Informal Caregiver Support

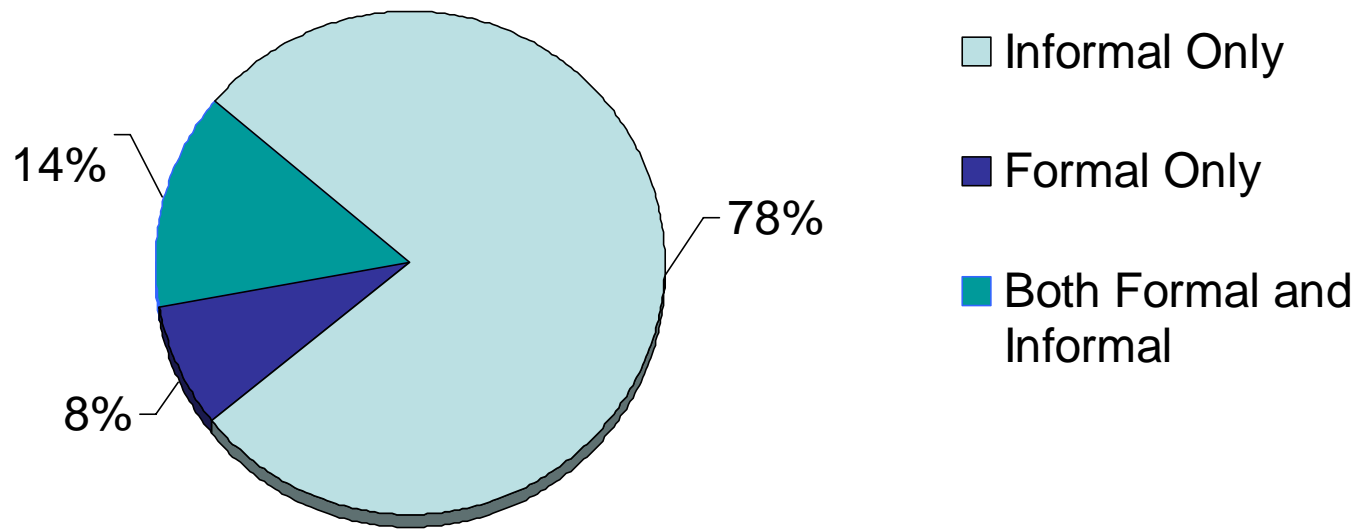## Susan C. Reinhard

CSHP

Rutgers Center for State Health Policy

CMS New Freedom
Initiative Conference
Baltimore, MD
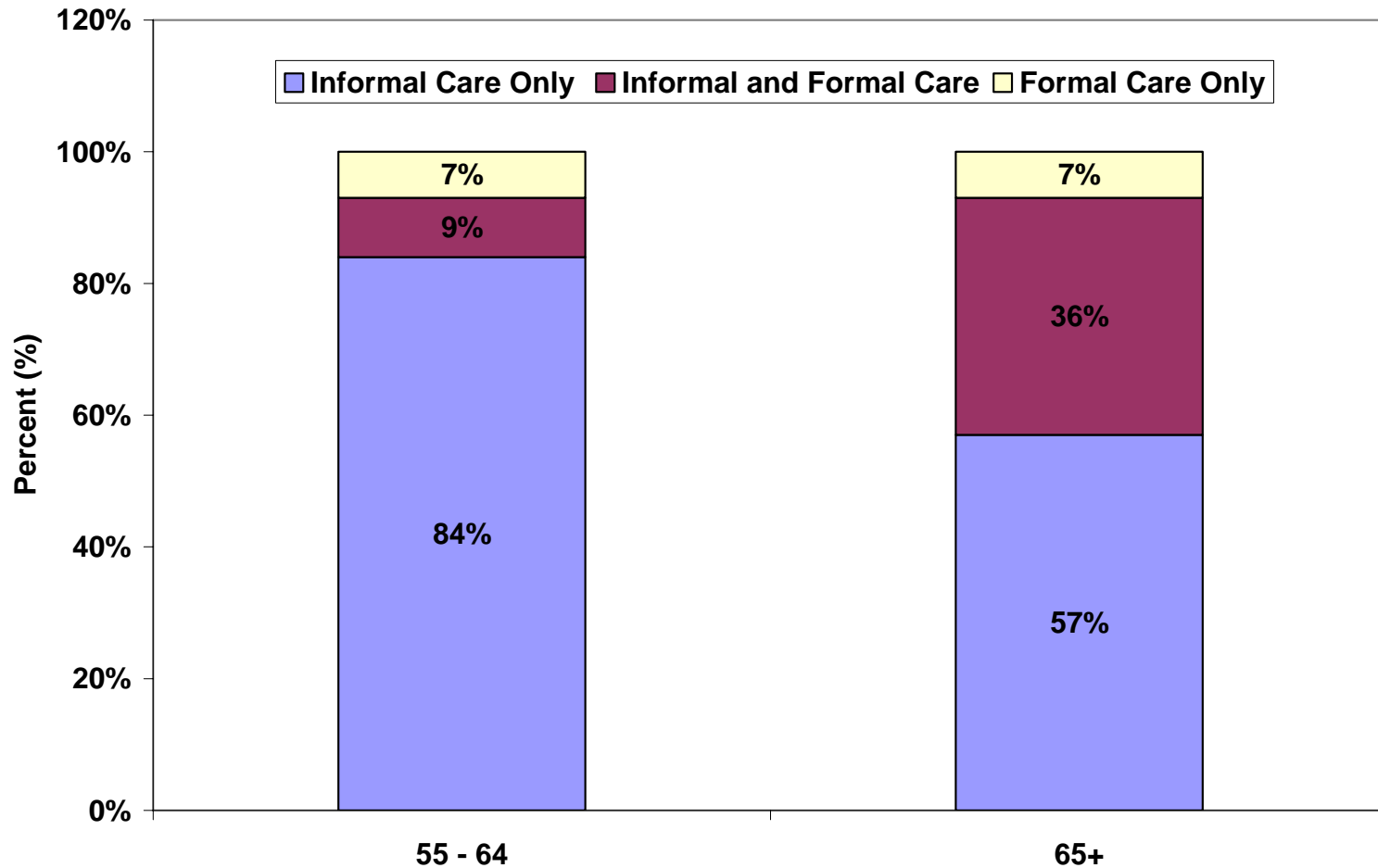March 5, 2007

Background

- Help from family, friends, and neighbors is known as "informal support" (as opposed to "formal support" by professional providers)

- Informal support is also known as "family caregiving, but "family" includes friends and neighbors

- Informal support is the most important source of assistance for people of all ages with disabilities

Distribution of Adults (age 18+) Receiving Long Term Services and Supports at Home

14%

8%

78%

- ☐ Informal Only
- ■ Formal Only
- ■ Both Formal and Informal

Level of Reliance of Informal Care Relative to Formal Care

Source: AARP – Beyond 50 2003 A Report to the Nation on Independent Living and Disability. www.aarp.org
Based on 1994 National Health Interview Survey, National Long Term Care Survey by AARP Public Policy Institute) and
The Characteristics of Long-Term Care Uses by AHRQ

Family Caregivers

- By 2050, 37 million unpaid caregivers will be providing support, an increase of 85% from 2000 (ASPE, 2003)

- About I in 5 caregivers provide more than 40 hours of care each week (National Alliance for Caregiving and AARP, 2004)

- Most caregivers are also employed

Caregiver Research

More than 25 years of research confirms that family caregivers are an "at risk" population:

