Strengthening Caregiving Families: Policy Recommendations from the Experts

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Session Objectives

1. Explain the changing roles and responsibilities of family caregivers providing hands-on care
2. Increase awareness of approaches recommended by a national panel of experts to improving the supply, retention, readiness and outcomes for family caregivers
3. Discuss implications of health care reform and the CLASS Act for family caregivers
Background

• Family caregivers and direct-care workers are regarded as the backbone of the long-term care workforce, delivering most of the hands-on care to chronically ill and impaired adults.

• The U.S. Administration on Aging (AoA) has overseen the expansion of services for family caregivers through the National Family Caregiver Support Program, created in November, 2000, by an amendment to the Older Americans Act.
Background

- AoA is sponsoring the Year of the Family Caregiver to mark the 10th anniversary of the National Family Caregiver Support Program (NFCSP)
- Through Area Agencies on Aging, NFCSP helps to provide information and referral services, eligibility screening, counseling and caregiver training, respite care, chore services and some medical supplies
- More than 81% of caregivers in a recent national survey said the NFCSP enabled them to care for their loved ones longer and avoid institutional placement
Distinctions between family caregivers and direct-care workers have become blurred

- Some family members perform caregiving functions that used to be done only by professional providers
- Family members can become paid helpers under consumer-directed care programs (eases financial burdens of caregiving/unemployment)
- Many direct-care workers also serve as family caregivers
Background

• Demographic changes affecting informal caregiving by peers, family members, non-kin and fictive kin
  ➢ Increased life expectancy
  ➢ Age 85+ fastest growing segment
  ➢ Decreasing birth rates
  ➢ Geographic dispersion of and blended families
  ➢ Decreasing number of women age 18-54
  ➢ Increasing number of women in the workforce
  ➢ Increasing diversity

• Current wage and benefit levels are a deterrent to the supply, recruitment and retention of paid direct-care workers
National Panel of Experts

- Convened by Benjamin Rose as part of a cooperative agreement with the U.S. Administration on Aging (AoA)
- Produced programmatic and policy-related approaches for strengthening the long-term direct-care workforce
- These suggested approaches take into account AoA’s mandate, authority, and influence to strengthen this workforce
National Panel of Experts

- Lisa Alecxih (Lewin Group)
- Roger Auerbach (Auerbach Consulting)
- Clarence Brown (DC Office on Aging)
- Lynn Kellogg (Michigan Region IV AAA)
- Peter Kemper (Penn State)
- Kathy Leitch (Washington State Aging & Disability Services Administration)
- Carol O’Shaughnessy (ex officio) (National Health Policy Forum)
- Martha Roherty (NASUAD)
- Joseph Ruby (Ohio 10B AAA)
- Robyn Stone (IFAS, AAHSA)
- Donna Wagner (Towson University)
Areas of Concern

- Increasing the **supply** of family caregivers to meet growing needs for home- and community-based services
- Improving **retention** of family caregivers in their caregiving role and in paid employment
- Improving the **readiness** or capacity of these helpers to provide care
- Maximizing positive **outcomes** for care recipients and caregivers
- Impact of the 2010 Patient Protection and Affordable Care Act, including the CLASS Act
Potential Actionable Policy Areas for AoA

- New and expanded labor pools
- Education and training initiatives
- New interventions and program initiatives
- New and/or amended public policies
- Partnerships with other government agencies and community organizations
Suggested Approaches: Increasing Supply and Retention

• Continue supporting expansion of consumer-directed care programs
  – Promote peer-to-peer care
  – Allow spouses, non-kin and fictive kin to qualify as paid caregivers

• Identify ways to fund home remodeling, home additions, and installation of assistive technologies in partnership with the construction trades, home remodelers, HUD, and technology companies

• Pursue strategies to expand the Family and Medical Leave Act to accommodate family caregivers’ needs and promote wage replacement
Suggested Approaches: Increasing Supply and Retention

