National Consensus Project
for Caregiver Assessment:
Translating Research into Policy & Practice

Caregiving Teleconference Seminar
May 17, 2006

Lynn Friss Feinberg, MSW
National Center on Caregiving
Family Caregiver Alliance
www.caregiver.org

Virginia Dize
National Association of State Units on Aging
www.nasua.org
Overview

• Background: Why a consensus project?
• Goals
• Areas of Consensus
  – Principles
  – Practice Guidelines
    • Who, What, When, Where & How
• Conclusions
• Final Products
National Consensus Project for Caregiver Assessment

Why FCA’s National Center on Caregiving undertook this project

How it was designed

What it achieved
Why is Assessment of Family Needs Important?

• Practitioners must consider not only how the family caregiver can help the care recipient, but how the service provider can help the family
  – Family-centered perspective

• Consensus on basic principles and practice guidelines is a necessary first step
Project Design

- **Convener:**
  - FCA’s National Center on Caregiving

- **Funders:**
  - The Robert Wood Johnson Foundation
  - Archstone Foundation
  - The California Endowment
Project Design

• Form Advisory Committee to guide project and plan consensus conference format and structure
• Commission background papers from leading experts
• Invite leaders and stakeholders to the conference with a range of perspectives and knowledge
• Field pre (and post) conference opinion survey to understand views and perspectives on caregiving, assessment and LTC
• Hold consensus development conference
Project Design

- Review consensus points (by conference participants) and revise
- Refine dissemination strategy
- Produce and widely disseminate consensus documents
- Encourage conference participants and others to disseminate, discuss and adopt consensus recommendations
Goals:

1. Generate principles and guidelines for caregiver assessment
2. Build common ground among leaders committed to innovation and the systematic generation of new knowledge
The Conference Achieved:

- Recognition of the importance of systematically assessing a caregiver’s own needs in health care and HCBS settings
- Consensus on principles and practice guidelines
- Identification of change strategies
- Heightened interest among the invited leaders to take steps to promote caregiver assessment
Working Definitions

**Family Caregiver** *(CG)* – Any relative, partner, friend or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition

**Care Recipient** *(CR)* – An adult with a chronic illness or disabling condition or an older person who needs ongoing assistance with everyday tasks to function on a daily basis
Working Definitions

**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 CG’s perspective and culture
- Focuses on what assistance the CG may need and the outcomes the family member wants for support
- Seeks to maintain the CG’s own health & well-being
Why Are Principles and Guidelines Important?

• Facilitate development and improvement of programs and services
• Guide practitioners and service providers to incorporate assessment of family needs into their work with frail elders and adults with chronic conditions and disabilities
Why Are Principles and Guidelines Important?

- Establish essential elements of good practice that promote quality, consistency, and reliability of services
- Expand access to caregiver assessment across settings

Source: Adapted from work of the National Consensus Project for Quality Palliative Care
Fundamental Principles
Fundamental Principles

54 nationally recognized leaders agree upon a set of 7 basic principles to guide caregiver assessment policy and practices.
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. CG assessment should embrace a family-centered perspective, inclusive of the needs and preferences of both the care recipient and the family caregiver.
3. CG assessment should result in a plan of care (developed collaboratively with the CG), that indicates the provision of services and intended measurable outcomes.
Fundamental Principles

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

5. CG assessment should reflect culturally competent practice.
6. Effective CG 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 CG assessment.
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

• Consensus based on
  – Scientific evidence
  – Clinical experience
  – Expert opinion
General Considerations:

A. Programs should recognize key dimensions of family caregiving:
   - The unit of care is the CR and the CG
   - The CG is part of the care team and service plan
   - Services should be consumer directed and family focused
   - CG assessment and support improves outcomes and continuity of care for the CR
Guidelines for Practice

General Considerations: (cont’d)

B. CG assessment should be tailored based upon the caregiving context, service setting and program

• There is no set protocol to follow for caregiver assessment and no single approach is optimal in all care settings and situations
• Purpose, ethical issues & technological resources & capabilities all have to be considered; these vary by settings and existing service programs
Guidelines for Practice

*General Considerations: (cont’d)*

C. The reasons for conducting a CG assessment need to be clear to both assessor and caregiver. These are:

- To identify the primary CG & other informal CGs
- To improve CG understanding of the role & what abilities are needed to carry out tasks
- To understand the caregiving situation – including service needs, unresolved problems, and potential risks – in order to meet the needs of the CG
- To identify services available for the CG & provide appropriate and timely referral for services
D. Assessment findings should be used in care planning and service interventions
   - Assessment is not an end in itself but should empower CGs to make informed decisions & link CGs with community services

E. Available information technology should be used to share assessment findings and make it easier for the CG to access help
Guidelines for Practice

Who Should Be Assessed?