- Health risks
- Financial burdens
- Emotional strain
- Mental health problems
- Workplace issues
- Retirement insecurity

Constellation of Goals and Approaches of Maximizing Caregiver Effectiveness and Minimizing Caregiver Stress

Develop Task & Problem Solving Skills

Delivery System Navigation

Linking to Resources

Stress Management

Caregiver Effectiveness & Wellbeing

Competence

Safety

Providing Information & Counseling

Caregiver Assessment

Confidence

Respect
Patient – Family- Professional Triad

Source: Adapted from Reinhard, S., Given, B., Petlick, N. & Bemis, A. "Supporting Family Caregivers in Providing Care., April, 2006.

Why Assessment of Family Caregivers' Needs?

Are family members seen merely as "resources", or as people with needs and rights of their own?

Lynn Friss Feinberg

Family Caregiver Alliance

Assessment of Family Caregivers' Needs

- We need to consider not only how the family caregiver can help the consumer, *but how we can help the family caregiver*

- Assessment is important for developing an individualized plan when the consumer chooses to seek family caregiver support in order to live in the community

Why Assessment?

- What is the "emergency back up" or "contingency planning" for a family caregiver who cannot provide the care that is assumed or stated in the "individualized care plan"? How would the state know unless there is a caregiver assessment?

