care coordination, supports in care transitions,**
- **New models of communication with health care providers**
  - **Physicians ask every adult**
  - **Electronic health records designate CG**



# ***Challenges: Address Long-Term Economic Costs of CG***

- **Economic incentives & financial relief**
  - **Tax credits**
  - **Tax deductions for LTC insurance premiums**
  - **CG Credits: Social Security**
- **Workplace policies**



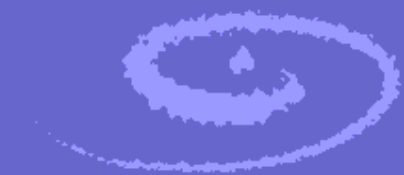
# ***Challenges: Cultural Competency Models***

- **Cultural competence more than single training or encounter**
  - **Relationship-based**
- **Outreach: Expand targeted evidence-based interventions in nontraditional community settings**



# ***Advocacy Essential***

- **At both individual & system levels**
  - **Broader system change & culture change**
  - **Recognize interconnections with underpaid caregivers (direct care staff)**
  - **Elder Care Workforce Alliance at national level**



# *Cross-Age Advocacy Coalitions*

