

Caregiver Assessment: Filling the Gap in Policy and Practice

Susan C. Reinhard



Rutgers Center for
State Health Policy

Family Caregiving: State of
the Art, Future Trends
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Objectives

- Share policy recommendations from the National Consensus Development Conference for Caregiver Assessment
- Integrate perspectives from policymakers and advocates
- Stimulate discussion on key questions and ideas to move forward in the policy arena

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



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

The Role of Policy

- How can identified policy strategies and actions advance caregiver assessment in health care and HCBS settings?
- How do we move from some awareness to full-scale, systematic inclusion of caregiver assessment in publicly funded programs?

Two Views of Caregivers

- Both have policy implications
- Caregiver as Client
- Caregiver as Provider

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

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*
 - Caregiver as Client
- Assessment is important for developing an individualized plan when the consumer chooses to seek family caregiver support in order to live in the community
 - Caregiver as Provider
 - Even in person-centered planning

Why Policy Must Address Caregiver Assessment

- If the State is paying for the individual's care (state funded or Medicaid), and the plan for the individual relies on support from the family caregiver, the state should require and fund a caregiver assessment.
- Should be part of the “health and safety” review and “risk mitigation” that CMS requires.

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?

National Consensus Conference

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

Change Strategies and Actions

1-3 Years

- A. Build support for family caregivers among the public, policymakers, government officials, practitioners, insurers, employers & funders (awareness and data)
 - Add a question on caregiving to the U.S. Census
 - Add questions on caregiving to the Centers for Disease Control's Behavioral Risk Factor Surveillance System (BRFSS) and state surveys
 - Involve professional associations to promote the use of caregiver assessments

Change Strategies and Actions

1-3 Years

- B. Conduct demonstration projects to develop & test caregiver assessment practices & protocols as part of the Older American Act's National Family Caregiver Support Program (NFCSP)

- C. Include caregiver assessment by trained assessors in the NFCSP, Alzheimers Disease Demonstration Grants to States (ADDGS), and the Aging and Disability Resource Centers (ADRC) programs

Change Strategies and Actions

1-3 Years

- B. Recognize the role of family caregivers in Medicare's Chronic Care demonstrations

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

Change Strategies and Actions

1-3 Years

- F. Develop caregiver assessment algorithms to assist decision making
- G. Add family caregiver assessment as a 6th category under the NFCSP
- H. Expand dialogue with consumers to discuss caregiver assessment in consumer-directed models of care

Change Strategies and Actions

4-6 Years

- A. Adopt a caregiver policy at CMS to acknowledge role and contributions of caregivers in the Medicare & Medicaid programs
- B. Develop professional education and training curricula that include caregiver assessment

Change Strategies and Actions

4-6 Years

C. Advocate for changing record keeping & information systems to include caregiver-related data elements. Focus on:

- Large health systems
- Mandated reporting systems
- Smaller electronic record systems