- Pursue strategies to amend the tax code to include Caregiver Tax Credits to ease financial burdens of caregiving
  - Direct care expenses and indirect expenses, such as lost wages
  - Of 6 panelists who indicated priorities, 4 endorsed this approach
- Study new care models in which unpaid caregivers can bank their work hours for later use when they or their family members need care
- Encourage the Aging Services Network to support community caregiver associations
- Increase funding for the National Family Caregiver Support Program to enhance services
  - Including respite services with 24-hour availability
Suggested Approaches: Improving Readiness

• Support hands-on training programs for family caregivers
  – Body mechanics, lifting, transferring, bathing, using assistive devices, managing medications, etc.
  – In consumer-directed programs, training in fiscal management, supervision of direct-care workers, and case management would be beneficial

• Determine the capacity of the Aging Services Network to offer 24/7 hotlines for caregivers to provide information, consultation and counseling on care-related problems

• Develop core competencies for Aging Services Network professionals to implement in their work with caregivers
Suggested Approaches: Improving Readiness

• Support demonstration-evaluation programs that build on core competencies to train family caregivers and paid direct-care workers jointly
  – Promote shared understanding of their roles
  – Enable paid direct-care workers to educate family caregivers about safe and effective care techniques
  – Possibly in collaboration with the Department of Labor
Suggested Approaches: Improving Outcomes for Care Recipients and Caregivers

• Promote the use of validated caregiver assessment tools
  – To identify training, service and support needs
  – Can be critical when care recipients’ needs increase or change
    • Discharge from hospital, rehabilitation unit, nursing home
    • Direct impact on care recipient’s successful transition back to the home setting
  – Possible adverse effects of assessments
    • Negative impact on supply
    • Possibility of accusations of elder neglect/abuse
    • Lack of caregiver receptiveness to offers of help, training
Health Care Reform and the CLASS Act

- Health care reform under the Patient Protection and Affordable Care Act incorporates the Community Living Assistance Services and Supports (CLASS) program
- Establishes a new public-private approach to financing long-term services and supports
- Gives enrollees flexibility in how to use their cash benefits
- Likely to encourage growth in consumer-directed care programs
Health Care Reform and the CLASS Act

Issues that must be addressed

• Adverse selection into the insurance program
• Assumptions actuaries use in setting insurance premiums
• Level of disability required for premiums
• Eligibility criteria for premiums
• Amount of the benefits and what it covers
• Relationship of this insurance program to other long-term care insurance programs
Suggested Approaches: Health Care Reform

- Promote the involvement of family caregivers in the care of older adults served by medical homes
- Invest in a significant role for the Aging Services Network in care transition and care coordination models that emphasize family involvement and education for anticipated changes in caregiving demands
- Enable the Aging Services Network to provide counseling and education about the use of benefits under the CLASS Act
Innovations in Caregiving Award

• Made possible by a gift from Elizabeth H. (Betty) Rose, an Emerita Board Member of Benjamin Rose
• Recognizes individuals on the frontlines of caregiving in a private home or residential setting who have:
  – Invented a device or technique that solves a caregiving challenge, or
  – Found a new way to use an existing device or technique that supports caregiving and eases the burden on caregivers
• Applications must be received by June 30, 2011
Resources for Caregivers

• Western Reserve Area Agency on Aging
  216-621-0303 or 800-581-6884

• Family Caregiver Alliance
  www.caregiver.org

• National Alliance for Caregiving
  www.caregiving.org

• National Family Caregivers Association
  www.thefamilycaregiver.org

• Eldercare Locator
  www.eldercare.gov
Resources for Caregivers

Webinar: The Impact of Healthcare Reform (PPACA) on Family Caregivers

Monday, November 8, 2010, at 1 p.m.

Presented by:
Gail Hunt, President and CEO, National Alliance for Caregiving
Suzanne Mintz, President and CEO, National Family Caregivers Association
Kathy Kelly, Executive Director, Family Caregiver Alliance
Thank you!

Strengthening the Direct Care Workforce for Long-term Services and Supports: Suggested Approaches From a National Panel of Experts can be found at:
www.benrose.org → Policy → Projects

For more information or questions contact:
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