- **"Caregiver as client"** and **"Caregiver as "provider**"…we should consider both.

Why Assessment?

- If the State is paying for the individual's care (state funded or Medicaid), and the plan for the individual <u>relies</u> on support from the family caregiver, the state <u>should require and fund</u> a caregiver assessment.

- Should be part of the "health and safety" review and "risk mitigation" that CMS requires.

Caregiver as Client

- Often referred to as "secondary patients" who need and deserve protection and guidance.
- Assessment focuses on how they are managing their caregiving responsibilities, which often place them at greater risk for injury and depression.
- Policy goal is to prevent them from becoming "patients" themselves.

Caregiver as Client

- Need to talk to the caregiver to assess these needs.
  - Should be part of the policy implementation protocols
  - Should be part of the assessor training
- Assessment should lead to interventions.
  - Referrals to support groups
  - Counseling
  - Respite

Caregiver as Provider

- Often need help to learn how to become competent, safe "workers" who can better support the individual and protect them from harm, such as a falling between the bed and the wheelchair
- Policy goal is to "keep them on the job"
  - Need to assess the caregiver's learning needs for caregiver training
  - How to interact with the individual and professionals involved

National Consensus Development Conference *for* Caregiver Assessment

September 7-9, 2005

- **Convener:**
  - FCA's National Center on Caregiving
- **Advisory Committee:**
  - 10 experts to guide the project & nominate conference participants
- **Participants:**
  - 54 widely recognized leaders in health & LTC
- **Funders:**
  - The Robert Wood Johnson Foundation
  - Archstone Foundation
  - The California Endowment

Definition of Caregiver Assessment

A systematic process of gathering information that describes a caregiving situation and identifies the particular problems, needs, resources and strengths of the family caregiver.

- – Approaches issues from the caregiver's perspective and culture
- – Focuses on what assistance the caregiver may need and the outcomes the family member wants for support
- – Seeks to maintain the caregiver's own health & well-being

Fundamental Principles

1. Because family caregivers are a core part of health care and long-term care, it is important to recognize, respect, assess and address their needs.

2. Caregiver assessment should embrace a family-centered perspective, inclusive of the needs and preferences of both the care recipient and the family caregiver.

Fundamental Principles (cont'd)

3. Caregiver assessment should result in a plan of care (developed collaboratively with the caregiver), that indicates the provision of services and intended measurable outcomes.

Fundamental Principles (cont'd)

4. Caregiver assessment should be multi-dimensional in approach and periodically updated.

5. Caregiver assessment should reflect culturally competent practice.

Fundamental Principles (cont'd)

6. Effective caregiver assessment requires assessors to have specialized knowledge and skills.

    - Practitioners & service providers' education and training should equip them with an understanding of the caregiving process and its impacts, as well as the benefits and elements of an effective caregiver assessment.

Fundamental Principles (cont'd)

7. Government and other third-party payers should recognize and pay for caregiver assessment as a part of care for older people and adults with disabilities.

Guidelines for Practice

Resource:

Family Caregiver Alliance (2002). *Selected Caregiver Assessment Measures: A Resource Inventory for Practitioners.* San Francisco: Author. Available at:

http://caregiver.org/caregiver/jsp/content_node.jsp?nodeid=470

Reources

Consensus Report

- *Caregiver Assessment: Principles, Guidelines and Strategies for Change* (Volume I)
  - Reflects the professional consensus achieved
- *Caregiver Assessment: Voices and Views from the Field* (Volume II)
  - 2 personal stories and 4 background papers

Toolkit

- *Caregivers Count Too!*
  - A toolkit to help practitioners assess the needs of family caregivers
  - Includes sample assessment tools

Available online at
www.caregiver.org

Policy Changes

Policy changes are needed to establish systematic caregiver assessment as a basic component of good practice in HCBS settings

Overall Policy Objective:

- Consider standardized assessment for all publicly funded programs

Selected Change Strategies

Build support for family caregivers among the public, policymakers, government officials, practitioners, insurers, employers & funders

- – Example, add a question on caregiving to the U.S. Census

Change Strategies

Conduct demo projects to develop & test caregiver assessment practices & protocols as part of the OAA's National Family Caregiver Support Program (NFCSP)

Incorporate caregiver assessment & support needs in Medicaid home & community-based services

Change Strategies

Adopt a caregiver policy at CMS to acknowledge role and contributions of caregivers in the Medicare & Medicaid programs

Develop professional education and training curricula that include caregiver assessment

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