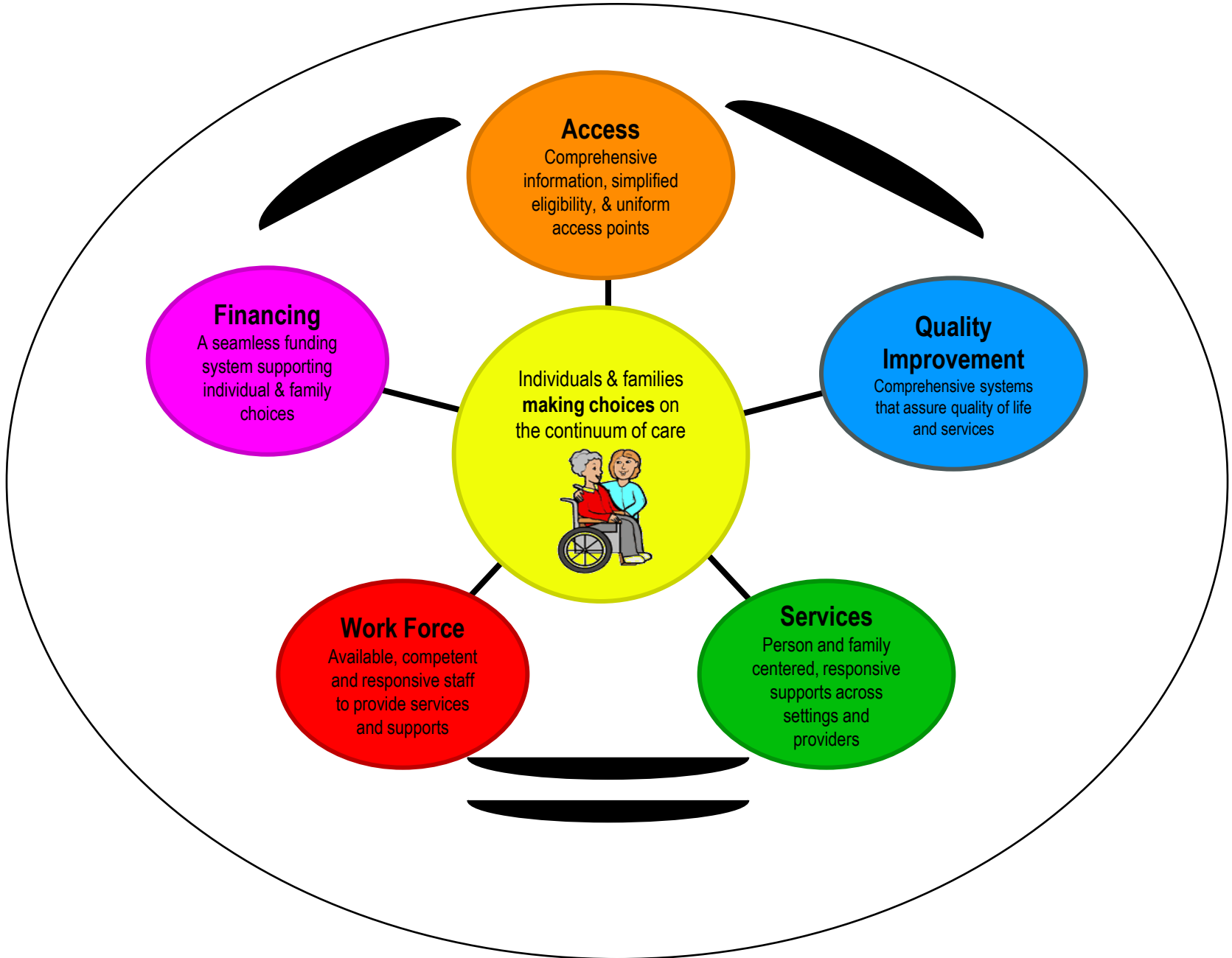
Change Strategies and Actions

4-6 Years

- D. Support development of a uniform data set & evaluative research to clarify:
- caregivers needs & contributions
 - Resources to meet needs of caregivers
 - Impact of different assessment approaches

Factors Facilitating Policy Change

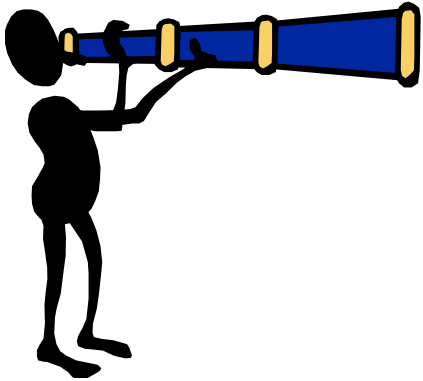
- A few states already envision a system of long term care and supportive services that explicitly recognizes family caregivers
- Strategic planning for North Carolina's Systems Transformation Initiative funded by CMS led to statewide mission and vision with families included in the center



Mission Statement for the North Carolina Office of Long Term Services & Supports

The mission is to create a statewide, integrated, person and family-centered system for those who need long term services and supports so that they can live and actively participate in communities of their choice.

Vision Statement for the North Carolina Office of Long Term Services & Supports



People of all ages and their families live in inclusive, responsive communities where they have choices and control over their long term services and supports.

Factors Facilitating Policy Change

- The Centers for Medicare & Medicaid services (CMS) has high-level policy group considering ways to support family caregivers
- Growing power of the Administration on Aging (AOA), the federal champion of caregivers
 - Partnerships with CMS at highest levels
 - Choices for Independence
 - ADRCs are part of the Lifespan Respite law...could be a lever for change

Factors Facilitating Policy Change

- Serious and sustained attention from major philanthropic organizations who are now partnering with each other to maximize their investments
- As we move closer to making family caregiver assessment an essential component of practice and policy, issues can surface and be addressed more directly

Issues Raised by State Policymakers

- Where is the family in “person-centered care”?
- If we assess it, won't we have to address it? (Don't Ask, Don't Act)
- Another assessment...we need to keep it simple
- How will we pay for it?

Issues Raised by Advocates for Consumers and Family Caregivers

- Is “assessment” the right term? Is there a better one? Does it matter?
- Is “family-centered care” taken from child care models and therefore not appropriate for adults? Is there a better way to express the policy goal of including families who are intricately involved in long-term services and supports?

How Can We Move Forward?

- Convening with strategic planning among participants who can act across public and private sectors with key groups
- CMS incentives to states to include caregiver assessments and linkages to appropriate supports
- Your ideas????

Susan C. Reinhard, RN, PhD, FAAN
Professor and Co-Director
Rutgers Center for State Health Policy

732-932-4649
sreinhard@ifh.rutgers.edu