• Anyone who self-identifies as a family caregiver should be offered a screening, leading to an assessment as appropriate

• Multiple caregivers within family may require group interview
  - Conflict resolution may be necessary
Guidelines for Practice

When Should Assessment Occur?

- Early as possible
- Distinct from a “screening”
- Reassessment should be built into process
- Numerous entry points are needed
Who Should Conduct Caregiver Assessments?

• A range of professionals (e.g., physicians, nurses, social workers, care managers)
• Assessors need to be trained in CG assessment and have the requisite abilities, knowledge and skills
Guidelines for Practice

How and Where Should Caregiver Assessments be Conducted?

– Process should always be clear to CG
– CG preferences should be determined and accommodated in conducting the assessment
Guidelines for Practice

What Should Be Included in a Caregiver Assessment?

Assessment should be driven by:

– A conceptual framework
– The service context and programs
– Subjective perceptions and preferences along with objective characteristics of the CG
Guidelines for Practice
7 Domains

1. Context
2. CG perception of CR’s health and functional status
3. CG values and preferences
4. CG well-being
5. Consequences of caregiving
6. Skills/abilities/knowledge to provide care
7. Potential resources
Guidelines for Practice
Domain 1

Context:

– CG relationship to CR
– Physical environment (home, facility)
– Household status (number in home, etc.)
– Financial status
– Quality of family relationships
– Duration of caregiving
– Employment status
Guidelines for Practice
Domain 2

CG Perception of Health and Functional Status of CR:

– ADLs and need for supervision
– IADLs
– Psycho-social needs
– Cognitive impairment
– Behavioral problems
– Medical tests and procedures
Guidelines for Practice
Domain 3

CG Values and Preferences:

– CG/CR willingness to assume/accept care
– Perceived filial obligation to provide care
– Culturally based norms
– Preferences for scheduling and delivery of care and services
Guidelines for Practice
Domain 4

Caregiver Well-Being:

- Self-rated health
- Health conditions and symptoms
- Depression or other emotional distress (e.g., anxiety)
- Life satisfaction/quality of life
Guidelines for Practice
Domain 5

Consequences of Caregiving:

– Perceived challenges
  • Social isolation
  • Work strain
  • Emotional, physical health and financial strain
  • Family relationship strain

– Perceived benefits
  • Satisfaction of helping family member
  • Developing new skills and competencies
  • Improved family relationships
Guidelines for Practice
Domain 6

Skills/Abilities/Knowledge to Provide CR
with Needed Care:

– CG confidence and competencies
– Appropriate knowledge of medical care tasks
  (e.g., wound care, etc.)
Guidelines for Practice
Domain 7

Potential Resources that CG Could Choose to Use:

– Formal and informal helping network and perceived quality of social support
– Existing or potential strengths (e.g., what is presently going well)
– Coping strategies
– Financial resources (e.g., VA benefits)
– Community resources and services (e.g., religious orgs.)
Guidelines for Practice

Things to keep in mind:

• Use established measures that are:
  – Practical and applicable
  – Previously applied, or could be applied, in service settings
  – Reliable and valid
  – Cited in the literature

Resource:
Conclusion

• Systematic caregiver assessment practices are both desirable & feasible
• The adoption of these principles and guidelines require a fundamental change of thinking in policy & practice
  – *Embrace a family-centered perspective*
• Efforts to bring this knowledge into practice offer hope for real & sustained improvement
Conclusion

Consistent approaches to caregiver assessment will:

• Help practitioners better understand family needs and capacities
• Enable caregivers to access support
• Assure optimal outcomes for the care recipient
• Provide solid information to policymakers and program administrators to improve service delivery
What Can You Do?

• Champion adoption and use of these principles and guidelines in your agency and your state
Final Products

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
  – 4 background papers

Caregivers Count Too!

– A Toolkit for practitioners (coming in June 2006)

Available online at
www.caregiver.org
Thank you for your participation!

For more information, please call or visit:

The National Center on Caregiving at Family Caregiver Alliance
(800) 445-8106
www.caregiver.org

National Consensus Project for Caregiver Assessment